FAMILY AND COMMUNITY DEVELOPMENT COMMITTEE

INQUIRY INTO SUPPORTED ACCOMMODATION FOR VICTORIANS WITH A DISABILITY AND/OR MENTAL ILLNESS

DECEMBER 2009

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Chair's Foreword

Over the past two decades in Victoria, opportunities for people with a disability and/or mental illness have changed with the increased recognition of their right to quality of life and the opportunity to participate in the community.

These changes have led to a transformation in the nature of supported accommodation provided in Victoria, resulting in the closure and redevelopment of nearly all residential institutions or congregate care across the state. Victoria has led the way in the move away from institutional care and developing supported accommodation options in the community. It has also explored a range of alternatives to supported accommodation with the goal of assisting people to live independently in the community.

The Victorian Government has enacted a new legislative framework through the introduction of the *Disability Act 2006* that establishes in law the rights of people with a disability and the kinds of support they have a right to expect. The Government also developed the *Victorian State Disability Plan 2002-2012* which sets out the Government's priorities, strategies and key actions that will put in place the programs and services to assist people with disabilities and those who help care for them.

A Fairer Victoria, the Government's social policy action plan that helps address socio-economic disadvantage in Victoria, recognises that many Victorians with a disability want the chance to be fully active in community life. Through *A Fairer Victoria*, the Government is significantly increasing support for families and carers, improving the built environment to increase accessibility for people with disability and is encouraging more individually–focused support.

Despite these reforms, the Committee's Inquiry revealed that there are improvements to be achieved to assist people with a disability and/or mental illness to live the lives they aspire to.

Demographic changes, such as ageing, greater complexity of need and increasing numbers of people with a disability and/or mental illness, present challenges for the future of supported accommodation in Victoria. Many family carers are ageing and seeking certainty for their family member with a disability and/or mental illness. Changes in eligibility for disability services with the introduction of the *Disability Act 2006* have led to increased demand on services and greater complexity of need. Increasing numbers of people with a serious mental illness has put pressure on existing services in meeting levels of demand.

The supported accommodation needs of people with a disability are different from the needs of people with a mental illness and there are two parallel systems that provide services. The report has focused on supported accommodation in

both service systems and while it considers the issues broadly together, there are notable differences in how services are provided.

The report points to the need for improved collaboration across mental health, disability and housing services to enable people with a disability and/or mental illness to receive the services that meet their individual needs for support and accommodation.

Opportunities for community participation are dependent on both the right support linked to appropriate accommodation. The Committee has recommended a need for strengthening these connections between support and accommodation in all options available to people with a disability and/or mental illness.

The Committee has made a large number of recommendations in its Report that focus on building the capacity of the service system, including the need for improved long-term planning, setting of funding priorities and improved implementation and evaluation.

There was significant community interest in the Inquiry and evidence was received from a range of individuals and organisations, including families, workers in the sector, service providers, advocacy organisations and representatives from relevant government departments. Over 125 submissions were received and 12 public hearings were held.

On behalf of members of the Family and Development Committee, I would like to thank these participants for their contribution, which has assisted in the Committee's considerations and preparation of this Report.

I thank former and current members of the Committee and staff for their contributions and considerations.

The Committee secretariat underwent significant staff changes during this Inquiry, which impacted on its resources and contributed to the need to extend the timelines for the tabling of the Report.

I would like to acknowledge the former Executive Officer of the Secretariat, Mr Paul Bourke, and Mr Marcus Bromley for acting in this role for three months. In addition, I want to thank Dr Janine Bush, who led the Inquiry from January 2009. I also extend my appreciation to the other staff of the secretariat, research officer Dr Tanya Caulfield, former committee administrative officer, Ms Lara Howe, and Mr David Critchley, the current acting committee administrative officer. I also acknowledge the contribution and assistance of the consultant, Deloitte Touche Tohmatsu.

Functions of the Committee

S. 11. The functions of the Family and Community Development Committee are, if so required or permitted under this Act, to inquire into, consider and report to the Parliament on:

(a)   any proposal, matter or thing concerned with –

   (i)   the family or the welfare of the family

   (ii)   community development or the welfare of the community

(b)   the role of Government in community development and welfare including the welfare of the family.

Members

COMMITTEE MEMBERS

Mr Jude Perera, MLA (Chair)   *Cranbourne*
Mrs Jeanette Powell, MLA   *Shepparton*
  (Deputy Chair; also A/g Chair from 9 February 2009 until 29 May 2009)
Mr Bernie Finn, MLC   *Western Metropolitan*
Ms Marlene Kairouz, MLA (from 26 February 2009)   *Kororoit*
Mr Wade Noonan, MLA   *Williamstown*
Mr Johan Scheffer, MLC   *Eastern Victoria*
Mr Adem Somyurek, MLC (until 25 February 2009)   *South Eastern*
Ms Mary Wooldridge, MLA   *Doncaster*

STAFF

Mr Paul Bourke   *Executive Officer*
  (until 10 October 2008; on leave 25 August 2008 until 10 October 2008)
Mr Marcus Bromley   *A/g Executive Officer*
  (from 27 August 2008 until 31 October 2008)
Dr Janine Bush (from 19 January 2009)   *Executive Officer*
Dr Tanya Caulfield   *Research Officer*
Ms Lara Howe (until 9 November 2009)   *Committee Administration Officer*
Mr David Critchley (from 28 September 2009)   *A/g Committee Administration Officer*

CONSULTANTS FROM DELOITTE (25 June 2009 to 8 October 2009)

Ms Melissa Skilbeck
Mr David Graham
Ms Leah Tang
Ms Sruthi Srikanthan

Terms of Reference

Inquiry into the Provision of Supported Accommodation for Victorians with a Disability or Mental Illness

To the Family and Community Development Committee — for inquiry, consideration and report no later than 30 June 2009 on the provision of supported accommodation for Victorians with a disability and/or mental illness and, in particular, the Committee is asked to report on the current situation in Victoria and compare it to best practice in other jurisdictions regarding:

1) the standard and range of accommodation currently available;

2) the extent of accommodation and services currently available, including the different models for service delivery and funding;

3) the methods for measuring unmet demand for accommodation and how these can be improved;

4) the process for managing service quality;

5) availability of sufficient accommodation to meet future demand with an appropriate range of services;

6) access and service issues for particular groups, including rural communities, culturally and linguistically diverse communities and indigenous Australians;

7) the impact on families of the current service provision of accommodation; and

8) for the purpose of this Inquiry 'supported accommodation' means public and private accommodation provided for people with a disability or mental illness who need additional support services but excludes mental health treatment services (SEC,[1] PARC[2]) and the disability forensic program (SFS[3])

The reporting date was extended to 15 December 2009 by resolution of the Legislative Assembly on 31 March 2009.

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[1]   Secure Extended Care
[2]   Prevention and Recovery Care
[3]   State-wide Forensic Services

Legislative Council

Inquiry on the State Governments Provision of Supported Accommodation for Victorians with a Disability or Mental Illness

That this house requires the Family and Community Development Committee to inquire, consider and report, no later then 30 June 2009, on the state government's provision of supported accommodation for Victorians with a disability and/or mental illness with regard to the following:

1) description of current government funded supported accommodation, including the number and location of places, occupancy, staffing, demand management, methods of funding and oversight;

2) the adequacy of the current number of places and care provided in community residential units, residential institutions, community care units, secure extended care units, prevention and recovery care facilities and other forms of supported accommodation;

3) the adequacy and appropriateness of care and accommodation provided in various government, private and community facilities that accommodate clients with a disability or mental illness because of insufficient places in the specialist system, and in particular including supported residential services, boarding houses, public hospitals, nursing homes and SAAP[4] funded services;

4) the impact on Victorian families of insufficient supported accommodation;

5) estimates of future supported accommodation needs and the appropriateness and transparency of the Government's management of demand and placement;

6) the government's response to unmet accommodation needs, including sources of funding, planning and delivery;

7) the ability of country Victorians to access supported accommodation and the appropriateness and quality of care they receive;

8) the ability of members of culturally and linguistically diverse communities to access supported accommodation and the appropriateness and quality of care they receive;

9) the appropriateness of the current mix of service providers, including government, private and community; and

10) alternate approaches addressing unmet needs in supported accommodation in Victoria.

The reporting date was extended to 15 December 2009 by resolution of the Legislative Council on 2 April 2009.

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[4]   Supported Accommodation Assistance Program

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Glossary of Acronyms

ABI	Acquired brain injury
ABS	Australian Bureau of Statistics
AIHW	Australian Institute of Health and Welfare
AMHS	Area mental health service
AOD	Alcohol and other drugs
ASD	Autism spectrum disorders
ATSI	Aboriginal and Torres Strait Islander
BEACH	Bettering the Evaluation and Care of Health
BIS	Behavioural intervention support
CALD	Culturally and Linguistically Diverse
CCU	Community care unit
CDDS	Centre for Disability Developmental Studies
COAG	Council of Australian Governments
CRIS	Client Relationship Information System
CRU	Community Residential Unit
CSO	Community service organisation
CSTDA	Commonwealth and State/Territory Disability Agreement
DADHC	Department of Ageing, Disability and Home Care (NSW)
DDSOs	Disability Development and Support Officers
DEECD	Department of Education and Early Childhood Development
DHS	Department of Human Services
DoHA	Department of Health and Ageing
DS NMDS	Disability Services National Minimum Data Set
DSD	Disability Services Division
DSR	Disability Support Register
GP	General practitioner
HACC	Home and community care
HACSU	Health and Community Services Union
HASI	Housing and Accommodation Support Initiative
HASP	Housing and Support Program
HBOS	Home based outreach services
IRRC	Integrated Rehabilitation and Recovery Care
ISP	Individual Support Packages

JGOS	Joint Guarantee of Service (NSW)
KRS	Kew Residential Services
MACN	Multiple and Complex Needs (initiative and program)
MDS	Minimum Data Set
MHCA	Mental Health Council of Australia
MST	Mobile Support Team
NDA	National Disability Agreement
NDS	National Disability Services
NGO	Non government organisation
NHMD	National Hospital Morbidity Database
NMHED	National Mental Health Establishments Database
NP	Nurse Practitioner
NRMHCD	National Residential Mental Health Care Database
PARC	Prevention and Recovery Care
PBS	Pharmaceutical Benefits Scheme
PDRSS	Psychiatric disability rehabilitation and support services
RAC	Residential Aged Care
RRS	Residential Rehabilitation Service
SAAP	Supported Accommodation and Assistance Program
SAS	Supported accommodation services [mental health]
SAVVI	Supporting Accommodation for Vulnerable Victorians Initiative
SDAC	Survey of Disability, Ageing and Carers
SECU	Secure extended care unit
SNR	Service Needs Register
SRS	Supported residential service
SSA	Shared supported accommodation
TAC	Transport Accident Commission
VWA	Victorian WorkCover Authority

Executive Summary

T he Committee has considered the provision of supported accommodation for Victorians with a disability and/or mental illness. People with a disability and/or mental illness are amongst the most vulnerable members of the community. The Committee recognises the importance of providing services that promote the rights and self-determination of people with a disability and/or mental illness, and that also ensures their living environments are safe, secure and promote community participation and social inclusion.

In its Inquiry, the Committee heard from many people and organisations that contributed a diverse range of perspectives. Families attended public hearings and told the Committee of the challenges they faced as carers of people with a disability and/or mental illness. Service providers informed the Inquiry of the pressures they experienced in service delivery and also of emerging innovative practices. The Committee also heard from peak organisations, researchers, unions and self-advocacy groups. The Victorian Government provided information to the Committee about the current provision of supported accommodation and new developments yet to be fully implemented.

In preparing its final report, the Committee has considered all of these views and has sought to strike a balance that reflects the diversity of experiences in the provision of supported accommodation for people with a disability and/or mental illness in Victoria.

The Committee found that responses to people with a disability and/or mental illness occur through two large service systems that are complex, diverse and interconnected. It also found that service needs of people with a disability often differ from those of people with a mental illness, and the report aims to reflect these differences.

The Committee recognises that significant policy and legislative reform is occurring in the provision of supported accommodation for Victorians with a disability and/or mental illness, and found that there is overwhelming support for the move away from institutionalised approaches. 'Institutionalisation' was consistently characterised as the manner in which care and support is provided to an individual, rather than the number of people who are co-located in the facility.

It was also made aware that the change necessary to meet the objectives of the Victorian Government brings with it challenges. In particular, the Committee heard a consistent message that there are high levels of demand that are not being met by the current levels of supported accommodation provision.

The report identified several broad themes relating to the future provision of supported accommodation for Victorians with a disability and/or mental illness. These are:

- Long-term planning for the future
- Strengthening the link between accommodation and support
- Setting funding priorities
- Improving cross-sector collaboration
- Promoting innovation and continuous improvement
- Improving implementation processes and evaluation.

While discussed separately at various stages in the report, the Committee is mindful that these issues overlap and are inter-connected.

Long-term planning for the future

The Committee identified that over the past two decades there have been broad reforms in both the mental health and disability sectors. These have led to the closure and redevelopment of institutions that provided support and accommodation for people with a disability and/or mental illness.

In this context of ongoing change, the current Victorian Government has outlined its broad vision for mental health and disability services in two key strategy documents – the *State Disability Plan, 2002-12* and *Because Mental Health Matters: Victorian Mental Health Reform Strategy, 2009-19*.

The Committee identified three broad areas of change impacting on supported accommodation:

1) changes in demand for services,

2) changes to the way services are provided, and

3) changes in community expectations.

The Committee recognised that for the Victorian Government to achieve its reform goals it must firstly have a comprehensive understanding of the trends and secondly, it must plan effectively within a changing environment.

Changes to demand for services

Demand for services is evolving as a consequence of

- Policy changes (for example, expanded definitions of disability with the introduction of the *Disability Act 2006*) and
- Changing demographics (for example, increasingly diverse and complex needs and an ageing population).

The expanded definition of disability has two consequences. Firstly, there is the potential that greater numbers of people with a disability will seek to access services in the system. Secondly, the different types of disability will result in people with more diverse and complex needs using services and trying to access them. For example, the Committee heard that the disability service system is not yet equipped to respond effectively to people of all levels of severity of autism spectrum disorder who became eligible to use disability services in December 2008.

The Committee found that there are demographic trends that will contribute to increased numbers of people with a disability and/or mental illness in the Victorian community. In addition, the ageing population will potentially impact on service provision and service demand for both disability and mental health services.

The Committee heard considerable evidence relating to the experiences of older carers who are concerned for the future of their family member with a disability and/or mental illness. Many people in these situations told the Committee of their fears and uncertainties about what will happen when they can no longer continue in their caring role. The Committee identified a need for the Victorian Government to improve planning for carers in these circumstances.

The Committee found that data collection in Victoria does not enable effective planning based on future needs of people with a disability and/or mental illness in Victoria. In view of increasing demand for services and limited availability of services, the Committee considered a need for the Victorian Government to improve population based planning for the support and accommodation needs of people with a disability and/or mental illness in Victoria.

Changes to the way services are provided

To successfully deliver person-centred and recovery-oriented approaches, the Committee identified a need for further changes to practices and the way services are provided. Evidence given to the Committee stressed the importance of developing sector capacity to provide individualised approaches and to contribute to social inclusion and community participation. Previous reviews by the Victorian Auditor-General (relating to disability services) and the Boston Consulting Group (relating to mental health services) have highlighted the need for improvements to practices and service provision.

The Committee found that the Victorian Government has introduced a range of initiatives relating to workforce capacity and quality systems in both the disability and mental health service systems.

The Committee heard that the workforce underpins the quality of service provision for people with a disability and/or mental illness. The Committee supports the Victorian Government's new initiatives that aim to build workforce capacity in both the disability and mental health sectors. At the time of the

Inquiry, these initiatives were either in the process of being implemented or yet to be rolled out.

Participants in the Inquiry also raised the issue of improving quality monitoring processes. A key challenge in regard to quality monitoring relates to new practices that are not subject to the same scrutiny as are supported accommodation services. The Committee supports the Victorian Government's new initiatives to improve quality service systems, complaints mechanisms and monitoring of services in the context of changing practices. It noted that in disability services, these new initiatives were yet to be fully implemented.

The Committee has recommended further strengthening the role of external monitors, such as the Disability Services Commissioner. In addition, it considers that the Victorian Government needs to ensure that external monitors, such as the Community Visitors, remain relevant to new practices and service approaches.

Changing community expectations

The Committee found that community expectations of mental health and disability services are increasing. This is due to generational change and new approaches to the provision of services, such as those that focus on the individual.

In addition to the perceived potential of new service models to enhance the quality of life of people with a disability and/or mental illness, the community has increased expectations regarding standards, communication and quality of service provision. Some families told the Committee they were yet to experience the benefits of reforms underway in relation to quality of service. The Committee considers there is a need for the Victorian Government to develop a strategy for more effectively communicating its progress and to manage expectations.

On the other hand, a number of participants were unaware of developments in these areas. The Committee has made recommendations relating to the need for improved methods of communication with participants in the disability and mental health sectors, particularly families in caring relationships.

The Committee has emphasised the importance of providing clear information about new approaches to accessing and delivering services. It considers the Victorian Government has a responsibility to minimise confusion, to clarify expectations and to assist people to adjust to reforms.

Strengthening the link between support and accommodation

Traditional supported accommodation services link support and accommodation in practical ways, which is a central reason they are a favoured model for people with a disability and/or mental illness. The Committee heard from participants that this link is critical.

The Committee also heard that the Victorian Government leads the way in exploring alternatives to traditional models of support and accommodation. As noted, the move to close or redevelop institutions was broadly supported by participants in the Inquiry. A consequence of the move to close institutions, however, has been an increasing separation of the provision of support and accommodation. The Committee therefore considers there is a need for the Victorian Government to strengthen the links between accommodation and support in both mental health and disability services.

The mental health sector has moved to a model where it assumes responsibility for support and treatment, yet not for long-term accommodation. The disability sector is increasingly investing in support in the form of Individual Support Packages that have no accommodation attached. The Committee supports the increased flexibility these options provide for people with a disability and/or mental illness, but realises they do not deliver for some people who need accommodation linked to the support.

The Victorian Government recognises the significance of ensuring accommodation options are made available for people with a disability and/or mental illness. The move away from more traditional models such as shared supported accommodation, however, has led to a focus on other forms of accommodation, such as public housing and housing associations, which have no formal support attached. Some people in these accommodation settings are unable to access the support they require. In addition, when families and carers can provide accommodation, they can't always access the level of support they require to maintain their caring responsibilities.

In view of these developments, the Committee has recognised a need for an improved continuum of services to ensure stronger linkages between accommodation and support. In addition to existing models of supported accommodation, this includes:

- increased availability of accommodation with appropriate levels of support attached

- improved exit strategies – in both mental health (from treatment to accommodation) and disability (from shared supported accommodation to independent living in the community)

- improved transition pathways – for example, from family home to shared supported accommodation.

Setting funding priorities

The Committee heard considerable evidence regarding the need for greater investment in supported accommodation options in view of the pressures on supply and high levels of demand.

The Committee learnt that in both disability and mental health services, Victoria provides more supported accommodation than other jurisdictions in Australia with less Commonwealth funding. At the same time, however, the Committee also recognised that Victoria needs to contribute additional resources to the provision of supported accommodation for Victorians with a disability and/or mental illness in view of current levels of unmet demand and expected demographic changes into the future.

The Committee identified three broad issues relating to funding for supported accommodation. Firstly, the likelihood that demand will be greater than supply will present an ongoing challenge for the Victorian Government. The Australian Institute of Health and Welfare (AIHW) has undertaken significant work relating to needs and demands in the context of social services. It notes that 'typically, the demand for publicly provided resources tends to exceed supply'.[5] In disability services, the number of people with current unmet needs is partly identified by the Disability Services Register and at the time of the Inquiry, nearly 1,300 people were registered as eligible for disability supported accommodation. In mental health services, on the other hand, there is no register that enables current unmet demand for accommodation with support to be effectively identified or measured.

It is likely that demand will continue to increase in view of the growing numbers of people with a disability and/or mental illness and increasing expectations of governments to provide services to support people with a disability and/or mental illness.

The Committee has found that the Victorian Government needs to invest more in stable, long-term supported accommodation options for people with a disability and/or mental illness. In addition, it found that the Victorian Government needs to invest further in respite options to support families to continue in their caring role and to give people with a disability and/or mental illness the option to stay at home.

Secondly, it heard that for many organisations the cost of delivering services is greater than the funds received to provide the service. In the disability sector, the Victorian Government has recognised this and commissioned an external review by PricewaterhouseCoopers. In 2009, this review recommended a price adjustment to reflect current service needs.

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[5]   Australian Institute of Health and Welfare (2007) *Current and future demand of specialist disability services.* Disability series, cat. no. DIS 50, AIHW, Canberra, p.16.

Thirdly, where there are limitations on available resources, the Committee identified the need for the Victorian Government to involve service providers and families more effectively in setting its funding priorities.

In particular, the Committee has found that there is scope for a more consultative approach to determining funding priorities based on the strategic directions outlined by the Victorian Government for the next five to 10 years in both the disability and mental health sectors.

Improving cross-sector collaboration

In looking at two sectors that provide support and accommodation to people with a disability and/or mental illness, the Committee was made aware of the need for the Victorian Government to further improve collaboration and linkages across the two service systems. People with dual and multiple disabilities require access to both mental health and disability services. Yet the Committee heard that for many people needing access to services from both systems, the lack of coordination often prevents people receiving the level of support, expertise and accommodation they need.

The Committee has recommended that the Victorian Government improve the collaboration and linkages across mental health and disability services and housing providers. More specifically, the Committee suggested that the Victorian Government:

- improve clarity of roles and responsibilities across divisions and departments in the context of support and accommodation
- develop and review cross-sector protocols
- increase understanding across workforces in different service systems and develop cross-sector workforce initiatives – through professional development and increased exposure to practices in other sectors.

Promoting innovation

The Committee's Inquiry has identified new visions and objectives for achieving social inclusion and community participation for Victorians with a disability and/or mental illness. These include new service approaches (such as person-centred support), specific initiatives (such as the Disability Services Accommodation Innovation Grants) and targeting innovation in the workforce (such as initiatives in the new Mental Health Reform Strategy).

The Committee found that when compared with other states, the Victorian Government is innovative in its approach to the development of supported and accommodation service models.

Nevertheless, the Committee also identified a need for greater innovation to create services that meet the support and accommodation requirements of those whose needs are currently not being met. For example, people with dual and multiple disabilities and people with high, complex and changing needs.

The Committee has made the following recommendations to the Victorian Government:

- The need for ongoing innovation in the context of change
- The importance of innovation to diversify models to meet the increased range of needs
- The importance of continuous improvement and ongoing learning from effective and evaluated models.

In addition, the Committee has determined that the Victorian Government needs to promote innovation to ensure that practices and service developments keep pace with broader policy objectives.

Improving implementation and evaluation

The Committee found both a perception and experience within the community that the implementation of the Victorian Government's reform agenda hasn't always matched the intended objectives for people with a disability and/or mental illness. The Committee considers there is a need to improve both implementation and evaluation processes to ensure that the intention becomes embedded in the experience of those who access services.

To ensure the Victorian Government is successfully implementing its broad range of strategies and frameworks, the Committee considers a stronger focus is needed on the delivery of these plans. Furthermore, this needs to be achieved through detailed implementation plans with clear accountabilities, specific timelines, funding allocations and intentions for communicating the implementation.

A key challenge identified in this is that the objectives of the Victorian reform agenda are very broad, such as 'community participation', 'quality of life' and 'recovery'. These are potentially difficult to measure. A critical measure of success is the extent to which people in the community experience the proposed improvements. How do we know if the lives of people with a disability and/or mental illness have improved? This measure will vary according to whether involvement with the service systems is as people with a disability and/or mental illness, families in caring roles or service providers.

The Committee identified a need for the Victorian Government to improve evaluation on three broad levels:

- Developing tools to measure broad objectives contained in overarching policy frameworks, such as increased social inclusion and participation for people with a disability and/or mental illness

- Ongoing evaluation of strategies introduced to further those goals – such as carer action plans, strategies for culturally and linguistically diverse communities, workforce strategies and quality frameworks

- Embedding evaluation into all new programs and service models.

The Committee found that many strategies developed by the Victorian Government to achieve improved service outcomes are based on sound principles and important objectives.

The Committee has recommended that the Victorian Government integrate ongoing evaluation, accountability and public reporting on progress in all strategy documents relating to the provision of support and accommodation for people with a disability and/or mental illness.

Summary of Recommendations

3. Legislative and Policy Frameworks

5. Need and Demand for Supported Accommodation

6. Supported Accommodation in Other States

7. Experiences of Supported Accommodation — Disability Services

8.   Experiences of Supported Accommodation — Mental Health

9. Quality Systems & Workforce Capacity

10. Caring relationships and people with a disability and/or mental illness

11.   Consequences of the Imbalance between Supply and Demand

12.   Alternative Supported Accommodation Options

Part A:

Context

Chapter One: Introduction

O n 26 February 2008, the Parliament of Victoria requested that the Family and Community Development Committee inquire into, consider and report on the provision of supported accommodation for Victorians with a disability and/or mental illness.

The Committee received separate references from the two Houses of Parliament, the Legislative Assembly and Legislative Council, relating to broadly the same issue. The Committee made a decision to combine the Terms of Reference. The rationale for this decision is explained later in this chapter.

Supported accommodation for Victorians with a disability and/or mental illness has seen significant changes over the past two decades, influenced by international moves to close institutions. This has led to shifts in the delivery of support services and the accommodation options for people with a disability and/or mental illness. Reforms have led to a greater focus on person-centred and self-directed approaches, with services increasingly tailored to individual needs. The broad social policy objective of increased social inclusion and community participation has also influenced these changed directions.

The provision of supported accommodation for people with a disability varies significantly from that provided for people with a mental illness. Furthermore, definitions of 'supported accommodation' differ across the two sectors. The Committee has sought to reflect these differences through this report.

In its Inquiry, the Committee found that the Victorian Government has in place policies, strategies and frameworks for service delivery, monitoring and regulations relating to supported accommodation. Furthermore, there continues to be ongoing work in the context of legislative review, the development of policy, new strategies and investment in areas related to supported accommodation.

The implementation of these wide-scale reforms has presented challenges for the Victorian Government. A number of recent reviews and inquiries have demonstrated that there are gaps between intended service models and the actual delivery of services. The Committee heard that key issues relate to workforce capacity to adapt to changing practices, service capacity to comply with standards and quality frameworks and the capacity of the service system to plan for and meet increasing demand for services. The Victorian Government's methods of communication with key participants were identified as an area in need of improvement.

While there have been dramatic shifts in the provision of support and accommodation, there has not been any extensive evaluation of the service systems to determine whether current models are providing the intended outcomes of increased social inclusion and community participation.

This report addresses these challenges.

1.1   Supported accommodation in Victoria

Supported accommodation services, as defined by the Committee, cover a number of arrangements of varying intensity and duration.

Most of the formal service options in the specialist systems involve two dimensions: the provision of accommodation itself, and the support services required for the person to live in the community. Many services provide both, with the significant exception of in-home support (personal care, assistance with other activities of daily living, transport etc) in disability and home-based outreach support in mental health.

The role of supported accommodation as part of a service response often differs greatly between the mental health and disability sectors.

Supported accommodation services vary widely in intensity and planned duration. The term generally describes the provision of support in a residential context, such as a group home. The duration of stay varies according to individual needs as well as to the service type, and can range from short periods in respite or in a transitional rehabilitation facility through to long-term placement in a permanent home.

In addition, the Committee has considered other support options (with no linked accommodation) that aim to make living at home – independently, with family or social networks – more sustainable. In the disability services system, these include in-home assistance (for example Health and Community Care services) as well as respite arrangements.

In addition to accommodation in the specialist systems, some people with a disability and/or mental illness may use mainstream housing services. Because these are out of the scope of the Inquiry, they are not addressed in detail.

1.1.1   Disability supported accommodation

The stated objective of disability services in Victoria is to provide opportunities for people with a disability to live in accommodation with support, with the goal of enriching their quality of life. This might be accommodation provided by the Victorian Government or accommodation in the community. The nature of the support provided varies according to the nature of the accommodation.

Approaches to supported accommodation in the specialist disability sector largely revolve around shared supported accommodation options. These are generally small group homes of four to six that are staffed by disability support workers who provide assistance with daily living tasks.

For people with a disability who require assistance with daily living tasks but are living independently in the community, the Victorian Government has

established individual support packages (ISPs). These packages are an emerging alternative to support and accommodation for people with a disability and enable people with a disability to choose the supports they require to meet their individual needs. While ISPs are an alternative to supported accommodation, the Committee has considered them in the context of the Inquiry.

Until 2002, supported accommodation services for people with a disability in Victoria largely responded to people with an intellectual disability. With the release of the *State Disability Plan* in 2002 and the commencement of the *Disability Act 2006* in July 2007, the definition of disability expanded to include a range of different types of disabilities, including physical disability, intellectual disability, sensory disability, acquired brain injury (ABI) and neurological impairment.

The recent re-orientation of disability services, therefore, has seen an expansion of eligibility for services, the introduction of person-centred approaches to support and new requirements for services to respond to different disabilities and associated individual needs.

1.1.2   Mental health supported accommodation

Supported accommodation for people with a mental illness is significantly different from the services provided by disability services. Based within the health system, residential mental health services have a strong medical and clinical focus. Two components of the mental health sector are relevant to the Committee's consideration of support and accommodation options: clinical bed-based treatment services and non-clinical bed-based services with support.

In view of its medical focus, the term 'accommodation' is not frequently used to define residential services provided in the mental health sector. The Victorian Government notes however, that some clinical services provide home-like settings to support people with a mental illness to make a transition back to the community following treatment. For example, the Department of Health explains that Community Care Units (CCU)

> provide medium to long-term accommodation, clinical care and rehabilitation services for people with a serious mental illness and psychosocial disability. Located in residential areas, they provide a 'home like' environment where people can learn or re-learn everyday skills necessary for successful community living. While it is envisaged that people will move through these units to other community residential options, some consumers require this level of support and supervision for a number of years.[6]

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[6]   Department of Health (2009) 'Victoria's Mental Health Services: Adult Specialist Mental Health Services'. Accessed from
<https://www.health.vic.gov.au/mentalhealth/services/adult/index.htm> on
30 September 2009.

Similarly, Prevention and Recovery Care (PARC) services are described by the Department of Health as a 'new supported residential service for people experiencing a significant mental health problem but who do not need or no longer require a hospital admission. In the continuum of care, they sit between adult acute psychiatric inpatient units and a client's usual place of residence'.[7]

In this Inquiry the Committee has considered residential clinical-based services, including Secure Extended Care Units (SECU), CCU and PARC services, in addition to residential non-clinical specialist mental health support such as residential rehabilitation. NorthWestern Mental Health expressed its view that these programs 'cited in the Inquiry's Terms of Reference should not be thought of as "supported accommodation services", but rather treatment and rehabilitation programs in bed-based/residential settings'.[8]

Unlike the supported accommodation settings provided in the disability sector, the residential services provided in the mental health sector are transitional forms of accommodation. Transitional stays in mental health residential settings can be up to two years.

The Committee heard that accessing affordable, safe and long-term accommodation is a significant issue for people with a mental illness. For a person with a mental illness, support is often required to sustain a tenancy. The Home Based Outreach Support (HBOS) provided by the Psychiatric Disability Rehabilitation and Support Services (PDRSS) is a key component of the options available to people with a mental illness seeking to live independently in the community and to sustain their accommodation. While HBOS is an alternative to supported accommodation, the Committee has considered its role in the continuum of related services provided.

1.2   The changing context for supported accommodation

This Inquiry was conducted at a time when reforms were underway in the provision of supported accommodation for people with a disability and/or mental illness. This section outlines key trends in the community services that have significantly changed service provision in recent years.

1.2.1   Person-centred support

Implicit in models of person-centred and self-directed support (which have largely underpinned the move to supported accommodation in the community rather than providing care in residential settings) is the objective of maximum self-determination for those with a mental illness and/or disability. In the context of supported accommodation, this has a number of implications.

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[7]   Department of Health, 'Victoria's Mental Health Services' [see Footnote 6].
[8]   *Submission* 119, p.1 (NorthWestern Mental Health).

Firstly, to adequately meet the needs of people with a mental illness and/or disability, the system must have a range of accommodation options available and accessible so that, to the extent possible based on needs, there is a choice of where to live.

Next, the planning of support and accommodation service provision should as far as possible be based on a person's own needs and aspirations.

Finally, the provision of these services should support and facilitate the maximum possible independence. In terms of accommodation, this may include appropriate accessibility through the location and design of the house, as well as ensuring that support is provided to the extent necessary.

1.2.2   Public administration trends

The closure of institutions has resulted in changes to the public administration of services. The provision of supported accommodation has been transferred from solely government-managed institutions to a mix of providers across government, health and community service organisations (CSOs) and private services. One the whole, service provision is largely carried out by external CSO bodies contracted by the Victorian Government, while in other areas the government continues to provide services.

An outcome of these changes has been a transition to a focus on service 'outputs'. This provides clarity in contracting arrangements, which include statements regarding the nature of the services purchased by government. Funding is increasingly based on these outputs, which differs from earlier arrangements where funds were allocated according to program inputs.

A parallel can be seen between these structural shifts and the change towards person-centred rather than service-centred conception of human services systems. Services that have been planned, funded and monitored on the basis of outputs should, in theory, be more amenable to the individualised approaches described above.

1.2.3   Demographic trends

Changes in community demographics have also been a factor in shaping overarching trends in the human services. In particular, the awareness of significant demographic shifts in future decades is contributing to service changes.

Trends suggest that there are increasing numbers of people with a disability and/or mental illness. In addition, the ageing of the population is likely to mean that a larger group of people with a disability and/or mental illness will require formal or additional supports. Two factors emerge from the ageing population.

Firstly, people with a disability and/or mental illness are getting older and living longer, often with associated complex health needs. Secondly, many carers are also ageing and, as the Committee identified, are sometimes no longer able to provide the levels of support required.

At the same time, these pressures will affect all of the human services, which will have flow-on effects in disability and mental health supports as funding must be spread further and the workforce (already, according to many, severely constrained) must similarly be increased.

Demographic changes can also generate shifts in community views and expectations concerning support services.

1.2.4   Closure of institutions

The shift from providing human services in residential institutions to community locations has been a significant change influencing service delivery in both the mental health and disability sectors. The closure of institutions, the reduction in entry to institutions and the re-location of residents to the community has reformed the principles and practices of accommodation for people with a mental illnesses and/or disability.

Historical trends led to the closure of institutions in developed counties across the world internationally from the 1950s. These trends included:

- Increasing recognition of the negative effects of institutionalisation
- Growing public awareness of poor conditions and mistreatment of residents in some institutions
- Development of relatively effective pharmacological and psychotherapeutic management of mental illness
- Politicisation of, in particular, people with a disability in 'disability rights' movements.

A number of factors further contributed to the move to close institutions. These included changing ideas about human services, shifting modes of public administration and financing of services, and the emergence of person-centred perspectives concerning support for both disability and mental health.

Research findings – Outcomes of the closure of institutions

One of the most significant criticisms of institutionalised models of care for people with a disability and/or mental illness was that the services they provided were a 'one size fits all' approach. This approach assumed that if a person couldn't live independently without support, they required residential care. The results of the closure of institutions –

a very substantial shift in both policy and practice – have not been uniform.[9]

Disability

In general, researchers have concluded that for people with intellectual, developmental and learning disabilities, the outcomes of deinstitutionalisation have been positive. In 1998, a review of Australian research on the closure of institutions found that there were positive results in six of the nine studies undertaken. These included improvements in a range of measures, such as adaptive behaviour, 'problem behaviour', and community participation.[10] Similar results have been reported in Kim et al's 2001 meta-analysis of American studies of residents who move from an institutional to a community based setting. This assessment reviewed 29 studies undertaken between 1980 and 1999. Of these, the researchers found that 19 reported significant improvements in adaptive behaviour, while five found significant improvements in behaviours of concern.[11]

These outcomes, however, are not conclusive. In both of the meta-analyses noted above, researchers found variation in impacts reported, and a minority of studies in fact showed significant declines in reported outcome measures. Jim Mansell notes that research findings about the effects of deinstitutionalisation on people with disabilities vary according to the range of abilities and characteristics of residents, as well as the model and quality of community based accommodation involved. Mansell identifies staff performance and service design as a key factor in the better outcomes. In particular, a critical component is the extent to which the service model involves active support of residents.[12]

Mental health

As in the case of people with a disability, the outcomes of closure of residential institutions for people with a mental illness are inconclusive. There is some evidence that the effects for former residents have been positive. The Team for Assessment of Psychiatric Services (the TAPS project) have undertaken long-term studies of outcomes for former patients of London psychiatric institutions. The study found that most

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[9]   Bostock, L., Gleeson, B., McPherson, A. & Pang, L. (2000) *Deinstitutionalisation and housing futures: positioning paper*. Australian Housing and Urban Research Institute, New South Wales, December.

[10] Young, L., Sigafoos, J., Suttie, J., Ashman, A. Grevell, P. (1998) 'Deinstitutionalisation of persons with intellectual disabilities: a review of Australian studies'. *Journal of Intellectual and Developmental Disability,* Vol. 23(2), pp.155-170.

[11] Kim, S., Larson, S. & Lakin, K. (2001) 'Behavioural outcomes of deinstitutionalisation for people with intellectual disability: a review of US studies conducted between 1980 and 1999'. *Journal of Intellectual & Developmental Disability*, Vol. 26(1), pp.35-50.

[12] Mansell, J. (2006) 'Deinstitutionalisation and community living: progress, problems and priorities'. *Journal of Intellectual & Developmental Disability,* Vol. 31(1), pp.65-76.

> former patients preferred being in the community, that few were re-admitted, and that almost none were 'lost' in follow up years.[13] In the Australian context, in 2000, Newton et al undertook an ethnographic study of a group of hospital patients as they moved to supported accommodation in the community. The research undertook a detailed 'analysis of the residents' daily lives. This study found that the majority of residents preferred living in the community, and noted some improvement in symptoms and living skills.[14]

The process of closing institutions in Victoria has occurred differently in the mental health and disability sectors. In the 1990s, large hospital institutions for people with a mental illness were closed across the state. From 1994 to 1995, 'with the exception of the forensic mental health service, the general health system took over management of all government-run mental health services'.[15] By mid-1998, all Victorian 'psychiatric institutions' had been closed (or were in the process of closure), and a range of inpatient, residential and community services had been established across the state in 21 area mental health services (AMHS).

The closure or 'redevelopment' of residential institutions in Victoria's disability sector, on the other hand, has occurred in a less systematic way and is still in progress. The options for people with a disability leaving institutions were to move into small group homes, previously known as community residential units (CRUs) and now referred to as shared supported accommodation (SSA), or to live independently with support in the community (generally with family).

Following these moves to close institutions, a range of different service models emerged that informed new directions in responses to people with a disability and/or mental illness. Notably, responses to mental illness and responses to disability were distinctly different in their new manifestation.

Furthermore, the historical arrangements of mental health and disability services still affect current services. For example, the traditional emphasis on clinical services in mental health means that it is funded through the health system.

It is important to acknowledge that the closure of institutions does not necessarily equal deinstitutionalisation. As the World Health Organisation notes, in relation to changes in mental health service paradigms,

> De-institutionalization … is not synonymous with de-hospitalization. De-institution-alization is a complex process leading to the implementation of

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[13] For a summary of TAPS work, see O'Driscoll, C. (1993) 'The TAPS project 7: mental hospital closure—a literature review of outcome studies and evaluative techniques'. *British Journal of Psychiatry,* Vol. 162 (Supplement).

[14] Newton, L., Rosen, A., Tennant, C., Hobbs, C., Lapsley, H. & Tribe, K. (2000) 'Deinstitutionalisation for Long-term Mental Illness: An Ethnographic Study'. *Australian and New Zealand Journal of Psychiatry,* Vol. 34, pp.484-490.

[15] Gerrand, V. (2005) 'Can deinstitutionalisation work? Mental health reform from 1993 to 1998 in Victoria, Australia'. *Health Sociology Review*, Vol.14(3), p.260.

a solid network of community alternatives. Closing mental hospitals without community alternatives is as dangerous as creating community alternatives without closing mental hospitals.[16]

Similarly, in 2006 researchers Christine Bigby & Chris Fyffe suggested that 'deinstitutionalisation' needs to be considered separately from the closure of institutions:

Institutional closure [is] the progressive reduction in the number of people with disabilities living in a large residential facility or the cessation of a facility's operations. In contrast, deinstitutionalisation is more complex, involving more than simply closure of institutions, requiring significant individualised support to people with intellectual disabilities as well as societal change.[17]

The Committee heard that the features of psychological institutionalisation may be seen in someone who has been involved with a service system regardless of whether services are located in the community or in a physical institution. These features have been identified as a set of reactions to living in institutions, including apathy, social isolation, reduced self-determination and resignation.

1.2.5   Human rights and social inclusion

There have also been less tangible changes in expectations and understanding of what is adequate in the context of supported accommodation.

People with a disability and/or mental illness, as well as their families and support networks, have consistently driven forward the idea of human rights as the basis of support services. The Victorian Government has increasingly turned to human rights frameworks to inform its service delivery to people with a disability and/or mental illness.

For example, in 2006 the Victorian Government introduced the *Charter of Human Rights and Responsibilities Act 2006* that informs service provision to people with a disability and/or mental illness. Furthermore, in 2008 the Australian Government ratified the United Nations Convention for the Rights of People with Disabilities, which contains specific Articles that inform approaches to support and accommodation for people with a disability (including people with a psychiatric disability).

International social policy developments promoting social inclusion and community participation have also significantly influenced Victorian social policy. The Victorian Government's social policy, *A Fairer Victoria*, is a broad,

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[16]   World Health Organisation (2001) *Mental Health: New Understanding, New Hope. World Mental Health Report 2001*. Accessed from <http://www.who.int/whr/2001/en/> on 1 October 2009.

[17]   Bigby, C. & Fyffe, C. (2006) 'Tensions between deinstitutionalisation and closure of institutions: what can be learned from Victoria's institutional redevelopment?'. *Disability and Society*, Vol.21(6), p.569.

whole-of-government social policy statement that aims to promote government and community commitment to principles of social inclusion, support for vulnerable members of society, and integration of services.

Social inclusion

The concept of social inclusion in Australia has emerged from theoretical and policy debates on the issue of social exclusion. These concepts have provided a widely used framework for thinking about the multiple dimensions of disadvantage.

Social exclusion describes a situation where someone experiences disadvantage across several areas of their life. This may include low income, low skills, low social connectedness, unemployment, poor housing, poor health, and inadequate access to services. Factors such as disability, mental illness, homelessness, violence, or substance abuse may arise from and contribute to this exclusion, and there is substantial evidence suggesting that there are also inter-generational effects as the social exclusion of parents can lead to social exclusion of their children.[18]

Because social exclusion can reproduce over time, and because its impacts are complex and cannot be addressed in any simple or singular way, policy makers are particularly interested in social inclusion frameworks as a response to a wide range of issues.

Ideas of social exclusion (and addressing it through policies supporting inclusion) emerged during the 1980s in Europe and particularly in European Union policies. In the UK, the establishment of a Social Exclusion Unit under the Blair Government turned substantial attention to policies of social inclusion. Key characteristics of this approach to social inclusion policy included joined-up-government approaches to disadvantage (rather than dealing with issues in a fragmented way), a focus on government and non-government partnership, and an emphasis on evidence-based policy and practice.

In Australia there have been a number of social inclusion strategies developed at state levels of government, which establish whole-of-government policy frameworks with similar objectives, including *A Fairer Victoria*.[19] More recently, the Rudd Government introduced a

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[18]   See, for example, Palmer, G., MacInnes, T. & Kenway, P. (2008) *Monitoring poverty and social exclusion 2008*. Joseph Rowntree Foundation and New Policy Institute; Saunders, P., Naidoo, Y. & Griffiths, M. (2007) *Towards new indicators of disadvantage: deprivation and social exclusion in Australia*. Social Policy Research Centre, UNSW; Levitas, R., Pantazis, C., Fahmy, E., Gordon, D., Lloyd, E. & Patsios, D. (2007) *The multi-dimensional analysis of social exclusion*. Department of Sociology and School for Social Policy and Bristol Institute for Public Affairs, University of Bristol.

[19]   Hayes, A., Gray, M. & Edwards, B. (2008) *Social Inclusion: origins, concepts and key themes*. Social Inclusion Unit, Department of Prime Minister and Cabinet, Canberra; Winter, I. (2000) *Social capital and public policy in Australia*. Australian Institute of Family Studies, Melbourne.

national Social Inclusion Unit in the Department of Prime Minister and Cabinet.[20]

Underlying these policy frameworks is an aspiration to increase social inclusion not only for its own sake (as a means of reducing systemic and entrenched disadvantage) but also because greater inclusion is seen to have benefits for society as a whole, including greater community cohesion, and reduced levels of need for human services.

1.3 Scope of current Inquiry

The current Inquiry is informed by two broadly similar Terms of Reference received from both the Legislative Assembly and the Legislative Council. The Committee identified the following overlaps across the references:

- The standard and range of accommodation currently available

- The availability of accommodation and support, including models of service delivery, funding and funding oversight

- The methods and processes for measuring need and demand

- The processes for managing service quality

- Availability of sufficient support and accommodation to meet future need and demand and processes

- Access and service issues for people from culturally and linguistically diverse communities and regional and rural communities

- The impact of current availability of supported accommodation.

Additional references were included in both the Assembly and Council Terms of Reference. These are outlined in the table below.

Table 1.3–1: Legislative Assembly and Legislative Council Terms of Reference

Legislative Assembly	Legislative Council
Access and service issues for indigenous Australians	The government's response to unmet accommodation needs, including sources of funding, planning and delivery
Comparison of the current situation in Victoria with best practice in other jurisdictions	The appropriateness of the current mix of service providers, including government, private and community

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20   See also, Australian Government (2009) *The Australian Public Service policy design and delivery toolkit.* Social Inclusion Unit, Department of Prime Minister and Cabinet, Canberra.

Legislative Assembly	Legislative Council
Supported accommodation means public and private accommodation for people with a disability and/or mental illness who need additional support services but excludes mental health treatment services (SEC, PARC) and the disability forensic program (SFS)	Adequacy and appropriateness of care and accommodation provided in various government, private and community facilities that accommodate clients with a disability or mental illness because of insufficient places in the specialist system, and in particular, including supported residential services, boarding houses, public hospitals, nursing homes and SAAP funded service
	Alternate approaches addressing unmet needs in supported accommodation in Victoria

While there are some differences between the two references, the Committee made a decision to combine the references. Both references focus on a range of key aspects relating to the provision of supported accommodation for Victorians with a disability and/or mental illness. The Committee developed a working document that combined and integrated the two references, which ensured all aspects of both references were included.

Combined Terms of Reference working document

An inquiry into the State Government's provision of supported accommodation for Victorians with a disability and/or mental illness with regard to:

- the standard, range, and adequacy of care and accommodation currently available in community residential units, residential institutions, community care units, secure extended care units, prevention and recovery care facilities and other forms of supported accommodation;

- description of current government funded supported accommodation, including:

  – the extent and location of available accommodation

  – different models for service delivery

  – methods of funding and oversight

  – demand management

  – occupancy and staffing

  – service quality management;

- the Government's response to and the methods for measuring unmet accommodation needs and how these can be improved, including sources of funding, planning, and delivery;

- alternate approaches to addressing unmet needs in supported accommodation in Victoria and how these can be improved;

- an estimation of supported accommodation to meet future demand with an appropriate range of services and the

> appropriateness and transparency of the Government's management of demand and placement;
>
> ▪ the adequacy and appropriateness of care and accommodation provided in various government, private and community facilities that accommodate clients with a disability or mental illness because of insufficient places in the specialist system, and in particular including supported residential services, boarding houses, public hospitals, nursing homes and SAAP[21] funded services;
>
> ▪ the appropriateness of the current mix of service providers, including government, private, and community;
>
> ▪ the impacts on families as a consequence of the insufficiency and current service provision of supported accommodation;
>
> ▪ accessibility, service quality, and appropriateness of supported accommodation for specific members of groups including:
>
> – rural and regional
>
> – culturally and linguistically diverse
>
> – indigenous;
>
> ▪ the comparison of Victorian supported accommodation with best practice in other jurisdictions.

The Committee used this document to inform its Inquiry. Public hearings and written submissions were considered in the context of the combined references. Throughout the report therefore, the Committee refers to the two Inquiries as a single Inquiry.

While the Terms of Reference ask the Committee to consider the impact on families, the Committee has considered people who are in caring relationships more broadly. This does not, however, include professional carers. Throughout the document therefore, reference to families also includes friends, neighbours and others who assume caring responsibilities for people with a disability and/or mental illness.

Some of the terms and concepts referred to in the Inquiry are open to interpretation. The terms relating to supported accommodation for people with a disability and/or mental illness are not static and can change depending on the context in which they are used. Definitions of 'disability' and 'mental illness' are not consistent in Australia, with variations in definitions developed for legislative purposes, data collection and research. Understandings of supported accommodation also differ according to the perspective of the individual, organisation or body using the term. This Inquiry seeks to go beyond the constraints imposed by legislative and policy definitions. Chapter Two discusses these issues in more detail.

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[21] Supported Accommodation Assistance Program.

1.4   Inquiry process

The Committee embarked upon an extensive research process in order to canvass the issues and receive input and information from as many individuals, agencies and organisations as possible that have an interest in the issues the Terms of Reference raised.

In conducting the Inquiry the Committee used a variety of processes to produce a comprehensive picture of supported accommodation for Victorians with a disability and/or mental illness. These processes are detailed below.

1.4.1   Background briefings and visits

To inform its understanding of the provision of supported accommodation for people with a disability and/or mental illness in Victoria, the Committee undertook a literature review, visits to supported accommodation sites and briefings from key participants in the field.

In the early stage of the inquiry, the Committee undertook a number of site visits to different models of supported accommodation in Victoria. Site visits were conducted at the following accommodation facilities.

Mental health services

- Prevention and Recovery Care Service (PARC), South Yarra
- Canterbury Community Care Units (CCU), Canterbury
- Edith Pardy House (Residential Rehabilitation), Albert Park
- Austin Health Secure and Extended Care Units (SECU), Austin Hospital.

Disability Services

- Marillac Accommodation Services, East Brighton
- Sandhurst Centre (congregate care facility), Bendigo
- Gateways Support Services, East Geelong.

Supported residential service

- Milford Hall, Armadale.

The site visits were valuable in assisting the Committee to understand the context of the provision of supported accommodation, including the nature of services provided and how mental health services differ from disability services. The Committee gained valuable insight and knowledge of supported accommodation through these visits, which assisted in its consideration of the evidence provided by participants in the Inquiry.

The Committee also invited a number of organisations and relevant Victorian Government departments to brief the Committee regarding the provision of supported accommodation in Victoria. The briefings further informed the Committee members' understanding of disability and mental health service systems.

Many organisations that appeared at the briefings also provided formal evidence by written submission and/or appearance at a public hearing.

1.4.2   Discussion paper

To facilitate discussion and the collection of evidence, the Committee developed a short discussion paper that outlined the issues and the objective of the Inquiry. The Committee developed a number of questions, based on the combined Terms of Reference, which it believed would help individuals and organisations frame their responses in submissions and witness statements. The discussion paper was posted on the Committee's website.

1.4.3   Written submissions

In August 2008, the Committee called for submissions in newspapers across Victoria asking for submissions from interested parties.

The Committee received 129 submissions from individuals and organisations. These included families and carers, service providers in the mental health, disability and homelessness sectors, peak organisations, support and advocacy bodies and statutory bodies. The submissions provided a substantial amount of diverse perspectives and experiences regarding the provision of supported accommodation.

1.4.4   Public hearings

The Committee conducted public hearings across rural and metropolitan Victoria, including Traralgon, Shepparton, Mildura, Geelong, Bendigo, Ballarat, and Melbourne. The Committee heard from families and carers, service providers, advocacy groups, and the Victorian Government.

The Committee heard from departmental officers representing the Disability Services Division in the Department of Human Services and Mental Health and Drugs Division in what is now the Department of Health. The Committee requested that the Chief Psychiatrist and the Senior Practitioner attend public hearings, but was advised by the Minister for Community Services that due to their statutory responsibilities the Senior Practitioner could not attend and the Chief Psychiatrist could attend an informal briefing. The Chief Psychiatrist provided permission for the Committee to use extracts from the briefing as formal evidence.

1.4.5   Inquiry participants

As the figures below reveal, the majority of participants who provided evidence to the Committee were families in caring relationships, service providers and advocacy bodies.

The figures are broken down into the following categories:

- Families in caring relationships – parents, siblings, and other friends and relatives who provided evidence in relation to their experiences in providing support to someone with a disability and/or mental illness
- Service providers – mostly health and community services that provide services in mental health, disability and housing
- Advocacy bodies – including peak advocacy organisations, self-advocacy bodies and advocacy networks
- Carer support groups
- Workers – former or current direct care workers in the mental health, disability and housing sectors
- Statutory bodies and government
- Other – union.

Figure 1.4.5–1 Breakdown of Submissions & Hearing Evidence received, by recipient category
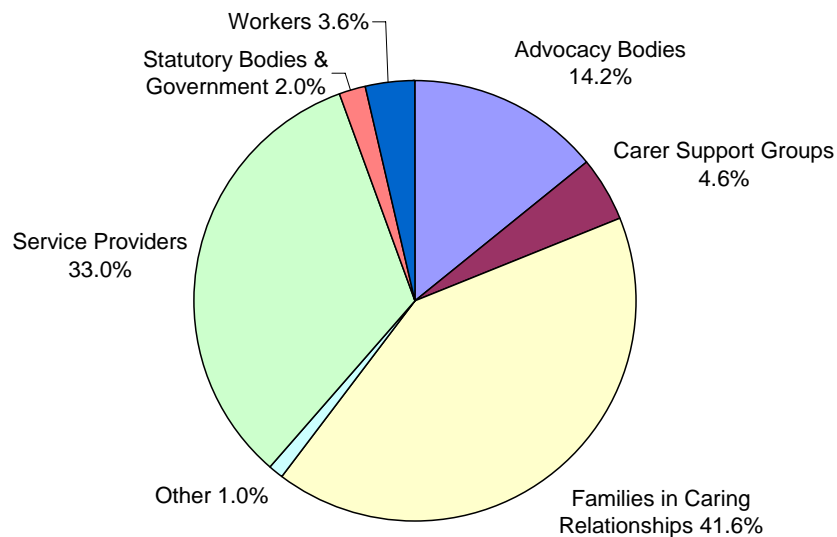
Figure 1.4.5–2 Breakdown of Submissions and Hearing Evidence received, by region
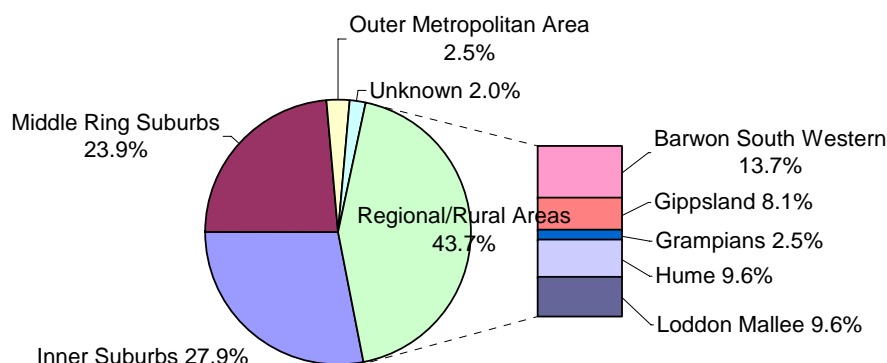
1.4.6   Information and data requests

In July 2008 the Committee invited the Victorian Government to provide a written submission to the Inquiry. On 6 December 2008 the Committee received written material containing data and information relating to the Committee's Inquiry. The Victorian Government, however, advised that while the Committee could use this material and refer to it in its final report, the material was not submitted as formal evidence under the *Parliamentary Committees Act 2003*.

In July 2009 the Committee sought supplementary information from the Victorian Government to update the information provided in December 2008 and to fill gaps in information received. The Committee also sought additional information regarding policy and program developments. The Minister for Community Services, the Hon. Lisa Neville, advised the Committee that information to update the earlier data could not be provided due to resource limitations. A commitment was made by the Minister to provide supplementary material for gaps in information and in relation to policy and program developments.

The Committee received supplementary material on 11 November 2009 with the same proviso that the material was not submitted as evidence under the *Parliamentary Committees Act 2003*.

1.4.7   Independent research

During the course of the Inquiry, the Committee secretariat underwent changes in staffing, which contributed to resourcing issues for the Committee. To assist in the preparation of the report, the Committee sought independent research support.

In view of the complexity of the issues that informed the Inquiry, the Committee needed support from a consultant that had a broad knowledge across several government sectors.

A small team of consultants from Deloitte Touche Tohmatsu entered a secondment contract and provided research support in a casual capacity in late stages of the Inquiry from 25 June 2009 to 8 October 2009. The consultants brought knowledge of the mental health system, disability services and supported residential services (SRS).

1.5   Report Overview

The report is structured around the key themes of the combined Terms of Reference and is divided into four distinct Parts – context, meeting need, experiences of support and accommodation, and alternatives. Each Part is divided into chapters, which are outlined below.

Part A provides background information regarding the provision of supported accommodation for individuals with a disability and/or mental illness in Victoria. This Part consists of three chapters that provide contextual information on support and accommodation in Victoria.

- **Chapter One** provides an introduction to the Inquiry

- **Chapter Two** considers who accesses supported accommodation in Victoria. It looks at definitions of disability and mental illness and provides a demographic picture of disability and mental illness based on statistical data sourced from a range of sources

- **Chapter Three** provides an overview of the legislative and policy context of the disability and mental health support services in Victoria.

Part B discusses the service framework for responding to need and demand and how the concepts relating to meeting need for supported accommodation can be interpreted. This Part has three chapters.

- **Chapter Four** outlines the service system and how the different service systems govern support and accommodation, core operations and models of funding

- **Chapter Five** outlines the concepts of demand and need for services and current methods of data collection relating to supported accommodation

- **Chapter Six** explores best practice and policy development in other jurisdictions in comparison with Victoria's policy and practice.

Part C reports on the experiences of those involved in the provision of supported accommodation. The views of individuals and organisations that provided evidence to the Committee are discussed with regard to the adequacy of accommodation and support for individuals with a disability and/or mental illness. This Part incorporates four chapters.

- **Chapter Seven** considers the diverse experiences of participants in accessing disability supported accommodation and related services

- **Chapter Eight** examines the diverse experiences of participants in accessing support and accommodation in the mental health sector, including long-term residential treatment services

- **Chapter Nine** focuses on the quality systems, monitoring and complaints mechanisms that aim to ensure expertise and quality provision of support and accommodation. Within this, it also considers the capacity of the workforce to achieve quality service provision

- **Chapter Ten** gives specific attention to the experiences of families in caring relationships with people with a disability and/or mental illness.

Part D contains two chapters that consider alternatives to the provision of specialist support and accommodation for people with a disability and/or mental illness.

- **Chapter Eleven** examines the consequences of the disparity between demand and supply and explores the alternative accommodation options that individuals may access when they are unable to secure a placement in the specialist supported accommodation system

- **Chapter Twelve** turns to the alternatives proposed by participants who gave evidence in the Inquiry. These suggestions were considered in the context of additional options to existing services.

Chapter Two: Victorians with a disability and/or mental illness

Committee findings

- That disability and mental illness have different meanings in different contexts. **(Section 2.1)**

- That there is substantial diversity among people with a disability and/or mental illness, in terms of demographic characteristics, service needs and expectations. **(Section 2.2)**

- That demographic shifts – population ageing and overall growth – will drive significant increases in the level and complexity of service needs in coming years. **(Section 2.2.4)**

- That specialist service providers will need to adapt to the diverse and changing needs of people with a disability and/or mental illness. **(Section 2.2.4)**

- That the link between support and accommodation is critical for people with a disability and/or mental illness. **(Section 2.3)**

Τhis chapter looks at the most significant people involved with the supported accommodation system – people with a disability and/or mental illness.

Like all people in the community, people with a disability and/or mental illness are unique and individual. They are men and women of all ages and ethnic backgrounds. Some are in the paid workforce and others are not, some are parents and others are children. Some people with a disability and/or mental illness have careers, others may not. Some live on their own, some with family or friends and some with a carer.

This chapter begins by examining the concepts of disability and mental illness. These concepts are not static but, for people seeking to access accommodation and support services, definitions are significant. There are specific services provided for people with a 'disability' and specific services provided for people with a 'mental illness'. Legislative definitions have been developed that determine eligibility for those services.

The chapter then provides an overview of key demographic characteristics of Victorians with a disability and/or mental illness using a population-based approach.

Finally, it considers the significant differences in experiences and service needs of people with a disability and people with a mental illness, and for people with dual or multiple disabilities.

2.1   Definitions of disability and/or mental illness

Broadly, the Committee's Terms of Reference require it to examine the provision of supported accommodation for Victorians with a disability and/or mental illness.

The Committee's Inquiry has a broad focus that encompasses disability, mental illness and dual and multiple disabilities in the context of supported accommodation. This section, therefore, outlines key factors in regard to the definition of terms.

2.1.1   Definitions of disability

There are many different definitions of disability used in Australia, including those used in administrative data collections, in Acts of Parliament and in academic literature. Understanding how the term 'disability' is conceptualised in supported accommodation in Victoria requires consideration of the range of definitions used for data purposes and for policy and legislative purposes.

Generally, disability is a term used to describe an impairment of a body structure or function or limitation in activities, or a restriction in participation. It is a

multi-dimensional and complex concept and is conceived as a dynamic interaction between health conditions and environment and personal factors. According to the Australian Institute of Health and Welfare (AIHW),

> A health condition may be a disease (acute or chronic), disorder, injury or trauma. Environmental factors make up the physical, social and attitudinal environment in which people live and conduct their lives. Personal factors relate to the individual, such as age, sex and Indigenous status.[22]

The United Nation's Convention on the Rights of Persons with Disabilities and Optional Protocol, ratified by Australia on 17 July 2008, defines 'persons with disabilities' as including those who have long-term physical, mental, intellectual or sensory impairments which, in interaction with various barriers, may hinder their full and effective participation in society on an equal basis with others.

The Australian Bureau of Statistic's (ABS) Survey of Disability, Ageing and Carers (SDAC) has been conducted over a number of years and is based on the International Classification of Functioning, Disability and Health and its predecessor.

The 2003 survey defined a disability as a limitation, restriction or impairment that has lasted, or is likely to last, for at least six months and restricts everyday activities. Self-care, mobility and communication are defined as core activities. The ABS defines levels of core activity limitation as follows:

- mild – where a person does not need assistance and has no difficulty with self-care, mobility and/or communication, but uses aids or equipment

- moderate – where a person does not need assistance, but has difficulty with self-care, mobility and/or communication severe – where a person sometimes needs assistance with self-care, mobility and/or communication tasks; has difficulty understanding or being understood by family or friends; or can communicate more easily using sign language or other non-spoken forms of communication

- profound – where a person is unable, or always needs assistance, to perform self-care, mobility and/or communication tasks.[23]

In Victoria, the definition of disability used to determine eligibility for service provision (and therefore for supported accommodation) is informed by the National Disability Agreement (NDA) (formerly the Commonwealth State/Territory Disability Agreement or CSTDA) and further clarified and defined by the Victorian *Disability Act 2006*.

The third CSTDA defined 'people with disabilities' as those whose disability manifests before the age of 65 years and for which they require significant

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22   Australian Institute of Health and Welfare (2006) 'Functioning and Disability Data Set Specification'. *Meteor Metadata Online Registry*. Accessed from <http://meteor.aihw.gov.au/content/index.phtml/itemId/181162> on 29 September 2009.

23   Australian Bureau of Statistics (2003) *Disability, Ageing and Carers: Summary of Findings*. ABS, Catalogue no. 4430, p.72.

ongoing and/or long-term episodic support. For these people, the disability will be attributable to an intellectual, psychiatric, sensory, physical or neurological impairment or acquired brain injury (ABI) (or some combination of these), which is likely to be permanent and results in substantially reduced capacity in either self-care/management, mobility and/or communication.

The Victorian *Disability Act 2006* similarly defines 'disability' in relation to a person as a sensory, physical or neurological impairment or ABI (or any combination) which is, or is likely to be, permanent and causes a substantially reduced capacity in at least one of the areas of self-care, self-management, mobility or communication. In addition, the Act specifies that the person will require significant ongoing or long-term episodic support. To receive disability services in Victoria, the disability cannot be related to ageing.

There are two distinct differences in Victorian legislation from the CSTDA definition. Notably, the *Disability Act 2006* provides a separate definition for intellectual disability. That is, the concurrent existence in a person over the age of five years of significant sub-average general intellectual functioning and significant deficits in adaptive behaviour, each of which became manifest before the age of 18 years.

Furthermore, unlike the CSTDA, the definition of disability in Victoria does not include psychiatric disability. Mental illness and disability resulting from a mental illness is categorised and defined by separate legislation and addressed in separate policy frameworks.

2.1.2 Definitions of mental illness

Similarly to definitions of disability, definitions of mental illness differ across jurisdictions, professions and in Acts of Parliament. Furthermore, there are significant challenges in defining mental illness. Legislators and researchers have noted that:

> Definitions of mental illness are notoriously difficult to draft. If they are framed too narrowly they deny services to people. If they are too broad they may result in unnecessary intervention.[24]

Recent research has acknowledged that there is a range of dimensions to consider in the definition of mental illness.[25] These include legal, clinical and social dimensions that inform definitions of mental illness. Legislative definitions are often associated with a diagnosis of psychosis and involuntary treatment. Clinical definitions are often very broad compared with legal definitions, which often need to be met in order to treat a mental illness. Social

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[24]   Wilson, B. (1995) 'Legal straitjackets: When reason fails: Law and mental illness'. In H. Selby (Ed.), *Tomorrow's Law*. Sydney, Federation Press, p.312.

[25]   Karras, M., McCarron, E., Gray, A. & Ardasinski, S. (2006) *On the edge of justice: the legal needs of people with a mental illness in NSW*. Sydney, Law and Justice Foundation of NSW, p.2.

definitions tend to refer to 'psychiatric disability', which is 'a narrower term than mental illness, as not all people with a mental illness will consider themselves, or be considered, to have a psychiatric disability'.[26] As noted above, legislative definitions of disability that determine eligibility for services generally refer to conditions that are 'permanent or likely to be permanent'. Mental illness, on the other hand, is considered temporal, and the condition can fluctuate.

The challenge in defining mental illness was highlighted in the recently released Community Consultation Report on the review of the Victorian *Mental Health Act 1986*, in which the panel commented that 'the definition of mental illness involves clinical considerations and we believe expert advice is needed about an appropriate definition that would reflect the intended scope of the new Act'.[27]

Notably, in contemporary policy mental illness is generally understood in the context of mental health. Within these policy contexts, there is recognition that a mental illness can sometimes lead to varying degrees of disability. The AIHW defines mental health as:

> the capacity of individuals and groups to interact with one another and the environment, in ways that promote subjective wellbeing, optimal development and the use of cognitive, affective and relational abilities.[28]

It goes on to explain that maintaining mental health is influenced by a range of factors. This is in keeping with understandings that mental illness is often cyclical in nature:

> A diverse range of social, environmental, biological and psychological factors can impact on an individual's mental health. In turn people can develop symptoms and behaviours that are distressing to themselves or others, and interfere with their social functioning and capacity to negotiate daily life. These symptoms and behaviours may require treatment and rehabilitation, even hospitalisation.[29]

While not defined by legislation, there is a range of disorders that are clinically recognised as a mental illness. These include anxiety disorders, affective disorders (such as clinical depression and bipolar disorder), substance use disorders and psychotic disorders (such as schizophrenia). These are often categorised as low prevalence disorders (psychotic disorders) and high prevalence (anxiety, affective and substance disorders).

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26   M. Karras et al. (2006) *On the edge of justice: the legal needs of people with a mental illness in NSW*. Sydney, Law and Justice Foundation of NSW, p.2.

27   Department of Human Services (2009) *Review of the Mental Health Act 1986: Community consultation report – July 2009*. Melbourne. Victorian Department of Human Services, Mental Health and Drugs Division, p.5.

28   Australian Institute of Health and Welfare (AIHW) (2009) *What is mental health?* Accessed from <http://www.aihw.gov.au/mentalhealth/faqs.cfm> on 30 September 2009.

29   AIHW, *What is mental health?* [see Footnote 28].

In Victoria, state funded mental health services generally respond to low prevalence disorders. The Commonwealth Government, on the other hand, provides funding to respond to high prevalence disorders.

2.2 Demographics

The different definitions of disability and mental illness have a significant influence on how data is collected and therefore on understandings of disability and mental illness. There are some important differences between the datasets, in particular relating to how they define disability, which have implications for the information they provide.

Key sources of data about people with a disability and/or mental illness are outlined below.

Data sources

Australian Bureau of Statistics (ABS):

> Survey of Disability, Ageing and Carers (last undertaken in 2003; note that questions about core activity limitation are also part of the Census)

> National Survey of Mental Health and Wellbeing.

Australian Institute of Health and Welfare (AIHW):

> Disability Services National Minimum Data Set
> (DS NMDS – formerly the Commonwealth, State and Territory Disability Agreement NMDS).

Annual Mental Health Services report which uses a range of data including:

> National Hospital Morbidity Database (NHMD)

> National Mental Health Establishments Database (NMHED)

> AIHW Medical Labour Force Survey

> Bettering the Evaluation and Care of Health (BEACH)
> survey of general practice activity

> Supported Accommodation Assistance Program (SAAP)
> National Data Collection

> Department of Health and Ageing's (DoHA's) Medicare, Pharmaceutical and Repatriation Pharmaceutical Benefits Schemes (MBS, PBS and RPBS) data collections.

> Productivity Commission:
>
>> Report on Government Services
>> (with input from all governments).

The ABS Survey of Disability, Ageing and Carers (SDAC) asks respondents to report on whether they have limitations to, or need assistance with, a range of life activities. Those with profound or severe core activity limitations (that is, where assistance is frequently needed with communication, mobility and self-care) are considered to have a disability, regardless of the reason for these activity limitations. Consequently, many people with temporary injuries (though longer than six months), or with disabilities arising from age, are included in these figures. On the other hand, data about who uses disability support services considers a fairly specific group of people, who by definition 'have a disability' (as defined by relevant legislative definitions) rather than having a functional restriction.

The key issues relating to data about population mental health are different from disability. In the context of data collection, the definitions of mental illness are broadly agreed, and general prevalence rates in the community can also be identified. It is difficult, however, based on existing information, to discern levels of either demand or need with any confidence. In large part this is because need for mental health support services is, in many cases, very dynamic. Simply having a mental illness does not automatically mean that a person needs a specific service. Furthermore, the nature of services needed may shift dramatically over relatively short periods of time.

In addition to the absence of a single 'indicator' of mental illness is the lack of a single indicator or dataset about mental health services. Information about existing service use is present. As the AIHW highlights, however, the use of mental health services is fragmented, which makes it problematic when trying to aggregate across service types.[30] It is difficult to identify the use of multiple services (for example, where a person may see a GP, use PBS medication, access PDRS services, and occasionally be an inpatient).

2.2.1   Victorians with a disability

In the 2006 Census, just over 205,000 Victorians reported that they had a severe or profound core activity limitation, defined as needing help or assistance in one or more of the three core activity areas of self-care, mobility and communication, because of a disability, long-term health condition or old age. Of these, just over 90,000, or one in 47 of the broader population, were under 65 years of age.

The Census does not provide more detailed information about the reasons for core activity limitations, however the earlier Survey of Disability, Ageing and

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[30]   Australian Institute of Health and Welfare (AIHW) (2009) *Mental Health Services in Australia 2006–07*. Mental Health Series no.11, Cat no. HSE 74, AIHW, Canberra.

Carers provides more detail. Table 2.2.1–1 below provides statistics regarding the numbers of severe and profound disabilities in Victoria by condition. In this context, the statistics also include disability associated with mental illness.

Table 2.2.1–1: People with a severe or profound disability by major condition, Victoria, 2003

Physical conditions	
Cancer, lymphomas and leukaemias	3,600
Endocrine, nutritional and metabolic disorders	7,000
Diseases of the nervous system	19,800
Diseases of the eye and adnexa	6,200
Diseases of the ear and mastoid process	13,700
Diseases of the circulatory system	30,200
Diseases of the respiratory system	18,100
Diseases of the digestive system	2,000
Diseases of the musculo-skeletal system and connective tissue	97,000
Congenital and perinatal disorders	5,700
Injury, poisoning and other external causes	19,100
Other physical conditions	20,300
Total	**242,800**

Mental and behavioural disorders	
Psychoses and mood affective disorders	35,700
Neurotic, stress-related and somatoform disorders	12,900
Intellectual and developmental disorders	21,400
Other mental and behavioural disorders	10,500
Total	**80,500**

Source: Australian Bureau of Statistics (2003) *Survey of Disability, Ageing and Carers*. ABS cat. no. 4430.0.

The AIHW estimates that during 2006-07 approximately 232,000 Australians used services funded through the CSTDA, and replaced by the NDA. Of this group, the most common reported group of primary or significant disabilities were intellectual, learning and developmental disabilities (close to 50 per cent), with the next most frequently reported disability groups being physical, neurological and ABI-related disability (35 per cent). A significant sensory or speech disability was reported by 21 per cent of service users, and a similar proportion reported psychiatric disability.[31]

A substantial number of people indicated that they have more than one significant disability. For example, over half of those with an intellectual disability or ABI had at least one other disability. As well, approximately a quarter of those with an intellectual disability or with autism spectrum disorder were reported to have little or no effective communication, higher than the rates among other groups.

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[31] Australian Institute of Health and Welfare (2008) *Disability support services 2006–07: national data on services provided under the Commonwealth State/Territory Disability Agreement*. Cat no. DIS 52, Disability Services, AIHW, Canberra, p.19. The Committee noted that 2007-08 data became available after its report had been completed. Due to time constraints, it was not possible to integrate the new data into the report.

The group of people using disability support services included around 3.8 per cent who were of Aboriginal or Torres Strait Islander origin – over-representative of population levels. A higher proportion of indigenous people with a disability reported multiple disabilities, compared with the non-indigenous population. Around 10 per cent of people using CSTDA/NDA services were born overseas. The greatest country of origin increases in 2006-07 were among people born in England, Vietnam, and China.

Of people using these services, around half were reported to have an informal carer. Among these carers, close to two-thirds were mothers of the service users, with smaller numbers indicating that a partner, other family member, or father was their carer. The majority of carers were aged between 25 and 64 years, although 13 per cent were over 65 and 146 carers were under 15.

The AIHW estimated that during 2006-07 less than half (45%) of service users in major cities had an informal carer. Service users in remote and very remote areas had a greater likelihood (54% and 66% respectively) of having an informal carer than service users in other areas.

More specifically regarding Victoria, data collected about the users of CSTDA/NDA services suggest that in 2006-07 approximately 85,506 Victorians accessed specialist disability services – accommodation support, community support, community access, respite, or employment support. Of these service users, the most commonly reported primary disability group was intellectual disability, with 26 per cent of people identified as using the services for this reason. Table 2.2.1–2 below outlines the primary disability groups for all CSTDA/NDA service users during 2006-07.

Table 2.2.1–2: Disability services users by primary disability group, Victoria, 2006-07

Intellectual	17,695	25.9%
Specific learning/ADD	1,035	1.5%
Autism	2,249	3.3%
Physical	5,935	8.7%
Acquired brain injury	2,858	4.2%
Neurological	3,568	5.2%
Deafblind (dual sensory)	322	0.5%
Vision	924	1.4%
Hearing	3,240	4.7%
Speech	135	0.2%
Psychiatric	13,452	19.7%
Developmental delay	113	0.2%
Not stated	16,113	23.6%

Source: Australian Institute of Health and Welfare (2008) *Disability support services 2006-07*. AIHW cat. no. DIS 52.

This analysis of service users is particularly relevant for considering supported accommodation needs as it affects both the level of support and/or accommodation someone might need, but also the nature of these supports. For

example, the needs of someone with an intellectual disability will differ substantially from those of someone with a sensory disability, and this will vary again depending on the degree of disability involved.

The age structure of populations in these two datasets illustrates the different definitional approaches.

Figure 2.2.1–3: Age structures of CSTDA/NDA service users and people with a disability according to SDAC, Victoria, 2003
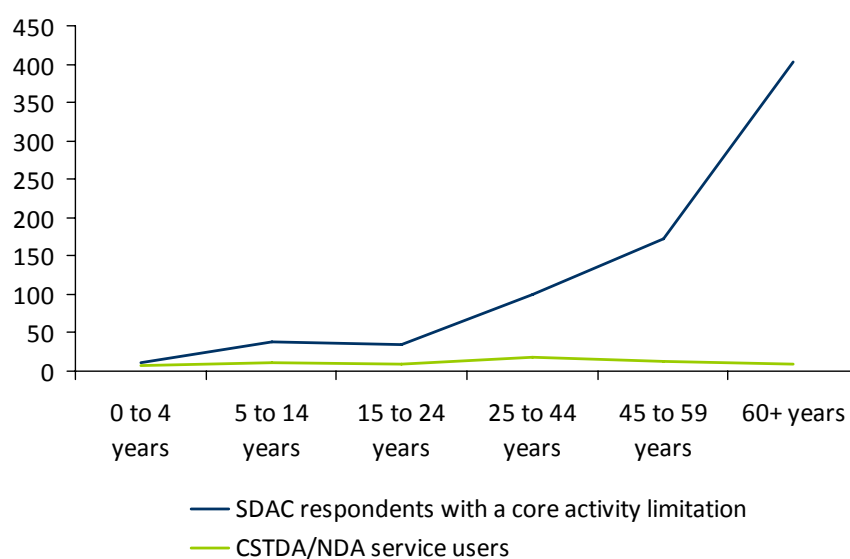
Sources: ABS (2003) *Survey of Disability, Ageing and Carers.* ABS cat. no. 4430.0; Australian Institute of Health and Welfare (2008) *Disability services 2006-07*. AIHW cat. no. DIS 52, table A1.

Among those using specialist disability services, younger people (those under 25 years of age) are disproportionately represented. Table 2.2.1–4 below illustrates the age distribution of service users.

Table 2.2.1–4: Disability services users by age, Victoria, 2006-07

Age (years)	CSTDA service users	Victorian population
0 to 4	10.1%	6.2%
5 to 14	15.2%	12.6%
15 to 24	14.5%	14.0%
25 to 44	27.8%	29.1%
45 to 59	19.1%	19.6%
60+	13.2%	18.5%

Source: Australian Institute of Health and Welfare (2008) *Disability support services 2006-07*. AIHW cat. no. DIS 52.

The percentage of males with a disability in the younger age groups is slightly higher than the percentage of younger males in the broader population. Among those over 45 years of age the proportion of females begins to increase.

Among people who use specialist disability services, those in supported accommodation are a distinct subset. Table 2.2.1–5 below illustrates the age

distribution of people living in shared supported accommodation (SSA) facilities in June 2008, showing the relatively greater proportion of middle-aged Victorians in group homes compared to the general population of people with disabilities.

Table 2.2.1–5: Disability services users 2006-07 compared with residents in SSA by age, June 2008

Age (years)	CSTDA service users	SSA residents
Under 25	39.8%	5.4%
25 to 44	27.8%	42.5%
45 +	32.3%	52.1%

Source: Australian Institute of Health and Welfare (2008) *Disability support services 2006-07*. AIHW cat. no. DIS 52; Victorian Government (2008) Data provided to the Family & Community Development Committee.

Indigenous Victorians are substantially over-represented among those using specialist disability services. Table 2.2.1–6 below illustrates this, although the high proportion of CSTDA service users for whom indigenous status is unknown confuses this calculation. Later chapters discuss issues relating to data collection for people from indigenous backgrounds in greater depth.

Table 2.2.1–6: Disability services users by indigenous status, Victoria, 2006-07

	Victoria	CSTDA service users	SSA residents
Indigenous (Aboriginal &/or Torres Strait Islander)	0.6%	3.0%	0.7%
Non-indigenous	98.4%	84.1%	83.3%
Not stated	—	12.4%	16.0%

Source: Australian Institute of Health and Welfare (2008) *Disability support services 2006-07*. AIHW cat. no. DIS 52; Victorian Government (2008) Data provided to Family & Community Development Committee.

Information about people with disabilities from culturally and linguistically diverse (CALD) backgrounds is collected through the CSTDA National Minimum Data Set (NMDS) by identifying country of birth (in particular noting when someone comes from a country which is not English speaking, as this may imply that an interpreter could be needed). Information about 'CALD background' per se is not collected as part of this dataset. DHS advised the Committee that only 1.8 per cent of those living in SSA facilities have been identified as being from CALD backgrounds. The Department advised the Committee, however, that in respecting the right to privacy, people are not required to identify their CALD background when they access disability services. Compared to the proportion of service users overall and to the broader population, this is a very low proportion.[32] No information is known about the CALD background of 63 per cent of SSA residents. The issue of data is discussed further in later chapters.

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[32] The impact of Australian immigration policy on these figures is not known.

Table 2.2.1–7: Disability services users by CALD background, Victoria, 2006-07

Born in Australia or overseas in an English-speaking country	54,418	80.0%
Born in a non-English-speaking country	5,172	7.6%
Not stated	8,049	11.8%

Source: Australian Institute of Health and Welfare (2008) *Disability support services 2006-07*. AIHW cat. no. DIS 52.

Data about where service users live is not recorded as part of the CSTDA dataset. The 2003 SDAC does identify whether people who reported that they had a severe or profound core activity limitation lived in metropolitan, major regional, or other areas. DHS also collects data about new requests for SSA places by region (see Table 2.2.1–9 below).

The AIHW estimated that overall in Australia there were 219,800 users of CSTDA-funded services in 2006-07 who were aged less than 65 years. Most service users lived in major cities (63 per cent), or inner regional areas (24 per cent). Only 0.4 per cent service users lived in a very remote area. Accommodation support services were the most common service type in all remoteness areas or locations except very remote areas. With increasing remoteness, the mix of service type outlets becomes more diverse, so that in remote and very remote areas, accommodation support services accounted for less than 30 per cent of outlets in 2006-07.

Table 2.2.1–8: VICTORIA - Disability status by remoteness[33]

	Profound or severe core-activity limitation [(a)]	All with reported disability	No reported disability	Total
Remoteness				
Major cities	218.8	679.3	2,976.6	3,655.9
Inner regional	79.7	245.2	774.7	1,019.9
Other [(b)]	24.8	67.8	215.9	283.7

[(a)] Core activities comprise communication, mobility and self-care.

[(b)] Includes Outer regional and Remote only. Excludes Very remote regions.

Source: Australian Bureau of Statistics (2003) Survey of Disability, Ageing and Carers.

For Aboriginal and Torres Strait Islander service users, 39 per cent lived in major cities compared with 65 per cent of non-indigenous service users. The proportion of service users who lived in inner regional areas was fairly similar for both indigenous and non-indigenous users. Aboriginal and Torres Strait Islander peoples made up 2.3 per cent of service users in major cities, 4.0 per cent in inner regional, 8.2 per cent in outer regional, 21.4 per cent in remote and 48 per cent in very remote areas. The reverse pattern can be seen for non-indigenous people where 93 per cent of service users lived in major cities and 51 per cent in very remote areas.

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[33] Remoteness Areas are based on the Australian Standard Geographical Classification developed by the ABS, including categories of: Major Cities, Inner Regional, Outer Regional, Remote and Very Remote areas.

Table 2.2.1–9: Residents in Shared Supported Accommodation by region, June 2008

Region	Number	
Metropolitan Areas		
Eastern Metropolitan	1,199	26.1%
North & West Metropolitan	1,227	26.8%
Southern Metropolitan	894	19.5%
Regional Areas		
Barwon-South Western	263	5.7%
Gippsland	190	4.1%
Grampians	359	7.8%
Hume	260	5.7%
Loddon Mallee	198	4.3%
Total	**4,590**	**100%**

Note: Excludes residents of residential institutions.

Source: Victorian Government (2008) Data provided Family & Community Development Committee.

In relation to Victoria, a regional breakdown of numbers of residents in SSA by type of disability, or clients in supported residential services (SRS) was not available.

Table 2.2.1–10: Requests for new SSA places by region, 2003-04 to 2007-08

Region	Financial Year					
	2003-04	2004-05	2005-06	2006-07	2007-08	5yr Total
Metropolitan Areas						
Eastern Metropolitan	42	54	43	37	49	225
North & West Metropolitan	102	73	62	42	50	329
Southern Metropolitan	85	71	45	55	59	315
Regional Areas						
Barwon-South Western	35	17	6	14	20	92
Gippsland	24	25	8	11	12	80
Grampians	15	13	14	15	19	76
Hume	27	23	11	21	18	100
Loddon Mallee	22	5	9	9	17	62
Total	**352**	**281**	**198**	**204**	**244**	**1,279**

Notes:
Excludes applications that were withdrawn, rejected or not yet verified/finalised by the end of the financial year
Excludes applications from existing SSA residents seeking a location transfer
Data prior to April 2006 are from the Service Needs Register (SNR)
Data from April 2006 are from the Disability Support Register (DSR)
Data for 2005-06 may be incomplete due to transition from SNR to DSR
Figures prior to April 2006 may not be comparable due to changes in registration methodology.

Source: Victorian Government (2008) Data provided to Family & Community Development Committee.

2.2.2   Demographics of mental illness

Mental illness is one of the more prevalent conditions affecting the Australian population. In the 2007 National Survey of Mental Health and Wellbeing, the ABS estimated that around 18 per cent of Australian adults had experienced a

mental illness in the 12 months preceding the survey.[34] Because there is no single set of data representing episodes of mental health service use, statistical information about mental illness is fragmentary. The AIHW aggregates information into three broad groups: ambulatory mental health care, admitted and residential mental health care, and mental health-related pharmaceuticals.

Among the group of Australians who received residential mental health care in 2005-06, the most common principal diagnosis was schizophrenia (59 per cent), followed by schizoaffective disorder (10 per cent) and bipolar affective disorders (6 per cent).[35] Of these people, there were significantly more males than females in residential care, particularly in the 25-44 year-old age group. Indigenous Australians were also represented at a significantly higher rate than their non-indigenous counterparts. The length of episode varied significantly, with the most common length of stay in a residential facility being three days while the average length was 311 days. This is because of a small number of residential stays of longer than eight years, as well as a significant minority (17 per cent) of stays over one year. The reported number of episodes in Victoria was 791, representing an average of 1.4 episodes per person.

This suggests the considerable diversity of experience among those with mental illness, in terms of how episodes affect their need for supported accommodation, and what type of support and/or accommodation is most appropriate. The potential for relatively rapid shifts in this need also has implications for how services such as supported accommodation are allocated and provided.

The 2007 National Survey of Mental Health and Wellbeing, conducted by the ABS, focused on three major groups of mental illness. The survey found that 3.2 million people aged between 16 and 85 years nationwide had experienced the symptoms of a mental illness during the last 12 months, and nearly 7.3 million had experienced this at some point in their lifetime.

This corresponds to approximately 860,200 Victorians with a mental illness in any given year. Of these, around 14.4 per cent (123,900) have an anxiety disorder such as panic disorder or generalised anxiety disorder, 6.2 per cent (53,300) have an affective disorder such as clinical depression or bipolar disorder, and 5.1 per cent (43,900) have a substance use disorder.

Information about the proportion of these people for whom the symptoms of mental illness are severe enough to require external support and/or supported accommodation is fragmented and partial.

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[34] Australian Bureau of Statistics (2007) *National Survey of Mental Health and Wellbeing.* ABS cat. no. 4326.0.

[35] AIHW, *Mental health services in Australia, 2006-07* [see Footnote 30].

In 1998 the AIHW calculated that approximately 192,200 Victorians had a psychiatric disability that led to severe or profound core activity limitations, arising from a mental illness.[36]

The ABS finds that just over one-third (34.9 per cent) of respondents who had experienced symptoms in the last year had sought mental health service support for these. Among those who have accessed mental health services, the AIHW uses a range of data sources to identify the most common conditions (see Table 2.2.2–1 below).

Table 2.2.2–1: Victorians with a mental illness seeking formal services 2006-07

	Approximate number of GP visits*	Presentations at emergency wards	Community mental health service contacts, principal diagnosis (%)
Depression	1,079	6,691	11.0%**
Bipolar disorder	n/a		6.7%
Anxiety	479	N/A	
Substance abuse	134	8,802	
Schizophrenia	118	5,074	31.8%
Dementia	320	N/A	

* Based on BEACH data

** Depressive episode

Source: Adapted from Australian Institute of Health and Welfare (2009) *Mental health services in Australia 2006-07.*

The AIHW reports that in 2006-07 there were just over 1,000 episodes of care in residential mental health facilities, which include all services defined by the Inquiry as supported accommodation. It was estimated that this represented approximately 610 individuals, and that on average each person had 1.6 episodes during the year.

Among these, over half were involuntary admissions (see Table 2.2.2–2 below).

Table 2.2.2–2: Legal status of Victorians in residential mental health services, 2006-07

	Number	%
Voluntary	435	43.4%
Involuntary	568	56.6%

Source: Australian Institute of Health and Welfare (2009) *Mental health services in Australia* 2006-07.

The proportion of younger people reporting that they have a mental illness is high compared to their percentages in the broader Victorian population. In addition, adults aged 25 to 34 who use residential mental health services are over-represented compared with other age groups. Middle-aged adults, on the other hand, are under-represented among people in residential mental health service (MHS) units.

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[36]   Australian Institute of Health and Welfare (AIHW) (2003) *Disability prevalence and trends.* Disability Series. AIHW Cat. No. DIS 34. AIHW, Canberra.

Table 2.2.2–3 below illustrates the age distribution of service users.

Table 2.2.2–3: Victorians with mental illness, by age, 2006-07

Age (years)	Residential MHS episodes	Any 12-month mental disorder	Victorian population over 15 years (2007)
15 to 24	11.2%	21.0%	17.3%
25 to 34	30.0%	21.8%	17.5%
35 to 44	21.8%	22.4%	18.2%
45 to 54	15.4%	19.2%	16.8%
55 to 64	9.5%	9.9%	13.6%
65+	12.1%	5.7%	16.6%

Sources: Australian Institute of Health and Welfare (2009) *Mental health services in Australia 2006-07*. ABS (2008) *Population by Age and Sex, Regions of Australia* ABS cat. no. 3235.0; ABS. (2008) *National Survey of Mental Health and Wellbeing: Summary of Results 2007*. ABS cat. no. 4326.0.

Although there are slightly more females reporting that they have a mental illness, almost two-thirds of residential mental health service episodes involved males (approximately 60 per cent). It is not clear whether this is because the number of men was greater, or because individuals were more likely to have multiple episodes.

Nationwide, approximately 2.5 per cent of those admitted to residential mental health facilities were indigenous, however data about Victoria is unavailable. Similarly, information about the CALD backgrounds of service users is not collected. This is discussed further in Chapters Five and Eight.

Although 50 per cent of reported residential care episodes were in major cities, the rate of reported episodes relative to the population for those living in inner regional areas was higher than those in major cities.[37]

Table 2.2.2–4: Episodes of residential mental health care by remoteness area, 2006–07

Patient demographics	Number of episodes	Percent of episodes	Rate (per 10,000 population)
Remoteness area of usual reference			
Major cities	1,240	50.0	0.9
Inner regional	1,086	43.8	2.8
Outer regional	151	6.1	0.8
Remote	5	0.2	0.2

Source: Australian Institute of Health and Welfare (2009) *Mental Health services in Australia 2006-07*.

The 2008 SRS Census reveals that mental illness with an associated psychiatric disability is more common in the Hume, North and West Metropolitan and Southern Metropolitan regions, and less common in the Eastern Metropolitan

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[37]   Australian Institute of Health and Welfare (AIHW) (2009) *Mental health services in Australia 2006–07*. Mental health series no. 11. Cat. no. HSE 74. AIHW, Canberra.

and Loddon Mallee regions. Intellectual disabilities are less prevalent than average among SRS residents in the Eastern Metropolitan region.[38]

2.2.3   Multiple and complex disabilities

In 2009, the AIHW released a report on people with multiple and complex disabilities. AIHW researchers noted that over half of those who have a disability (including the broad groupings of intellectual, psychiatric, sensory/speech, ABI, and physical/diverse disabilities) experience more than one of these conditions. This has a significant impact on someone's need for assistance in core activities, as well as participation in other life areas.[39]

The report also finds that people with multiple disabilities are more likely to also have multiple health conditions, including dementia, ASD, Parkinson's disease, schizophrenia, speech problems, and stroke. The number of health conditions increases with the number of disabilities reported, from 3.5 for those with two disabilities to 6.2 among people with five disabilities. This suggests that the complexity of needs among this group is significantly higher than among groups with a single disability or mental illness.

In 2003, 51 per cent of those with a disability had two or more disabling conditions (see Table 2.2.3–1 below). Intellectual disability and ABI were most commonly reported to be one of three or more disabilities, followed by psychiatric disability.

Table 2.2.3–1: People with multiple disabilities, 2003

	One	Two	Three	Four	Five
Proportion of all with a disability	48.7%	34.6%	11.1%	4.6%	1.0%

Source: Australian Institute of Health and Welfare (2009) *Disability in Australia: multiple disabilities and need for assistance*. AIHW cat. no. DIS 55.

The proportion of people with multiple disabilities appears to be higher among the very young and the elderly, suggesting that while some complexity is generated by ageing, this is not always the case. The AIHW reports that

> Multiple disabilities in childhood were mostly associated with intellectual disability.
> For people with disability aged 15–64 years, those with multiple disabilities often had physical and psychiatric disabilities, in combination with another type of disability.

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[38]   The Social Research Centre (2009) *2008 Census of Supported Residential Services – Report*. Prepared for the Victorian Department of Human Services, Melbourne, p.171.

[39]   Australian Institute of Health and Welfare (AIHW) (2009) *Disability in Australia: multiple disabilities and need for Assistance*. Disability series. Cat. no. DIS 55. AIHW, Canberra, p.8.

> For people with disability aged 65 years or over, multiple disabilities were most commonly associated with people who had physical/diverse and sensory/speech disabilities.[40]

Supported accommodation is increasingly a service for people with complex and high intensity of needs resulting from their disability. Furthermore, it is increasingly likely that people with a disability and/or mental illness who require supported accommodation will have more than one disabling condition.

Having multiple disabilities often affects a person's need for assistance with activities of daily living. Table 2.2.3–2 below illustrates the effects increasing complexity has on these needs.

Table 2.2.3–2: People with multiple disabilities by severity of core activity limitation, 2003

	One	Two	Three	Four	Five
Proportion with severe or profound core activity limitation	22.0%	32.0%	48.5%	74.7%	77.5%

Source: Australian Institute of Health and Welfare (2009) *Disability in Australia: multiple disabilities and need for assistance*. AIHW cat. no. DIS 55.

It also appears that there is a substantial proportion of partially met need among this group of people. Table 2.2.3–3 below illustrates that, while the proportion of people with multiple disabilities who do not have core activity support needs met is no higher than that among people with a single condition, there is a higher degree of only partly met need.

Table 2.2.3–3: People with multiple disabilities by extent to which need for assistance is met, 2003

	One	Two	Three	Four	Five
Fully	81.8%	78.7%	70.1%	61.2%	77.0%
Partly	11.3%	14.4%	22.8%	33.9%	16.2%
Not at all	7.0%	6.9%	7.1%	4.9%	6.8%

Source: Australian Institute of Health and Welfare (2009) *Disability in Australia: multiple disabilities and need for assistance*. AIHW cat. no. DIS 55.

2.2.4 Demographic shifts

Ageing population

The Victorian Government has recognised that the Victorian population will age dramatically in the years leading to 2020. In 2007, just under 14 per cent of Victorians were aged 65 years and over; by 2030 it is projected that over 20 per cent will be in this group.

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[40] AIHW, *Disability in Australia*, p.6 [see Footnote 39].

This demographic shift will affect people with a disability and/or mental illness at similar rates to the broader population. People with a disability in particular, are now living longer than in earlier generations, and complexities associated with ageing are likely to affect people who may already have complex needs to a greater extent. It is therefore likely that, as well as a greater number of people who are ageing with a disability and/or mental illness, the level of need for assistance among this group will be higher than in the general population.

Demographic shifts also have implications for the systemic reliance on families in caring relationships with people with a disability and/or mental illness. At the same time, a demographic shift may have effects on the number of people in the formal community services workforce.

Combined, it is likely these trends will result in significant constraints to system capacity to provide adequate services based on existing models.

Table 2.2.4–1: Age-standardised prevalence rates of disabilities with severe or profound core activity restriction, 1981 to 1998

	1981	1988	1992	1998
5 to 14	1.6%	2.2%	2.3%	3.7%
15 to 64	2.2%	2.3%	2.4%	3.3%
65+	16.2%	17.9%	17.1%	19.6%
All ages	3.9%	4.3%	4.3%	5.5%

Source: Australian Institute of Health and Welfare (2003) *Disability prevalence and trends*. AIHW cat. no. DIS 34.

Increase in disability and mental illness

Across all disability groups, the population prevalence of severe and profound core activity limitations appears to have increased during the past two decades. In 2003, the AIHW estimated that in all age groups, need for assistance due to one of the major disability groups (including psychiatric disability) increased over the period from 1981 to 1998. It is likely that this is, at least partially, indicative of shifts in community identification of disabilities, and changing expectations of the extent to which support services are required (see Table 2.2.4-1).

In its most recent report on Australia's Welfare, the AIHW estimates that the rate of growth in the number of people with a profound or severe core activity limitation (that is, people who need help with core daily activities) will increase by 173 per cent. It estimates that by 2010 around 1.5 million Australians will have this high level of disability, and by 2030 this will increase to approximately 2.3 million.[41]

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[41] Australian Institute of Health and Welfare (2009) *Australia's welfare 2009* Australia's welfare series No.9. Cat. No. AUS 117. Canberra, AIHW.

It is likely that these trends, alongside the population shifts described above, will have a significant effect on the level and nature of supported accommodation and other services required by people with a disability and/or mental illness.

Data used by the Victorian Government similarly indicates that there is likely to be an increase in the population of people with a disability and/or mental illness. For example, the Victorian Government advised the Committee that it has undertaken work to estimate future demand. Between 2003 and 2006 it commissioned two independent studies to explore demand drivers for people with a disability. The results suggested demand for disability services is expected to increase by between 3.5 and 5.3 per cent per year as a result of underlying population growth, increasing community expectations for government-funded services and the reduction of available informal care (due to ageing carers and increasing labour force participation of female carers).[42]

Similar observations have been made in the mental health sector. In 2002, the Victorian Auditor-General reviewed mental health services in Victoria and stated that demand for services was expected to increase in the five years ahead.[43] The Victorian Government has acknowledged the likely increase in people with a mental illness. In its 2009 mental health strategy, *Because Mental Health Matters*, the Victorian Government has acknowledged the challenges it confronts in regard to increasing demand for mental health services. It recognises that on the basis of population growth alone, over the next 10 years the numbers of people with a mental illness requiring access to services will increase.[44]

2.3 Links between support and accommodation for people with a disability and/or mental illness

In regard to accommodation and support needs, the Committee heard that people with a disability and/or mental illness are like all Victorians in their desire to live in an environment that enables them to be safe, secure and connected to their community.

The Australian Government's recent ratification of the United Nations Convention on the Rights of People with Disabilities has enshrined the right of people with a disability and/or mental illness to an adequate standard of living and to social protection associated with disability. This includes adequate food, clothing and accommodation, continuous improvement of living conditions and access to appropriate and affordable services.

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[42] Victorian Government (2008) Data provided to the Family & Community Development Committee.

[43] Victorian Auditor-General's Office (2002) *Mental health services for people in crisis*. Government Printer for the State of Victoria, Melbourne, p.3.

[44] Department of Human Services (2009) *Because mental health matters: Victorian mental health strategy, 2009-19*. Mental Health and Drugs Division, DHS, Melbourne, p.29.

To sustain accommodation and to live as independently as possible, people with a disability and/or mental illness often require support. Research has argued that all 'persons regardless of level of disability are in fact interdependent'.[45] People with a disability will often rely on others for assistance with activities of daily living and to have their recognised needs met. This can include informal family and social supports and more formal supports provided through government services.

The level of support required by people with a disability and/or mental illness can vary significantly. It may involve a range of approaches with differing levels of intensity. For example it could include:

- Financial or income support to allow the person to access mainstream accommodation

- The provision of supported accommodation in the community

- The provision of accommodation with support services

- The provision of residential services

- Assistance with activities of daily living, such as personal care, mobility, communication

- Assistance with instrumental activities of independent living, such as household management, transport, or arranging health care

- Support to undertake activities, including social and leisure activities, education, training and employment.

In the absence of support, the accommodation available to people with mental illness and/or disability can prove unstable and not able to meet their needs.

The link between support and accommodation is significant for many people with a disability and/or mental illness. Linkages can occur in many ways, and lead to a range of accommodation and support options. In a research project on the linkages between accommodation and support, the relationship was explained in the following way:

> The concept of housing is not restricted to the physical place in which one lives, but encompasses a wider range of variables about the context in which one lives… Support includes a range of informal and formal networks and services. Linkages encompass all the ways that programs, services, sectors, governments and their departments work together to achieve coordinated responses for individuals.[46]

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[45] Bridge, C., Kendig, H. Quine, S. & Parsons, A. (2002) *Housing and care for older and younger adults with disabilities*. AHURI Positioning Paper No.23, Australian Housing and Urban Research Institute, Sydney Research Centre, p.6.

[46] Reynolds, A., Inglis, S. & O'Brien, A. (2002) *Linkages between housing and support – what is important from the perspective of people living with a mental illness*. AHURI Positioning Paper No.33, Australian Housing and Urban Research Institute, Swinburne/Monash Research Centre, p.3.

The key is that the nature of the linkage needs to vary according to the needs of the person with a disability and/or mental illness. Ideally, therefore, a level of flexibility in creating these linkages is critical.

The types of linkages can vary across a range of tenancy and support arrangements:

Table 2.3–1

Type of tenancy	Type of accommodation	Type of support
Independent tenancy	Public housing Private rental Share housing	No formal support
Independent tenancy	Public housing Private rental Share housing	Formal support
Limited tenancy	Shared supported accommodation Cluster accommodation Supported Residential Service	Formal support
No tenancy	Congregate care Clinical bed-based residential	Formal support

Source: Family & Community Development Committee.

It is evident therefore, that supported accommodation is not a singular service type. Rather, it is recognised that the type and intensity of service provided will vary significantly according to many factors, including individual needs, and over time. It is also likely that the mix of 'support' and 'accommodation' will vary.

The Committee found that support and accommodation in service systems have generally evolved rather than been planned. The development of services has been based on historical circumstances, available resources, value determinants and/or understandings of people with a disability and/or mental illness at different points in time.

2.3.1 People with a disability and the service system

Since 2002 the scope of disability services, including SSA, has broadened to support people with disabilities other than intellectual disability. This presents a significant challenge for the sector. Chapter Three outlines the legislative and policy changes that have informed this new direction.

Disability services now provide support and accommodation to people with a range of different disabilities. These include intellectual disability, physical disability, sensory disability, ABI, neurological impairment and dual disability (that is, a disability and a mental illness). They do not provide services to people with a disability that relates to ageing.

The provision of supports to people with an ABI, some neurological conditions and dual disability remains a small component of service delivery in the disability

sector. In shared supported accommodation, people with an intellectual disability continue to be major recipients of services. As at 30 June 2008, people with an intellectual disability represented 88 per cent of people with a disability accommodated in SSA. People with a physical disability represented 3.2 per cent of those in SSA, followed by people with a neurological impairment (1.9 per cent) and people with an ABI (1.7 per cent).[47]

This is beginning to change, however, with increases in demand for SSA from people with disabilities other than intellectual disability. As at 30 June 2008, 71 per cent of all new requests for supported accommodation were by people with an intellectual disability. People with an ABI on the other hand, represented 7 per cent, indicating an increase in comparison with those receiving a service at that time.[48] Furthermore, Disability Services only extended its service provision to include people with autism spectrum disorder (ASD) in December 2008, and the implications are yet to be observed.[49]

An outcome of this distribution of people with different disabilities in SSA is that staff in these facilities are often skilled in providing support to people with an intellectual disability, but less skilled in responding to the needs of people with an ABI, autism or Huntington's Disease. These conditions are different from intellectual disability and people will often have needs specific to their disability. Issues relating to workforce capacity are addressed in Chapter Nine.

2.3.2   People with a mental illness and the service system

It is widely accepted that the symptoms of mental illness may reduce a person's quality of life and make it more difficult to manage the demands of day-to-day life, including work, study and relationships.

The Victorian mental health system largely responds to people with a serious mental illness. People with a serious mental illness are often vulnerable in the community. Those requiring support from the Victorian mental health service system – both clinical and non-clinical – generally include people who have significant and, at times, severe disturbances. They are often at high risk of harm to themselves or to others, and can be disinhibited and/or have impaired judgement. Frequently they are treatment resistant, and often they will have multiple conditions, including drug and alcohol problems, an ABI or an intellectual disability.

People with a mental illness are diverse, with different life experiences, aspirations, social backgrounds, personalities and levels of informal supports.

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[47]   Victorian Government (2008) Data provided to Family & Community Development Committee.

[48]   Victorian Government (2008) Data provided to Family & Community Development Committee.

[49]   Minister for Community Services (2008) *Media Release: Disability Assistance for Victorians with Autism.* Accessed from <http://www.premier.vic.gov.au/minister-for-community-services/disability-assistance-for-victorians-with-autism.html> on 8 October 2009.

Furthermore, their experiences of mental illness can be equally diverse, with medication and treatment having different effects. Despite this diversity, frequently, there are similarities in the accommodation outcomes for people with a mental illness.

The implications of having a serious mental illness can affect a person's basic ability to access and sustain a tenancy. For people with a mental illness, their capacity for independent living and need for support can fluctuate and be unpredictable. The support they require can be needed in diverse areas of their life and they may often require coordination of several services. When unwell, a person with a mental illness can be heavily reliant on others to ensure they receive available, coordinated and adequate support. In addition, people with a mental illness can also experience social isolation, poor physical health and poverty.[50]

2.3.3 Additional factors

Other factors can shape the experiences of people with a disability and/or mental illness. Aboriginal or Torres Strait Islander people with a disability and/or mental illness may have specific cultural needs. Similarly, people from CALD backgrounds may require additional support in communication if they face language barriers, or may be less likely to have family members or others who can provide support.

Some people with a disability and/or mental illness do not have family or support networks and may need additional practical and social support. People with a disability living in rural and regional areas may require particular assistance to ensure they can access appropriate services.

Although people with a disability and/or mental illness are at the centre of the systems providing support in accommodation or other aspects of life, their voices are sometimes not heard in conversations about whether services adequately meet their needs.

When capacity is an issue for a person with a disability and/or mental illness, additional complexities can arise in understanding their needs. For example, if comprehension or communication is difficult or not possible, a guardian or advocate (often a family member) may represent an individual's needs.

An advocate or a guardian might make statements on behalf of the person with disability and/or mental illness. Although the advocate or guardian may want the best for their relative, it can never be assumed that the guardian is speaking for someone. They can only ever speak on behalf of them.

The importance of appropriate communication and advocacy support is noted in the *Disability Act 2006*, which refers to the role of adequate advocacy in

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[50]   Reynolds, et al. *Linkages between housing and support*, p.7.

ensuring that individuals with a disability can participate in making decisions about their services.[51] The Disability Services Division (DSD) Industry Standards describe in more detail some areas where this support is needed, requiring service providers to support people with a disability in accessing advocacy or an 'independent support' to assist in making decisions about services, complaints, privacy and personal information, and concerns about abuse or neglect.[52]

In the context of mental health services, this issue arises most sharply in circumstances of involuntary assessment or treatment. A central purpose of the *Mental Health Act 1986* is to provide protection for the human rights of people with mental illness in this situation, acknowledging that decisions made by a guardian, even if in the best interests of an individual, may not be ideal.

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[51] See Sections 5 and 52 of the *Disability Act 2006*.

[52] Department of Human Services (2007) S*tandards for Disability Services in Victoria*. DHS, Victorian Government, Melbourne.

Chapter Three: Legislative and policy frameworks

Committee findings

- That there have been significant legislative and social policy developments in Victoria with a goal of promoting rights and enhancing social inclusion. (**Section 3.1**)

- That within this framework, disability and mental health services serve different goals. 'Recovery' is a key concept currently informing the provision of mental health services, while disability services are increasingly based on quality of life indicators, including self-determination, independence and choice. (**Section 3.2**)

- That there is a diverse and often complex range of national and state policies and legislative frameworks informing the delivery of disability and mental health services. (**Sections 3.3 & 3.4**)

T his chapter provides an overview of the current legislative and policy frameworks for disability and mental health support services in Victoria. Over the past two decades there have been significant changes in the policy and legislative frameworks that inform responses to people with a disability and/or mental illness. The impact of these changes has been multi-dimensional and profound in influencing how services respond to people with disabilities and/or mental illness in the context of support and accommodation.

An overview of the legislative frameworks in both the disability and mental health sectors helps to provide a sense of the legal and regulatory requirements for service provision. These requirements also influence the formation of policy, along with other factors including professional best practice and broader community expectations.

Policy frameworks determine the strategic direction of government actions in the context of disability and mental health services. These include investment in new kinds of programs, approaches to funding, and requirements of service providers. Policies shape the services available to Victorians with disabilities and/or mental illness in more specific ways than legislation. They determine the kinds of services provided, the availability of these services to people in different circumstances and different locations, and who provides the service.

Importantly, both the legislative and policy frameworks contribute to, and reflect, community expectations regarding the nature of services for Victorians with a disability and/or mental illness, their families and carers.

3.1   Overarching legislative and policy frameworks

As Chapter One outlined, one of the major shifts in disability and mental health has been the growth of a rights-based and social inclusion approach to policy and services.

From legislative and policy perspectives, Victorian approaches to disability and mental health services have been influenced by two frameworks expressive of these changes.

3.1.1   Victorian Charter of Human Rights

The Victorian *Charter of Human Rights and Responsibilities Act 2006* formally establishes a set of rights and responsibilities for all Victorians. The Charter was introduced to play a legal, political, educational and symbolic role. Importantly, it establishes a commitment that shared understanding of human rights should be the underlying principle of civic life. This is reflected in, for example, the strong human rights focus of the modernised *Disability Act 2006*. The Charter aims to ensure that human rights are valued and protected within government and the community.

The Charter also places an obligation on all public authorities, including private sector organisations that perform functions of a public nature, to comply with the rights contained in the Charter. This applies to every facet of the work of government, including law making, policy development and service delivery

3.1.2   A Fairer Victoria

The Victorian Government's social policy, *A Fairer Victoria*, is a broad, whole-of-government social policy statement that aims to promote government and community commitment to principles of social inclusion, support for vulnerable members of society, and integration of services. In 2005, the Victorian Government stated that it is a long-term framework that aims to:

- Ensure universal services provide equal opportunity for all
- Reduce barriers to opportunity
- Strengthen assistance to disadvantaged groups
- Provide targeted support to the highest risk areas
- Involve communities in decisions affecting their lives and make it easier to work with Government.

A Fairer Victoria contains annual details about planned investments in mental health, disability services and other social policy initiatives aimed at increasing social inclusion in Victoria. It reflects the objectives of state level mental health and disability policy documents.

Responses to both disability and mental health have featured under *A Fairer Victoria*, with the Victorian Government identifying its objective to create new opportunities for people with a disability and to increase support for mental health services. This has led to a range of initiatives in both the disability and mental health sectors over the past four years.

In 2009, for example, *A Fairer Victoria* stated that the Victorian Government's goal was to ensure improved care coordination for people with a severe mental illness through the introduction of new packages. The government also committed to developing a state-wide training and development program to support mental health experts to deliver highest quality services.

In regard to disability services, in 2009 the Victorian Government committed to assisting service providers deliver individualised approaches, better support to people with complex needs and comply with quality assurance processes.

A Fairer Victoria has provided a social inclusion framework for articulating the Victorian Government's human services aspirations. It has also played a role in policy development, as all divisions within departments are required to report against strategy goals.

3.1.3   Other policy frameworks

A range of other policy initiatives have implications for how the Victorian Government is currently responding to people with a disability and/or mental illness, such as housing and health care.

A feature of the human services policy framework is that there is a significant degree of 'siloing' – that is, services are planned and provided according to whether they target people with disabilities, or people with mental illness, or needing housing assistance, hospital care, aged care, or child protection (among others). Despite broad acceptance that for most people requiring social support the best responses deal with needs holistically and in an integrated way, there remains fragmentation in planning, funding, collection of data and service delivery. While in practice many service providers can meet complex needs, the system has not been structured with this person-centred approach in mind.

Additional policies that do not fall within the scope of this Inquiry also have some relevance. In particular, new policies and initiatives relating to housing and homelessness are influencing service responses to people with a disability and/or mental illness.

3.2   Legislative and policy differences between disability and mental health service systems

The philosophical base differs significantly between disability services legislation and mental health legislation. The new *Disability Act 2006* is broad in its scope and has a human rights basis, while the *Mental Health Act 1986* is retaining its more specific focus on involuntary treatment (with the issue of rights focused on civil and political dimensions).

The fundamental service objective of disability support is not to 'remove' or 'fix' the disability but to enhance the individual's quality of life in the context of their disability. The concept of quality of life is discussed in greater detail below. It reflects substantial differences from the idea of support services within the mental health recovery paradigm.

Despite these differences, there are many practical similarities between the two groups. In particular, some people with a disability and/or mental illness can require additional support in daily living. Other factors, such as a person's family situation and complexities of multiple issues, such as homelessness, substance use or abuse and neglect, may have similar impacts on people in either group.

There is also a group of people who have a disability (or multiple disabilities) and a mental illness. For these people, generalisations are less relevant. Trends associated with complexity, however, may emerge. Due to the structure of the service system outlined above, people in these circumstances can have particular

issues with accessing services that fully meet their requirements. This is detailed in later chapters.

Whether as a result of history or definition, there are often broad differences between the objectives of support services for those people with a mental illness as opposed to a disability. For many people with a mental illness, these services focus on physical and social rehabilitation in a clinical and medical framework. Services for people with a disability, on the other hand, are based on a 'social' framework with a focus on enhancing quality of life. These differences have implications for considering people's needs as well as for identifying the success of services in meeting those needs.

On a practical level, the frequently episodic nature of mental illness can mean that the need for supported accommodation is on a different cycle compared with someone who has a lifetime disability. While the needs of a person with a lifetime disability will potentially change with time or circumstances, the fluctuations are different. This affects the nature of the services required.

In addition, while both disability and mental health services provide forms of supported accommodation, differences between the underlying objectives of providing support in the sectors lead to quite different service types. For example, the service objectives associated with mental illness are increasingly framed within a 'recovery' paradigm, which holds that the individual is distinct from his or her illness, leading to more episodic services. In contrast, the provision of disability support is moving in a direction where a person's disability is regarded as an intrinsic part of his or her being with an increasing recognition of the need for person-centred approaches to suit individual needs and aspirations that contribute to their quality of life.

3.2.1 Disability and quality of life

The concept of quality of life has become increasingly influential in informing the provision of disability services. The concept has largely emerged from research and theory focused on people with an intellectual disability. The integration of quality of life key indicators into intellectual disability policy, however, suggests the likelihood of the concept extending to influence the experiences of people with other disabilities. A critical factor of quality of life initiatives is the opportunity provided for strengthening the voice of people with a disability to inform future directions in disability policy.

In recent research, a person's quality of life is considered an important dimension of adequate support. Measuring quality of life, however, is not straightforward, particularly measuring it in a way that is comparable between different people and over time.

The concept of quality of life in disability emerged in the 1980s.[53]   More recently, research has centred on developing application-focused approaches that provide a measurement scale and can potentially be used operationally to evaluate the quality of support services.[54]

Within a multi-dimensional quality of life framework, a number of core domains are considered to be important. These are:

- Interpersonal relations
- Material wellbeing
- Personal development
- Physical wellbeing
- Self-determination
- Social inclusion
- Rights.[55]

Within each domain, there is a range of indicators – for example, emotional wellbeing was most commonly considered to be indicated by:

- Contentment (described as satisfaction, moods, and enjoyment)
- Self-concept (described as identity, self-worth, and self-esteem)
- Lack of stress (predictability and control).

Identifying the objective factors may be relatively straightforward, while the subjective factors – which are often intangible, cannot be easily expressed, and are difficult to compare – present a substantial challenge.

Along with this, there are additional challenges in the case of people with a disability, who may not be able to identify or communicate where their quality of life fits on these scales. While it is possible for someone who knows the person well – a family member or carer, for example – to act as a proxy, there appears to be uncertainty about the reliability of such reports.[56]

Finally, it is important to note that a good or better quality of life does not necessarily imply equal quality of life – given the very wide range of functional disability present in the group of people with mental illness and/or disability, it is inevitable that the extent to which aspirations may be met will vary.

The concept of quality of life has informed much of the approach to disability service provision in recent years. Person-centred support and a focus on self-

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[53]   D'Eath, M., Walls, M. Hodgins, M. & Cronin, M. (2009) *Quality of Life of Young People with Intellectual Disability in Ireland.* National Disability Authority, Accessed from <http://www.nda.ie/cntmgmtnew.nsf/0/92B4C7518B89DE568025706600506DF8?Open Document> on 19 October 2009.

[54]   Department of Human Services (2007) S*tandards for Disability Services in Victoria.* DHS, Victorian Government, Melbourne.

[55]   D'Eath et al, *Quality of Life of Young People with Intellectual Disability in Ireland* [see Footnote 53].

[56]   D'Eath et al, *Quality of Life of Young People with Intellectual Disability in Ireland* [see Footnote 53].

directed support are outcomes of these broader changes in understanding of the needs of people with a disability.

Implicit in models of person-centred and self-directed support (which have largely underpinned the move to supported accommodation in the community rather than providing care in residential settings) is the objective of maximum self-determination for people with a disability.

Several participants in the Inquiry spoke of the significance of the concept of quality of life, and of the key indicators. In particular, choice and self-determination were considered important. Ms Helen Johnson from Interchange Central Gippsland, a group supporting people in caring relationships, stated that:

> All young adults should have the option to move out of home, and young adults with a disability should be supported to do so if they wish. This should be a part of life process, if this option is chosen, just like any other young person without a disability may choose to do when the time is right for either them personally, or their family, or their parents' circumstances change.[57]

Interchange Central Gippsland explained that to achieve this, 'we don't believe there should be large-scale housing developments that create segregation, but rather unique, individual accommodation options of varying styles and choices'.[58]

In making similar arguments, several organisations provided evidence to the Committee based on surveys they undertook with people with a disability associated with their services. Dawn Accommodation, for example, explained that:

> We had some surveys undertaken by DAWN which indicate people with a disability, on the surveys that came back to us, wanted to live with their friends or on their own. There was a need there for a range of accommodation options. Independent living of course with support in community settings. All of this is with support but people living on their own, perhaps in one-bedroom units, people living with friends in two-bedroom units, people with a disability also living in cluster neighbourhood arrangements with care available if needed, and the need, of course, [for] 24 hour care for high needs if with a disability.[59]

Similarly, the Committee heard from Karingal that in describing their goals and aspirations, people with a disability had very clear views. The types of aspirations raised included being free and independent, living in 'my own home', living with friends and having improved accommodation. Notably, Karingal emphasised that 'not one person said, "I want to live with my family forever", so I think that is getting it straight from the horse's mouth'.[60] The current

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57   *Committee Transcript*, 21.10.08, p.4 (Interchange Central Gippsland).
58   *Committee Transcript*, 21.10.08, p.4 (Interchange Central Gippsland).
59   *Committee Transcript*, 23.10.08, p.2 (Dawn Accommodation).
60   *Committee Transcript*, 23.10.08, p.7 (Karingal).

policy direction of the Victorian Government has a strong focus on the family providing care and support. The lack of accommodation options reduces the opportunity for people with a disability to have the range of choices to be self-directed in living their own life, deciding what they want to do and making it happen.

Interconnected with issues relating to the desire to live independently and to have choice in living arrangements, the Committee was told that it is important to effectively work towards social inclusion at the service level. For example, the Health and Community Services Union (HACSU) explained the importance of the workforce being skilled in building people's social needs:

> The social needs are very important, because if we just address the physical side and the direct care needs, we are not dealing with the inclusion and the social needs of growing the individual and including them in our society.[61]

Some organisations informed the Committee that they explicitly aim to work towards social inclusion. Gateways Support Service explained to the Committee that 'our mission is to empower and support children and adults who have a disability and additional need and their families to maximise their quality of life, their potential and their positive relationships in the community. We are a community based organisation'.[62] Their CEO, Ms Rosemary Malone, explained further that:

> for us quality is really assisting people with a disability to actually live the life they want to live. We respect and actively support our residents to make decisions and to promote their quality of life. We encourage them to continue to develop their skills and confidence.[63]

The Committee also heard that some families in caring relationships did not believe that all service providers were focused on maximising quality of life. One family carer explained her view about the importance of getting the right balance between legal obligations and supporting people with a disability to achieve quality of life:

> I think there needs to be a balance between the disability services legal requirements and quality of life issues, because that is crucial to a successful housing placement. It is no good just providing the shelter of a house and food and cleaning. People have to live, and if that is not happening, then it is cruel, and they have got enough to deal with.[64]

Some individuals and organisations also raised the link between quality of life and behaviours of concern. The CEO of Golden City Support Services, Mr Ian McClean, for example, highlighted that:

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61   *Committee Transcript*, 22.10.08, p.4 (HACSU).

62   *Committee Transcript*, 23.10.08, p.2 (Gateways Support Services).

63   *Committee Transcript*, 23.10.08, p.2 (Gateways Support Services).

64   *Committee Transcript*, 23.10.08, p.6 (Gateways Support Services).

> People need to be engaged in everything to do with their life, and all the work with people with higher support needs due to challenging behaviour [suggests that] one of the key reasons for challenging behaviour is boredom.

> If people aren't engaged in their own life – if they're plonked on a chair to be cared for – then simple boredom causes challenging behaviour. We don't have anyone that enters into challenging behaviour when they are actively engaged in things that they want to be doing. It's not that simple, but it is – that is a very core component. Choice and control is really important. The feeling of being in control of your own life and having some say over it is important, in fact, to us all…[65]

The issue of behaviours of concern is discussed in greater depth in later chapters.

Broadly, the evidence received by the Committee indicated the significance of the concept of quality of life and its links to adequate accommodation and support for people with a disability. The Committee heard how important it is for people with a disability being supported in their home (whatever form of accommodation that might be) to have choice, independence and the opportunity to pursue their goals and aspirations. The remainder of this chapter considers the availability of support and accommodation in meeting the needs of people with a disability.

3.2.2   Mental health and recovery

The recovery paradigm is increasingly informing directions in responding to mental health issues, particularly for those with a serious mental illness. In their 2008 meta-analysis, Bonney and Stickley note that while 'recovery is not a new concept within mental health, … in recent times, it has come to the forefront of the policy agenda'.[66]

The concept of 'recovery' remains contested. Importantly, recovery is not necessarily about 'cure'. The preferred conceptualisation of recovery will depend on the context of its use, and who is using the concept. For example, consumers may have a very different understanding of recovery from service providers.

In the context of service provision, some models of recovery conceptualise it as a process whereby a person with a mental illness moves through a state of 'being "dependent/unaware" to "dependent aware", "independent aware" and ultimately "interdependent aware"'.[67] This is the model preferred by the

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[65]   *Committee Transcript*, 19.11.08, p.9 (Golden City Support Services).
[66]   Bonney, S. & Stickley, T. (2008) 'Recovery and mental health: a review of the British literature'. *Journal of Psychiatric and Mental Health Nursing*, Vol.15, p.140.
[67]   Bonney & Stickley, 'Recovery and mental health', p.146 [see Footnote 66].

National Institute for Mental Health in England. Frequently the concept of recovery also has a social dimension, incorporating the goal of social inclusion.[68]

The recently released Victorian mental health strategy, *Because Mental Health Matters*, has adopted 'recovery' as one of the four core elements in its reform strategy. Recovery is defined as:

> promoting access to client-centred treatment and ongoing support that aims to achieve real change and the best possible individual outcomes. Recovery-focused care should foster independence and the capacity of affected individuals to achieve their personal goals and lead meaningful and productive lives.[69]

Several participants stressed the importance of recovery. In its evidence, Ballarat Adult Community Psychiatric Service stated that 'recovery is a reasonable expectation in all instances and, as a result of that, impairment disability and handicap ought to be minimised provided effective clinical treatments are delivered in a timely and orderly fashion'.[70] The service also emphasised the related component of 'prevention', stating 'the longer a disorder remains untreated, the greater the likelihood of ongoing problems and difficulty that can lead into issues such as this housing problem'.[71] Notably, prevention is another of the four core elements of the mental health reform strategy identified by the Victorian Government. The Committee heard that accommodation and prevention of mental illness are strongly interconnected.

In her submission to the Committee's Inquiry, Ms Leesa Cornthwaite, a former medical officer in a secure extended care unit (SECU), outlined her view regarding the connections between accommodation and clinical-based treatment in residential settings:

> The necessary level of restriction within the environment of SECU makes the adequate provision of alternative accommodation for those who are suitable to be housed elsewhere an ethical and moral responsibility.[72]

She also provided insight into the significance of the appropriate treatment length, exit strategies in achieving recovery and the importance of adequate accommodation and provided her perspective regarding the negative consequences for recovery when a person with a mental illness is unable to exit into appropriate accommodation. Ms Cornthwaite explained that the consequences can affect consumer morale and can lead to disruptions for other consumers. [73]

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[68]   Bonney & Stickley, 'Recovery and mental health', p.146 [see Footnote 66].

[69]   Department of Human Services (2009) *Because mental health matters: Victorian mental health strategy, 2009-19*. Mental Health and Drugs Division, DHS, Melbourne, p.22.

[70]   *Committee Transcript*, 20.11.08, p.2 (Ballarat Health Services).

[71]   *Committee Transcript*, 20.11.08, p.2 (Ballarat Health Services).

[72]   *Submission* 7, p.1 (L. Cornthwaite).

[73]   *Submission* 7, p.1 (L. Cornthwaite).

Other organisations expressed similar views. For example, VICSERV and SNAP in Gippsland referred to the association between accommodation and clinical improvement, stating that stable accommodation has been shown to be a better predictor of reduced hospital admissions than clinical interventions.[74] NorthWestern Mental Health similarly commented that 'without adequate and safe accommodation, effective treatment and rehabilitation strategies cannot be implemented'.[75]

Reinforcing this, the Chief Psychiatrist advised the Committee that 'people need clinical support and living support and accommodation… it is about balancing sufficient clinical support with sufficient other support and making sure they are well coordinated and then thinking about the style of accommodation'.[76] Associate Professor Harry Minas from the Victorian Transcultural Psychiatry Unit further commented that 'supported housing is clearly critically important to the success of all aspects of our mental health service provision in Victoria'.[77]

The Committee was also informed that people with a mental illness often view accommodation as the key to their improved recovery. VICSERV told the Committee 'mental health service consumers repeatedly tell us that stable housing is critical to the quality of their lives and support to retain that housing is the most important issue they are faced with'.[78] This is supported by a national survey conducted in 2007 by the Schizophrenia Fellowships of Australia indicating that 66 per cent of members who responded to the survey (most of whom were people with a mental illness) considered accommodation to be the most important issue in their lives.[79] Similarly, Sane undertook a survey in which 87 per cent of respondents stated that a barrier to maintaining suitable accommodation was the lack of support around the time they became unwell.[80] Respondents suggested they needed support to prevent them from losing their accommodation during vulnerable periods, such as post-hospitalisation.

In regard to the recovery path, the Committee heard of the importance of ensuring that people with a mental illness have choice. The Mental Illness Fellowship Victoria stated clearly that 'recovery outcomes are best fostered through supported accommodation approaches that maximize personal choice for the person with mental illness'.[81] Further to this, HomeGround Services maintain that mental health support is most effective when decent, permanent

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[74]   *Committee Transcript*, 21.10.08, p.2 (SNAP Gippsland); *Committee Transcript*, 30.4.2009, pp.2-3 (VICSERV). See also Reynolds, A., Inglis, S. & O'Brien, A. (2002) Linkages between housing and support – what is important from the perspective of people living with a mental illness'. AHURI Positioning Paper No.33, Australian Housing and Urban Research Institute, Swinburne/Monash Research Centre, p.4.

[75]   *Submission* 119, p.1 (NorthWestern Mental Health).

[76]   Chief Psychiatrist (2009) Permission to use extracts from briefing evidence, email received 10 December 2009.

[77]   *Committee Transcript*, 30.4.09, p.2 (Victorian Transcultural Psychiatry Unit).

[78]   *Committee Transcript*, 30.4.20, p.2 (VICSERV).

[79]   Mental Illness Fellowship Victoria (2008) *Mental illness and housing: preliminary discussion paper*, Mental Illness Fellowship Victoria, p.5.

[80]   Sane (2008) 'Housing and mental Illness'. *Sane Research Bulletin*, No.7 , June.

[81]   *Submission* 98, p.14 (Mental Illness Fellowship Victoria).

and affordable accommodation is provided and is developed around the individual needs of people, providing adaptable and continuous forms of support.[82] The Committee received very little evidence from individuals with a mental illness. In addition to a small number of submissions, they were represented by consumer advocacy bodies, such as the Victorian Mental Illness Awareness Council.

Many participants based their evidence provided to the Committee on information they secured through surveys of consumers. For example, Pathways Homeless Outreach Psychiatric Service told the Committee that 'an overwhelming 90 per cent of clients would prefer not to live in shared accommodation, preferring their own unit'.[83] Mr Eugene Meegan of Psychiatric Services, Bendigo Health Care Group, provided an example of an exchange he had with a consumer of the service:

> I'm mindful of a client who once brought to my attention that what he wanted was to live in a flat, in association with others without interference from outsiders. But, because he suffered from mental illness, he knew that he had to have others involved. What the mental health providers wanted him to do was to live in a six-room accommodation. He put it to me that I wouldn't be able to cope with living with five other people with mental illness, and we expected that he could do that, and he's suffering from mental illness, which is a very telling comment.[84]

Research in the field supports this view. Most notably, a research project undertaken by the Australian Housing and Urban Research Institute in 2002, explored the preferred accommodation characteristics and living arrangements of people with a mental illness. This project concluded that most 'indicated that living in a "private" house or flat is the preferred option, with the emphasis on living independently, which could be in a range of housing tenures including public housing, private rental or home ownership'.[85] The authors noted that 'there was a strong preference not to live with others with a mental illness'.[86]

Many participants emphasised the significance of choice and self-determination. SNAP in Gippsland referred to research it was familiar with and emphasised that 'choice of housing must be based on consumer preference… [and] housing should foster consumer control over their environment'.[87]

Despite recognition of the importance of independence, self-determination and choice in accommodation options, the Committee heard that many people with a mental illness cannot access appropriate accommodation options. Concerns

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[82]   *Submission* 71, p.3 (HomeGround Services).

[83]   *Committee Transcript*, 23.10.08, p.6 (Pathways Homeless Outreach Psychiatric Service).

[84]   *Committee Transcript*, 19.11.08, p.2 (Bendigo Health Care Group).

[85]   Reynolds, A., Inglis, S. & O'Brien, A. (2002) *Linkages between housing and support – what is important from the perspective of people living with a mental illness*. AHURI Positioning Paper No.33, Australian Housing and Urban Research Institute, Swinburne/Monash Research Centre, p.12.

[86]   Reynolds, Inglis, & O'Brien *Linkages between housing and support*, p.12. [see Footnote 85].

[87]   *Committee Transcript*, 21.10.08, p.6 (SNAP Gippsland).

highlighting perceived gaps between demand and the allocation of services related to the level of availability of services at the time required, the nature of the available services and the extent to which they meet individual needs and the duration and timeliness of those services.

3.3   Disability services: legislative and policy frameworks

This section describes key elements of the national and state legislative and policy framework within which disability support services are provided in Victoria.

Legislative framework

The introduction of the *Disability Act 2006* represents a significant shift in legislative approach to the provision of disability services. The Act replaced the *Intellectually Disabled Persons' Services Act 1986* and *Disability Services Act 1991*. It is intended to align legal requirements with the direction of disability support provision in Victoria as outlined in the *State Disability Plan 2002-2012*.

> **Disability Act 2006**
>
> The *Disability Act 2006* commenced on 1 July 2007. The purpose of the new disability legislation 'is to enact a new legislative scheme for persons with a disability which reaffirms and strengthens their rights and responsibilities and which is based on the recognition that this requires support across the government sector and within the community'.[88]
>
> The CSTDA/NDA definition of disability is used in the Act but is adapted to reflect the direction of the *State Disability Plan 2002-2012*. The Act outlines an approach to planning that reflects an individualised planning and support approach, which is about self-determination, community membership and citizenship.
>
> There are six broad components to the new legislation. A legislative framework is provided for the following areas of the disability sector:
>
> 1)   Administration – including roles and responsibilities
>
> 2)   The provision of disability services
>
> 3)   The provision of residential services
>
> 4)   Oversight of the service system – including the protection of rights and mechanisms for ensuring accountability
>
> 5)   The use of restrictive interventions
>
> 6)   The provision of compulsory treatment.

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[88]   *Disability Act 2006* (Victoria), p.1.

> The legislative requirements are made operational through the *Disability Services Regulations 2007*.

The *Disability Act 2006* is underpinned by a value framework that promotes person-centred planning and support, with a focus on self-determination, community membership and citizenship. The changed direction that this represents has had a substantial impact on the provision of disability services in Victoria, including supported accommodation services.

The Act seeks to re-centre concepts of support, moving from a service-centred approach towards one where supports are provided on the basis of individual needs. This implies that provision should be built around person-centred planning approaches, and service providers are now required to undertake this practice shift where necessary.

The Act sets out quality requirements for disability services provided. Implemented by DHS through its *Quality Framework for Disability Services*, central aspects of these new requirements are the introduction of outcomes standards to complement existing service quality standards, and the phasing in of a system of external quality monitoring and registration of disability service providers. The Act also legislates the roles of Disability Services Commissioner, Senior Practitioner and Community Visitors.

The evidence received by the Committee reveals significant support for the new directions in the *Disability Act 2006*. For example, the following comments were made:

> The *Disability Act 2006* places a high value on planning, and on providing for individual needs and choices.[89]

> The *Disability Act 2006* … is a development that provides a new legislative framework for promoting the rights of people with disability. While the legislation is in its infancy and there are some discrepancies in its implementation, it has the potential to improve the quality of life and opportunities for people with a disability.[90]

The Committee heard that concerns largely relate to the perceived gap between the vision and the reality.

The Committee acknowledges that the Victorian Government is undertaking an evaluation of the implementation of the *Disability Act 2006* with a view to identifying improvements in future directions relating to its implementation.

The principle objectives of this project are to undertake a comprehensive evaluation of the implementation of the legislation, and to identify further activities required to support the management and operations of disability

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[89]   *Submission* 49, p.1 (Mackillop Family Services).
[90]   *Submission* 100, p.12 (Office of the Public Advocate).

service providers to meet the requirements, practice and cultural changes to fulfil the Act's intent.

The evaluation will focus on:

- The effectiveness of the implementation at a state-wide, regional and organisational level

- The appropriateness of strategies, activities and support of the implementation at a state-wide, regional and organisational level

- Insight into the awareness and understanding of people with a disability, their parents, carers and families about the Act.

While this review will shed potential light on the effectiveness of implementation, the Committee considers that a review of the outcomes established by the Act will be critical and that it would be appropriate to do this five years after the commencement of the legislation.

Recommendation

3.1 That in 2012, the Victorian Government undertakes an external evaluation to determine the extent of the achievement of the policy objectives in the *Disability Act 2006*.

Policy framework

Policy frameworks relating to disability support services consist of Commonwealth and State policies. Both have seen significant shifts in recent years.

Figure 3.3–1 illustrates the relationships between Commonwealth and State disability policies.

Figure 3.3–1: Key disability legislation and policies at Commonwealth and State level

Commonwealth   State

Policy
• National Disability Agreement (formerly CSTDA) *sets out funding and performance arrangements for disability services*
• National Disability Strategy (under development *will ensure a consistent rights-based approach to the needs of people with a disability*)

Legislation
•Disability Act 2006 *establishes the legislative framework for the provision of disability services in Victoria*
Policy
• State Disability Plan 2002-12 *sets out the Government's priority strategies relating to people with a disability*

Non-disability specific policy
• A Fairer Victoria

In Victoria, the *State Disability Plan, 2002-12* and the subsequent introduction of the *Disability Act 2006* represent important conceptual changes that have had an impact on practical arrangements for support, including supported accommodation.

The *State Disability Plan* reflects a shift in the focus of disability policy from specific programs such as personal care, day programs and accommodation to a focus on supporting people with a disability in flexible ways, based on their individual needs.

State Disability Plan 2002-12

The *State Disability Plan, 2002–12* brings into focus the Victorian Government's approach to disability, reaffirming the rights of people with a disability to live and take part in community life as citizens of Victoria. From 2013, the *Disability Act 2006* requires that a new State Disability Plan is tabled every four years to establish goals to assist in furthering the objectives and principles outlined in the Act.

Priority strategies and key actions are identified in the plan, which sets out five priority strategies:

- Reorient disability supports – to ensure that disability supports focus on assisting people with a disability to live in the community and participate in activities of their choice in ways that are meaningful to them

- Develop strong foundations for disability supports – develop mechanisms which ensure disability supports can respond to people's needs – both at the individual level and the system level

- Promote and protect people's rights – ensuring that support providers and the community as a whole respects and promotes the rights of people with a disability. The document defines rights as they are written in law and also outlines five others which are not

- Strengthen local communities – creating safe and healthy environments which are more accessible and more inclusive of people with a disability

- Make public services accessible – this includes access to education, public transport, health services, employment opportunities, as well as access to buildings and other venues.

In the *State Disability Plan*, the Victorian Government commits that all government departments will develop Disability Action Plans with the aims of eliminating discrimination and providing people with disabilities with equal opportunities for inclusion and participation.

As part of the *State Disability Plan*, the Victorian Government currently produces three-yearly Implementation Plans. The most recent of these plans, for the period 2005 to 2008, outlined a number of actions directly relating to supported accommodation.

These involved a range of provisions for Shared Supported Accommodation (SSA), the major supported accommodation option funded and/or provided by the Department of Human Services. The plans have stated that:

- Cultural and practice changes will be promoted to ensure a person-centred approach in supporting people with a disability in shared supported accommodation

- Disability Services will work with housing providers, such as the Disability Housing Trust, Housing Associations, Office of Housing and private rental market to develop a broader range of accommodation opportunities for people in receipt of flexible disability support packages.

- Opportunities will be provided for people currently living in SSA to move to independent living options

- In partnership with the Commonwealth government, Disability Services Division will implement a five-year initiative for younger people in residential aged care, by providing alternative accommodation and support arrangements and improved care for younger people who remain in

residential aged care (RAC) and divert referrals of younger people to other residential options.

At the national level, funding and policy strategies which determine priorities and directions for disability services overall may influence supported accommodation.

Commonwealth State Disability Agreement/National Disability Agreement

The Commonwealth State and Territory Disability Agreement (CSTDA) is a five-year agreement between the Australian and State/Territory Governments that lays out the national framework to fund, monitor and support quality services for people with a disability. It was first established in 1992, with the goal of rationalising the provision of specialist disability services in Australia and to develop, on a national basis, integrated services to ensure access to appropriate services which meet individual needs. Since then, two CSTDA documents followed, each building on the previous document.

During 2009, the federal agreements have been substantially restructured. Whereas the former arrangements, including the CSTDA, provided for funding transfers from the Australian government to the states and territories on the basis of defined services provided, the new agreements are significantly broader. Rather than being structured around the services, the new National Disability Agreement (NDA) focuses on setting out the overarching objectives that must be achieved.

This new agreement is designed specifically to assist people with a disability to live as independently as possible, helping them to establish stable and sustainable living arrangements, increasing their choices and improving their health and wellbeing.

Within the NDA, the parties have agreed on several priority areas to guide policy directions and reform in the service system. While a number of these reflect the importance of needs-based provision, and of access to and availability of 'the most appropriate' supports, the issue of supported accommodation is not explicitly addressed.

In 2007 the Senate Committee on the Inquiry into the Funding and Operation of the CSTDA made a number of recommendations, one of which highlighted the need for a coordinated, high level, strategic policy to address the complexity of needs of people with a disability, their family and carers in all aspects of their lives. To this end, the Commonwealth government has committed to the implementation of a National Disability Strategy.

National Disability Strategy

The National Disability Strategy will aim to address the barriers that are faced by Australians with disability and promote social inclusion. The National Disability Strategy will be developed in consultation with people with a disability, disability and carer peak bodies, employers, industry experts and the broader community.

The National Disability Strategy will be informed by consultations and is expected to be released within the next year. It will serve as an important mechanism in ensuring the principles underpinning the United Nations Convention on the Rights of Persons with Disabilities, recently ratified by the Commonwealth government, are integrated into policies and programs affecting people with disability, their families and carers.

The development of the National Disability Strategy includes the establishment of the National People with Disabilities and Carer Council chaired by Dr Rhonda Galbally. The consultation process on the Strategy included 2,500 people across Australia, both in capital cities and regional and remote areas. The Council released a consultation feedback report 'Shut Out: The Experience of People with Disabilities and their Families in Australia' on 5 August 2009. The report is informed by the consultations and independent qualitative and quantitative analysis of them.

3.4 Mental health services: legislative and policy frameworks

This section outlines major parts of the legal and policy framework for mental health support services in Victoria.

Legislative framework

The *Mental Health Act 1986* provides a legislative framework for the care, treatment and protection of people with a mental illness in Victoria. The Act is the oldest mental health law in Australia. Parts of the Act have been amended several times, in particular the provisions concerning involuntary consent to treatment or restriction.

The Act covers mental health services, defined as including:

- An approved mental health service
- An agency providing community support services that provides residential services and 24 hour nursing care for people with a mental disorder.

The legislation outlines a process for approval services and the staff who work within the sector.

The Act sets out the role of the Chief Psychiatrist, who is responsible for the medical care and welfare of persons receiving treatment or care for a mental illness. It also legislates the role of Community Visitors.

In 2008 the Victorian Minister for Community Services, the Hon. Lisa Neville, announced a review of the Act. The focus of the review provides an indication of the key areas for reform. In addition to greater recognition of specific needs and of the role of carers, the review committee is looking at how the Act deals with involuntary treatment and how it may provide more appropriate requirements in line with human rights.

It is likely that, following modernisation of the *Mental Health Act 1986*, legal requirements relating to service provision will change to some degree in order to implement the concepts expressed in the new Act.

Review of the Mental Health Act

The review of the Act is shaped by the new vision for mental health in Victoria, outlined in the policy document *Because Mental Health Matters: Victorian mental health reform strategy 2009-19*. The review recommends a series of broad recommendations to be considered when the Act is modernised. These include:

- The promotion of voluntary treatment including promotion of supported decision making

- Formal recognition of the important role of carers

- Greater recognition of specific needs including those of people receiving treatment on a voluntary basis, indigenous people, culturally and linguistically diverse people and children and young people, among others

- The protection of human rights in line with the requirements of the Victorian Charter of Human Rights and Responsibilities and the United Nations Convention on the Rights of Persons with Disabilities

- A recovery focus.

The review process has involved community consultation with a broad range of stakeholders. In July 2009, the review committee released a summary of stakeholder views, *Review of the Mental Health Act 1986 Community Consultation Report*.

Policy framework

Victorian mental health services are shaped by both national and state level policy frameworks. States have responsibility for service provision and have

produced strategic and practically-focused policy documents. National level frameworks, on the other hand, have set out a range of directions for change including reform oriented programs (often Commonwealth funded) and national consistency (eg through data collection requirements and service standards).

A simplified impression of this policy framework, including both Commonwealth and State policy is provided in Figure 3.4–1.

Figure 3.4–1: Key mental health legislation and policies at Commonwealth and State level

Commonwealth

Policy
•National Action Plan on Mental Health 2006-11 *CoAG-endorsed plan to focus strategies across Australia*
• National Mental Health Policy 2008 *replacing earlier policy*

State

Legislation
•Mental Health Act 1986 *establishes legislative basis for service provision, with a focus on ensuring rights during treatment*
Policy
• Because Mental Health Matters *sets out the Government's priority strategies relating to people with a mental illness*

Non-disability specific policy
• A Fairer Victoria

Because Mental Health Matters is the state level strategy that sets out a 'whole of Victorian Government' 10-year plan for mental health. The document itself is divided into two parts. Part one outlines the case for reform and the overall framework including principles that underpin reform, the proposed outcomes, key target groups and a holistic description of the wider mental health service system.

The strategy builds on the change in approaches marked by the Commonwealth's *National Action Plan on Mental Health*. It has four core elements:

- Prevention – the social and economic benefits of promoting community and individual resilience

- Early Intervention – early in life, in the development of a disease and in the manifestation of any given episode

- Recovery – foster the independence of an individual and their capacity to achieve personal goals

- Social Inclusion – social inclusion and freedom from stigma and discrimination.

Part two of *Because Mental Health Matters* is structured around eight reform areas:

1) Promoting mental health and wellbeing – preventing mental health problems by addressing risk and protective factors

2) Early in life – helping children, adolescents and young people and their families

3) Pathways to care – streamlining service access and emergency responses

4) Specialist care – meeting the needs of adults and older people with moderate to severe mental illness

5) Support in the community – building the foundations for recovery and participation in community life

6) Reducing inequalities – responding better to vulnerable people

7) Workforce and innovation – improving capacity, skills, leadership and knowledge

8) Partnerships and accountability – strengthening planning, governance and shared responsibility for outcomes.

The document contains few budgetary commitments, and by virtue of its timeframe outlines aspirations rather than programs. The proposed next steps in reform include the development of a series of action plans based on the priorities outlined in the overarching strategy document.

National level policies include the *National Mental Health Strategy*, which comprises a National Mental Health Policy, the *First National Mental Health Plan*, the Mental Health Statement of Rights and Responsibilities and a funding agreement between the Commonwealth and the states and territories.

In 1991, Australian Health Ministers agreed to the Mental Health Statement of Rights and Responsibilities. The following year, Australian Health Ministers agreed to the National Mental Health Policy.

The *First National Mental Health Plan* emphasised structural changes in where and how mental health services were delivered. There have since been three National Mental Health Plans, with the most recent being the 2003-08 plan. Subsequent plans have broadened the approach to give a stronger focus on partnerships between different sectors, inclusion of promotion, prevention and early intervention activity, and a greater emphasis on the roles of consumers and carers. These plans have been linked to funding through the Australian Health Care Agreements. Each of the plans is subject to evaluation following their expiration.

The most recent *National Mental Health Plan (2003-08)* identified the need for consumers to participate with politicians, policy makers, planners, managers and service deliverers as equal partners in national, state/territory and local decision making that affects their quality of life.

The *National Mental Health Strategy* set up a framework in which strategic and aspirational directions – ensuring quality of services provided, emphasis on health promotion, prevention and early intervention, inclusion of consumers and carers in planning and decision making – have been linked to the funding provided to state and territory governments to provide the support services involved.

In addition to Australian Government policy frameworks, national policies have been developed through the Council of Australian Governments (COAG) forum. In July 2006, COAG endorsed a *National Action Plan on Mental Health (2006-2011).* The document was released in response to the growing recognition of the scale and significance of mental health issues and the importance of issues such as housing and support to enhance recovery from mental illness.

The *National Action Plan on Mental Health* was designed to sharpen the focus on areas that had not progressed sufficiently under the *National Mental Health Strategy*. COAG governments agreed that further effort was required to overcome historical boundaries between jurisdictions and to better engage government portfolios to bring a whole-of-government focus to mental health reform. The *National Action Plan on Mental Health 2006-2011* brought a whole-of-government approach to mental health as part of COAG's National Reform Agenda. A number of jurisdictions have created new ministerial portfolios or departmental responsibilities to support this renewed emphasis on care coordination and governments working together.

As part of the *National Action Plan on Mental Health*, governments from each of the states and territories contributed Individual Implementation Plans. In its Individual Implementation section, the Victorian Government committed $427.4 million from 2006 to 2011 towards building a comprehensive strategy for significant and sustained mental health support and reform. The Government identifies four target areas for investment, one of which aims to provide for the wider support needs of people with a serious psychiatric disability, in particular for their supported accommodation. The funds allocated to achieving this objective include:

- a proposed investment of $38.6 million in psychiatric disability and rehabilitation support services (PDRSS), which provide a range of community-based rehabilitation and supported accommodation services

- $40.4 million of funding to be invested in pension-level supported residential services (SRS). While not strictly part of the mental health service system, it is estimated that around 62 per cent of pension-level SRS residents have a mental illness; therefore these form an important de facto element of the supported accommodation system.

More recently, the Australian government has developed the *National Mental Health Policy 2008*. This recognises the need for ongoing national reform and the need for collaboration across a range of services provided or funded by different government and private sectors, non-government agencies, individuals and organisations in the community. The document states that access to clinical care must be complemented by access to a range of supported accommodation options, stable housing and community support services and that these services should be readily accessible and should not discriminate on the basis of mental health status. The document also specifies Aboriginal and Torres Strait Islander specific services, including community-controlled services as being of particular importance.

Part B:

Meeting Need

Chapter Four:
Service framework

Committee findings

- That the range of participants in the disability and mental health sectors includes people with a disability and/or mental illness, families, service providers, advocacy bodies, external monitors and government (**Section 4.1**)

- That services that fall within the Committee's definition of 'supported accommodation' include (but are not limited to) group homes, congregate care, bed-based clinical and non-clinical mental health services (**Section 4.2**)

- That the provision of support and accommodation differs significantly across the disability sector and the mental health sector

    – Disability services are often long-term and have a community-based, disability-specific focus (**Section 4.2.1**)

    – Mental health services are episodic and have a strong health and treatment focus (**Section 4.2.2**)

- That the mix of service providers varies across the two service sectors, and includes government, non-government organisations and private providers (**Section 4.3**)

- That the funding models for both mental health and disability are complex and not always consistent. (**Section 4.4**)

T his chapter outlines the central individuals, organisations, systems and structures in supported accommodation for people with a disability and/or mental illness and their roles within the service systems.

The involvement of individuals, families, and service providers is discussed along with some features of service provider mix. Also outlined are the core operations, funding models for support and accommodation in both the disability and mental health systems.

The chapter is largely descriptive and highlights the complexity of the two service systems.

4.1 Key participants and perspectives

There are many people involved with the disability and mental health service systems.

Figure 4.1–1: Key participants in the service landscape

Source: Family & Community Development Committee.

Figure 4.1–1 above illustrates key participants in the service landscape, outlining the funding and accountability relationships between these participants in addition to the services they provide.

In view of the complex nature of the service system, it is important to outline who these key participants are and the nature of their role and involvement with the systems.

4.1.1   People with a disability and/or mental illness

Chapter Two provided a detailed overview of people with a disability and/or mental illness. They are the most significant people involved with the disability and mental health service systems. People with a disability and/or mental illness are unique and individual and have very different experiences and service needs.

4.1.2   Families in caring relationships

The voices of people who support a family member with a disability and/or mental illness were prominent in the evidence received by the Committee. Families in caring relationships provide an important perspective on the provision of supported accommodation and the extent to which the needs and aspirations of people with a disability and/or mental illness are being met. As noted in Chapter One, the definition of families in caring relationships includes friends, neighbours and others in non-professional caring relationships.

While based on a personal relationship, the family/carer relationship is integral to the operations of the service system. Families in caring relationships often play a key role in the provision of support and advocacy for their family member with a disability and/or mental illness. The types of support they provide are varied and occur in diverse circumstances. Such support can include providing:

- Support in the family home (with or without additional support services)
- Support and advocacy to a family member living in a supported accommodation facility (including clinical mental health services)
- Support to a family member living independently in the community, with or without additional supports

Many families in caring relationships assume responsibility for providing the support required by their family member with a disability and/or mental illness. Their family member is integrated into family life and their needs and aspirations are responded to as they emerge at different stages of their life. For many families, the support they provide to their family member with a disability and/or mental illness is a rewarding experience. At the same time, however, families informed the Committee that there are numerous challenges associated with the caring role.

Regardless of the preference and willingness of families to provide the support needed by their family member, many families benefit from additional support from the service system. This might include the opportunity to take a break from the role to prevent 'burnout', such as respite. It might include support to undertake certain tasks in the home associated with the needs of the family member with a disability. Other supports provided could include opportunities for coaching on strategies for responding to behaviours of concern. Furthermore, families might need a range of supports in place to effectively assist them to continue in their caring role.

The responsibilities of a full-time caring role are significant, and vary depending on the degree of disability of their family member. Without adequate support, these responsibilities can become overwhelming and can lead to significant implications for the health and wellbeing of families and carers. This is discussed in greater depth in Chapter Ten.

In the context of supported accommodation, the perspectives of families in caring relationships are significant. As this chapter outlines, there is a range of different ways in which a person with a disability and/or mental illness can be supported and many different accommodation arrangements in which they can receive this support. For the large majority of people with a disability and/or mental illness, support and accommodation are provided in the family home. Yet for some, this is not a viable option.

The Committee heard from families in caring relationships who said they were unable to continue in a caring role. The majority of these families wanted to maintain some level of caring responsibility, but due to circumstances were no longer in a position to, or were anticipating that they would soon be unable to care for their family member. For example, many carers who were in their 70s and 80s and were caring for family members in their 40s and 50s were concerned about their health and physical ability to continue in their caring roles. At the same time, many of these carers had considerable concerns about the future for their family member when they die. Other carers were in ill-health and unable to provide the level of support their family member required. Some carers revealed that their family member required a level of support and expertise they could not provide, due to complex medical needs or behaviours of concern.

Importantly, the point was made to the Committee that not all people with a disability and/or mental illness want to live in the family home their entire life. They expressed a desire to live independently in the community and to have opportunities to participate in the community. Family members expressed their awareness that while they may be willing to continue to provide support for their son, daughter, niece or nephew, this might not be the aspiration of their family member.

The perspectives family carers brought to the Committee relate to the need to access forms of support and accommodation to enable their family member to achieve quality of life or a recovery goal. While many families in caring relationships expressed a need to access specialist facilities, the perspectives of family carers revealed the diversity of needs, the intersections of family carer needs with their family member's needs, and the range of options required to meet those needs.

4.1.3   Government

Government roles in mental health and disability support services can be grouped into four broad categories:

- Funding
- Policy development
- Service provision
- Regulation and monitoring.

Both federal and state governments have key roles in the provision of disability and mental health services. In particular, the Commonwealth has broad responsibility for funding and developing policy direction. State governments, on the other hand, are largely responsible for the provision, regulation and monitoring of services. In the provision of disability and mental health services, state governments have a responsibility to contribute funding based on national service agreements. Agreements between state and federal governments clarify roles and responsibilities, particularly with regard to funding. Chapter Three outlined the National Disability Agreement (NDA) in disability. Funding arrangements in mental health are integrated within the health system.

In the disability sector, the Committee has noted with interest developments in thinking about a national disability insurance scheme. In November 2009, the Commonwealth Government asked the Productivity Commission to undertake a feasibility study into new approaches for funding and delivering long-term disability care and support. This study will include consideration of whether a no-fault social insurance approach to disability is appropriate in Australia.

At the state level, the provision of mental health services occurs through the newly established Department of Health. Responsibility for disability support services is largely through the Department of Human Services (DHS), with relatively small amounts of funding provided to programs in Department of Education and Early Childhood Development (DEECD).

The Disability Services Division (DSD) both provides services directly (through regional offices), and oversees funding to non-government community service organisations (CSOs) for the provision of support and accommodation for people with a range of disabilities. The Victorian Government has responsibility for the development of State disability policy.

In mental health, the Victorian Government has responsibility for mental health and drugs policy relating to Victoria's public mental health system. Mental Health and Drugs Division oversees funding and service delivery. This includes both clinical services, which are managed by public hospitals and provide assessment, diagnosis, treatment and clinical case management, across a range of inpatient, residential and community based settings, and Psychiatric Disability Rehabilitation and Support Services (PDRSSs), which are often based in a

community health setting. PDRSSs provide a number of forms of residential rehabilitation and supported accommodation options.

In addition, the Housing and Community Building Division owns, manages, and/or provides agency funding for subsidised housing, including crisis, transitional, public and community housing.

4.1.4   Community Service Organisations

CSOs provide a substantial proportion of support and accommodation services to people with a disability and/or mental illness. This varies across the mental health and disability specialist systems. It also varies across the service types within each system. For example, in disability services a higher proportion of day services are provided by CSOs than by supported accommodation services.

Health and community services range from specialist providers of targeted services through to larger organisations providing a wide range of community and other services. While the majority of these organisations are small, and receive relatively low amounts of funding, a significant minority fall into the category of large service providers. These organisations provide a wide range of services and are funded by multiple divisions of government.

The majority of service providers that gave evidence to the Committee were CSOs. Some were involved in providing a range of programs and services, others specialise in one specific area. In the mental health sector, for example, CSOs representing community health organisations, prevention and recovery care (PARC) services and outreach programs provided evidence.   In the disability sector, services that provide day programs, supported accommodation and individual support packages (ISPs) gave evidence to the Committee.   In addition, CSOs providing accommodation services such as crisis and transitional housing were represented.

4.1.5   Advocacy groups

Advocacy organisations in the mental health and disability sectors provide a wide range of services. In addition to systems and individual advocacy this can include education, provision of information, research and support.

These organisations can be relatively broad, or focus on more specific issues or conditions. While some organisations deal exclusively with particular conditions or illnesses, others work with specific groups of people, including young people, persons from diverse ethnic backgrounds and carers.

Advocacy may include participation in policy making and service planning, through formal consultation channels as well as by ensuring representation in key forums.

The Committee heard from a number of advocacy groups, unions and peak organisations. These included National Disability Services (NDS), Victorian Advocacy League for Individuals with Disability (VALID), Carers Victoria, Health and Community Services Union (HACSU), Victorian Council of Social Services (VCOSS), Sane Australia, VICSERV and the Community Housing Federation of Victoria (CHFV).

These organisations brought a perspective that tended to focus on the systems level and the need for effective policies and strategies to enable services to provide support and accommodation that meets the needs and aspirations of people with a disability and/or mental illness. These organisations also tended to focus on the effectiveness of existing resources to achieve strategic goals at a systems level and within individual services. Industry planning and workforce capacity were other key areas of concern for many advocacy and peak organisations. Interlinked with this was a focus on the importance of quality, accreditation and monitoring.

4.1.6   External monitors

A number of external bodies have a statutory oversight role in mental health and disability services. The Chief Psychiatrist, Disability Services Commissioner and the Community Visitors are statutory appointments with specific roles that inform their perspectives and expectations of the service system. These key individuals attended hearings and briefings held by the Committee. The Senior Practitioner is also a key participant in the disability sector within the new legislative framework. The Committee, however, did not hear from the Senior Practitioner based on a decision by the Minister for Community Services that it was inappropriate due to his statutory responsibilities.

These statutory roles are largely concerned with providing independent checks and balances on the service system. In general, they provide mechanisms for complaints, for monitoring practices and for visiting and reporting on service compliance with regulations. In addition, they can advocate for people with a disability and/or mental illness and aim to provide solutions in individual circumstances.

In addition to their specific functions, these independent statutory roles are often concerned with the effectiveness of systems. For example, the Community Visitors (linked to the Office of the Public Advocate) report annually to Parliament recommending improvements to policy and systems, with the ultimate goal of improving responses to people with a disability and/or mental illness.

4.2 Supported accommodation services

This section describes key features of the specialist service systems providing supported accommodation for those with mental illness and/or disability.

In particular, it describes the service types providing supported accommodation as defined in this Inquiry. The majority of service use data has been provided by the DHS, with additional information from the Australian Institute of Health and Welfare (AIHW). Funding is discussed in more detail later in this chapter.

4.2.1 Disability specialist system

Services provided in the disability support system include:

- Residential and accommodation services
- Respite services
- Support to live at home
- Day programs
- Aids and equipment.

Table 4.2.1-1 describes the form these services take.

Table 4.2.1–1 Disability support system

Service	Target group	Support	Accommodation
Residential care	People with an intellectual disability requiring intense and specialised support	Intense, specialised support	Long-term accommodation
Shared Supported Accommodation (group homes)	People with a disability as defined in the Act and in line with access guidelines	Variable intensity support	Long-term accommodation
Individual Support Packages	People with a disability with a current need for ongoing support	Support to remain in private accommodation may be required, variable intensity and duration in line with individual plans	
Respite services	Primary carers of people with a disability, based on priority guidelines	May be day, weekend or residential based	May include short-term residential or non-residential

Sources: Disability Services Division (2008-09) *Policy and Funding Plan, Annual Update*. Victorian Government (2008) Data provided to Family and Community Development Committee. Metropolitan Health and Aged Care Division (2003) *Psychiatric Disability Rehabilitation and Support Services: Guidelines for Service Delivery*.

Table 4.2.1–2 summarises the number of people using these supported accommodation services in Victoria.

Table 4.2.1–2: DSD supported accommodation places, 2007-08

Service type	Number of facilities/ Allocations*	Number of places**
Residential facilities	2	199
Shared Supported Accommodation	922	4784

* Note: Excludes facilities not currently operating (part of the Strategic Replacement and Realignment Program), Facility-Based Respite facilities; and Criminal Justice accommodation facilities.

** Note: Excludes beds not currently operating (part of the Strategic Replacement and Realignment Program), beds within Facility-Based Respite Services and Criminal Justice accommodation facilities; and beds currently occupied by residents receiving flexible funding through an Individual Support Package. Includes beds funded under the Shared Supported Accommodation and Residential Institutions (formerly congregate care) activities.

Additional note: It is not possible to identify the proportion of ISPs involving in-home support to enable a person with a disability to remain in existing accommodation.

Source: Victorian Government (2008) Data provided to Family & Community Development Committee.

Residential facilities

Intensive residential support for people with intellectual disabilities is provided in the form of two institutional facilities (Sandhurst Centre and Colanda Residential Services) and through the Long-Term Residential Program of the State-wide Forensic Program. In 2008, approximately 200 Victorians lived in these residential institutions.

Each of these services is provided by DHS, and registration under the *Disability Act 2006* is not required. Admission to these facilities is according to the Colanda and Sandhurst Admission Policy and Operating Procedure.

Shared Supported Accommodation

The Shared Supported Accommodation (SSA) services are provided either by DHS regional offices or through CSOs. As of June 2008, there were 922 SSA facilities, or Community Residential Units (CRUs) in Victoria (distribution illustrated in Figure 4.2.1–3). Around 4,700 Victorians lived in these group homes.

Figure 4.2.1–3: Distribution of SSA facilities throughout Victoria
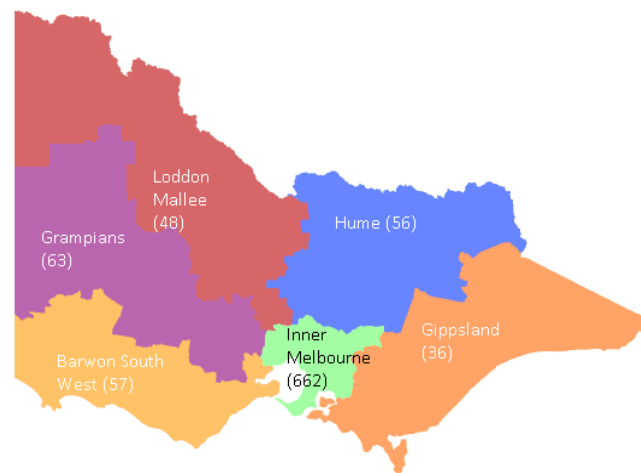
SSA accommodation generally takes the form of shared accommodation, located in the community, and houses four to six people. The majority of SSA facilities (905 out of a total 922) are small group homes, although there are also a number of larger facilities. Houses are usually owned either by DHS, the CSO provider, or are rented through the Housing Division (or a housing association). In these cases, the residential tenancy agreement is administered by the service provider, who is required under the Disability Act to provide a Resident Statement that outlines what services will be received for what fees. Residents pay for rent, which may be up to 25 per cent of income, in addition to some common household expenses.

Support provided within the accommodation includes household management, general self-care, personal hygiene and local community participation. Staff are generally rostered for shifts of variable lengths depending on the support needs of residents, with either a sleepover or an active night shift.

The majority of people living in SSA facilities have an intellectual disability (see Table 4.2.1–4 below).

Table 4.2.1–4: Residents in SSA by primary disability, June 2008

Primary disability	Number of residents	
Intellectual	4,027	87.8%
Acquired brain injury	78	1.7%
Neurological	85	1.9%
Physical	147	3.2%
Sensory	28	0.6%
Autism/specific learning disorder	33	0.7%
Multiple	19	0.4%

Primary disability	Number of residents	
Non-intellectual (N.E.C.)	57	1.2%
Not stated	116	2.5%
Total	**4,590**	**100%**

Note: Excludes residents of Residential Institutions.

Source: Victorian Government (2008) Data provided to Family & Community Development Committee.

The age structure of SSA unit residents leans considerably more towards middle-age groups than that of the Victorian population as whole. Over half of all SSA residents are aged between 35 and 55 years, compared to just 30 per cent of the general population. The proportion of residents who are younger than 25 or older than 65, however, is lower than that in the broader community.

Table 4.2.1–5: Residents in SSA by age compared to Victorian population, 2008

	SSA residents*		Victoria	
	Number	**%**	**Number**	**%**
Under 25	247	5.4	1,745,054	32.8
25 to 34	708	15.4	755,134	14.2
35 to 44	1,242	27.1	783,794	14.8
45 to 54	1,377	30.0	725,251	13.7
55 to 64	705	15.4	586,422	11.0
65+	282	6.1	718,168	13.5
Not stated	29	0.6	N/A	N/A
Total	**4,590**	100.0	**5,313,823**	100.0

Note: Excludes residents of Residential Institutions

Source: Victorian Government (2008) Data provided to Family & Community Development Committee; Australian Bureau of Statistics (December 2008) *Australian Demographic Statistics*. ABS cat. no. 3201.0.

DHS does not collect information about the average length of stay in SSA, though entry data is available for those entering after 2006.

Disability Support Register

The Disability Support Register (DSR) is a prioritisation and allocation mechanism in Victorian disability services. It allocates services to people who have expressed a need for supports. The DSR records current need for ongoing disability supports, which includes supported accommodation and also day programs and ISPs.

The DSR was introduced in April 2006 and replaced the Service Needs Register (SNR) with the intention of reflecting the shift in practice following the introduction of individualised planning and support.

Table 4.2.1–6: Number of people on the DSR at 30 June 2009

DSR	Category All Requests
Disability Services Supported Accommodation options	1,292
Support to live in the community	1,095
Daytime activities	188
Total	**2,575**

Source: Department of Human Services website. Accessed on 16 November 2009 from http://www.dhs.vic.gov.au/disability/supports_for_people/information,_planning_and_advocacy/how-we-provide-services-to-people.

In addition, the following table provides a regional breakdown of requests for support and accommodation recorded on the DSR.

Table 4.2.1–7: Number of people registered on the DSR waiting for supported accommodation and other programs at 30 June 2009

Region	People waiting for SSA options	People waiting for support to live in community	People waiting for day programs
Metropolitan			
Eastern Metropolitan	296	185	28
North & West Metropolitan	309	230	31
Southern Metropolitan	338	316	46
Regional			
Barwon-South Western	95	82	34
Gippsland	58	69	12
Grampians	59	37	13
Hume	80	93	3
Loddon Mallee	57	83	21
Total	**1,292**	**1,095**	**188**

Source: Victorian Parliamentary Debates, *Legislative Assembly*, 13 October 2009, pp.3723-41.

In-home services

Where people with disabilities live with a carer or family, in-home support services are funded to help make these arrangements sustainable.

In Victoria, in line with strategies articulated in the State Disability Plan, existing programs are now arranged into ISPs, with portable funding that can be used to purchase a range of support services.

Many services are provided through the Home and Community Care (HACC) program. The HACC target population is defined in the *Home and Community Care Act 1985*, which provides that the HACC program will assist those living in the community who would otherwise be at risk of premature or inappropriate long-term residential care. This group specifically includes:

- Older and frail persons, with moderate, severe or profound disabilities
- Younger persons with moderate, severe or profound disabilities
- Such other classes of persons as are agreed upon by the Commonwealth Minister and the State Minister.

HACC services include home help, personal care assistance, nursing, allied health services (eg physiotherapy, podiatry, dietetics), property maintenance, food services such as meals on wheels and centre-based meals, Linkages packages (provide case management and brokerage), and social support services.

Respite

In 2007-08, funding for respite services totalled $64.6 million. In its 2007-08 Annual Report DHS reported that there were approximately 20,000 episodes of respite provided.[91]

Respite services aim to support the individual with a disability and their family and carers through the provision of short-term and time-limited breaks on a regular, occasional and/or emergency basis. These services can be funded through ISPs. They may be provided in the form of facility-based or residential respite, in-home or community based respite activities, or holiday camps. In addition, DHS funds community-based weekend respite.

Respite services differ from other supported accommodation services as the service target is the family (or other carers) in a caring relationship with a person with a disability.

Table 4.2.1-8: Respite beds and families using respite in Victoria, June 2009

Region	Respite beds available	Families using facility-based respite
Metropolitan		
Eastern Metropolitan	71	672
North & West Metropolitan	92	800
Southern Metropolitan	63	767
Regional		
Barwon South-west	60	404
Gippsland	22	345
Grampians	41	125
Hume	56	355
Loddon Mallee	25	169
TOTAL	**430**	**3637**

Source: Victorian Parliamentary Debates, *Legislative Assembly*, 13 October 2009, pp.3723-40.

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[91]   Victorian Government (2008) Data provided to Family & Community Development Committee. Department of Human Services (2008), *Annual Report 2007-08*, DHS, Victorian Government, Melbourne, p.151.

In the 2008-09 Budget, the Victorian government committed $500,000 ($1.0 million over two years) to establish a centralised respite accommodation service that will better inform and enable carers to get advice and access to respite services when and where they are needed.

4.2.2   Mental health services

The supported accommodation options in mental health are funded as either clinical-based treatment and rehabilitation services or specialist mental health non-clinical support services provided by Psychiatric Disability Rehabilitation and Support Services (PDRSS).

Table 4.2.2-1 describes the form these services take.

Table 4.2.2–1: Mental health support system

Service	Target group	Support	Accommodation
Community Care Units (CCUs)	Patients with severe ongoing symptoms transitioning to community living	Clinical care	Short to medium-term accommodation, varying depending on response to treatment. (State average 2007-08 193 days)
Secure Extended Care Units (SECUs)	Patients with severe unremitting symptoms assessed as needing a secure environment	Extended clinical treatment and supervision	Short to medium-term accommodation (State average 2007-08 232 days)
Prevention and Recovery Care units (PARCs)	Patients 'stepping down' from acute inpatient care or 'stepping up' from community care	Clinical care and PDRSS support	Short-term accommodation (State average 2007-08 20 days)
Residential rehabilitation services (RRS)	Eligible clients who are considered likely to benefit from, and desire, intensive rehabilitation prior to living independently	Rehabilitation support may be 24 hour or non-24 hour	Short to medium-term accommodation, average 18 to 26 months

Service	Target group	Support	Accommodation
Supported accommodation services (SAS)	Similar to residential rehabilitation, except that the desire and willingness to participate in an extended rehabilitation program is not required	Support may be 24 hour or non-24 hour	Long-term accommodation
Respite	People with a psychiatric disability and their carers	May be day, weekend or residential based	May include short-term residential or non-residential
Home Based Outreach Support	Similar to residential rehabilitation	4 to 8 hours per week depending of level of intensity eligible for	

Sources: Disability Services Division (2008-09) *Policy and Funding Plan, Annual Update.* Victorian Government (2008) Data provided to Family & Community Development Committee. Metropolitan Health and Aged Care Division (2003) *Psychiatric Disability Rehabilitation and Support Services: Guidelines for Service Delivery.*

Table 4.2.2–2 indicates the number of people using these supported accommodation services in Victoria. Because services are funded on the basis of bed days, and because in most cases these services do not provide long-term accommodation, it is not possible to discern how many people are using the services based on the available data.

Table 4.2.2–2: Mental health system supported accommodation places, 2007-08

Service type	Number of facilities	Number of places	Average length of stay (State-wide)
Community Care Units	20	336	193 days
Secure Extended Care Units	8	103	232 days
Prevention and Recovery Care	8 (13 following planned expansions)	78 (138 following planned expansions)	20 days
Residential rehabilitation	26	264	18 to 26 months
Supported accommodation	8	102	N/A

Source: Victorian Government (2009) Supplementary data provided to Family & Community Development Committee.

Clinical residential services

Clinical services include community care units (CCU), Prevention and Recovery Care units (PARC), and Secure Extended Care Units (SECU). These services are

provided by area mental health services (auspiced by public hospitals), and, aside from CCUs, are generally physically co-located with these services.

CCUs provide short to medium-term accommodation, clinical care and rehabilitation services. Located in residential areas, they provide a 'home like' environment where people can learn or re-learn everyday skills necessary for successful community living. While it is envisaged that people will move through these units to other community residential options, some consumers require this level of support and supervision for a number of years. The average length of stay in a Victorian CCU in 2007-08 varied significantly across facilities, between 53 and 812 days; the state average was 192.7 days. Table 4.2.2–3 below shows the average stay range across the 19 CCU facilities.

Table 4.2.2–3: Average length of stay in CCU facilities, 2007-08

CCU	Average stay (days)
Barwon	97.9
Central East (see Note 1)	77.3
Dandenong	207.5
Gippsland	129.3
Glenelg (see Note 2)	352.3
Goulburn Valley (see Note 3)	260.0
Grampians	92.5
Inner South East	250.5
Inner Urban East	158.2
Inner West	176.5
Loddon South Mallee	68.1
Mid West	249.6
Middle South	121.6
North Eastern Metro (see Note 4)	
North Eastern Victoria	485.0
North West	812.0
Northern Metro	302.9
Northern Mallee (see Note 5)	
Outer East	53.1
Peninsula	404.6
South West	235.7
State-wide average	**192.7**

Note 1: Central East (Canterbury) CCU: The 2005/2006 Budget allocated $6.4M for the redevelopment and expansion of the Eastern Health (EH) Canterbury Road CCU from 10 beds to a 20 bed facility. The redevelopment of the Canterbury Road site necessitated the temporary relocation of staff and residents for the period of the building works, until completion in December 2007. Timeframes and key dates for the refurbishment included a redevelopment/construction phase from 20 July 2006 to practical completion on 25 October 2007. New staff commenced in early December 2007 with clients relocating on 17 December 2007. The 2007-08 reporting period includes the gradual increase in occupancy.

Note 2: CCU beds in Warrnambool (Glenelg) are part of a combined 5-bed SECU/CCU unit that has the capacity to use the beds interchangeably to meet the needs of local patients and for this reason it is possible for occupancy to be over 100%.

Note 3: Goulburn Valley figures are for Jul-Dec only and not included in the state-wide totals.

Note 4: There is no data recorded against North East metro as this AMHS shares a CCU with the Northern AMHS.

Note 5: Northern Mallee (Mildura) does not have a CCU but has access to beds at Loddon Sth. Mallee.

Source: Victorian Government (2008) Data provided to Family & Community Development Committee.

There were 336 CCU beds funded in Victoria, suggesting that around 550 people were resident in a CCU during the year.

SECUs provide intensive treatment in the context of short to medium-term accommodation in a structured environment. These services target adults with severe and unremitting symptoms, and are often co-located or located onsite with inpatient services. In 2007-08, the average length of stay in a SECU was 232 days (see Table 4.2.2–4 below).

Table 4.2.2–4: Average length of stay in SECU facilities, 2007-08

SECU	Average stay (days)
Dandenong	430.0
Gippsland	96.1
Glenelg	27.0
Grampians	188.9
Loddon South Mallee	85.3
Mid West	541.1
North East Metro	562.8
State-wide average	**232.1**

Note: The length of stay in the Glenelg CCU/SEC reflects the fact that CCU beds are part of a combined 5-bed SECU/CCU unit that has the capacity to use beds interchangeably to meet the needs of local patients.

Source: Victorian Government (2008) Data provided to Family & Community Development Committee.

PARC units provide an intermediate service between adult acute psychiatric inpatient units and the person's usual place of residence. Key objectives of the PARC service are to prevent acute inpatient admissions and facilitate earlier discharge. PARC services are usually a partnership between PDRSS and clinical services. At December 2009 there were 10 operational PARC services across Victoria, providing 98 places (92 beds). An additional 68 PARC placements are planned and in development. Because the PARC model has been introduced only relatively recently, service use figures are thought to not necessarily reflect accurately the likely level of use once programs have been fully rolled out.[92] Table 4.2.2–5 below provides some early numbers about use of PARC units in 2008.

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[92]   Victorian Government (2009) Supplementary data provided to Family & Community
        Development Committee; see also, *Final Report for Evaluation of the Prevention and Recovery Care
        (PARC) Services Project*, completed in December 2008 by Dench McClean Carlson for the
        Department of Human Services.

Table 4.2.2–5: Average length of stay in PARC facilities, 2007-08

PARC	Average stay
Barwon	17.0
Central East	17.3
Dandenong	17.6
Goulburn Valley	17.8
Inner South East	21.4
Inner West	51.5
Loddon South Mallee	11.9
State-wide average	**20.1**

Notes:

Average length of stay excludes same-day separations.

Inner West service was transiting to a PARC at the time the information was provided. Under its operating guidelines, patients could stay for periods beyond the PARC guidelines of a maximum stay of 28 days. This in turn increased the state-wide average length of stay.

Source: Victorian Government (2008) Data provided to Family & Community Development Committee.

PDRSS residential services

Psychiatric Disability Rehabilitation and Support Services (PDRSS) have a different focus to, and are designed to complement, the clinical services in the mental health system. They provide psychosocial assessment, rehabilitation and support, and are managed by non-government organisations in the community as well as Community Health Services. Residential services funded through PDRSS are delivered in a range of facilities, including private rental stock or rental from housing associations, buildings owned by the CSO, or housing allocated by the Housing and Community Building Division.

These services include residential rehabilitation services (RRS) and supported accommodation services (SAS). Both services are available either with 24 hour support or with lower levels of support.

Residential rehabilitation units provide a transitional service enabling people with a mental illness to develop skills to move into independent living. The target group for RRSs include people who:

- Will benefit from, and desire, intensive rehabilitation prior to living independently

- Can live in a congregate living situation

- Need assistance with making the transition from institutional dependency to community based support.[93]

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[93]   Department of Human Services (2003) *Victoria's Mental Health Services: Psychiatric Disability Rehabilitation and Support Services, Guidelines for Service Delivery.* DHS, Victorian Government, Melbourne.

RRS requires a commitment by clients of typically one to two years of active engagement to enable a process of individual growth and the transition to independent living.

Clients may enter residential rehabilitation services following an acute inpatient admission; referrals may also be made from a clinical CCU where a participant may have already been involved in rehabilitation and treatment.

In 2007-08, there were approximately 260 Victorians in RRS. The average length of stay ranges from 18 to 26 months.

As well as this more intensive service, PDRSS also provide supported accommodation, which does not necessarily aim to achieve independent living. For this client group, psychosocial rehabilitation occurs under a 'slow-stream' model and may continue over a period of many years or even life.

SAS provide long-term accommodation linked to support for people with a psychiatric disability. The target group is similar to residential rehabilitation, except that the desire and willingness to participate in an extended rehabilitation program is not required.

In 2007-08, 102 bed based SAS were funded by the government across eight sites. Five of the eight units provide a 24 hour onsite support model, which is provided in a shared accommodation environment. Three of the eight units are funded at a lower unit cost to provide non-24 hour support, involving a mix of onsite support and after hours on call where residents typically have their own unit or share a house with residents and have staff support during business hours.

Table 4.2.2–6: PDRSS supported accommodation services, 2008-9

	Number of facilities
24 hour support	5
Non-24 hour support	3
Total	**8**

Source: Victorian Government (2009) Supplementary data provided to Family & Community Development Committee.

4.3   The providers of supported accommodation

This section is a brief overview of the structural features of service provision. As noted above, the key providers of supported accommodation include DHS and CSOs. This section describes important differences between supported accommodation in the two sectors.

State government-funded supported accommodation for Victorians with a disability and/or mental illness is managed, and in some cases provided by, the

DHS and Department of Health. In addition, a significant proportion of services are provided by the health and community sector.

The mix of government and CSO provision of supported accommodation in disability services differs significantly from that in the mental health service system. This is largely a product of historical arrangements in the two sectors, which have been described in Chapter Nine. In the disability services sector, there is a relatively even split between DHS and CSO provided residential services including supported accommodation, while other supports for people with disabilities (such as day programs) tend to be provided by the non-government organisations.

In the mental health service system, on the other hand, the major split is between clinical services (including some residential based services) – which are provided as part of the public health system of 'step down' services from inpatient treatment – and the community based PDRSS residential and supported accommodation services, which are almost entirely provided by CSOs.

4.3.1   Community Service Organisation providers

In Victoria, over 400 non-government organisations are funded by DHS to provide supported accommodation services in the disability and mental health sectors.

In 2007-08, more than 300 CSOs represent approximately 43 per cent of total funding for residential disability services. (See Table 4.3.1–1)

Table 4.3.1–1: Total State Government Expenditure ($millions) for Disability Residential Services by type and region, 2007-08

Region	CSO provided	DHS provided
Metropolitan areas		
Head Office	61.3	18.7
Eastern Metropolitan	47.5	62.5
North & West Metropolitan	33.5	89.6
Southern Metropolitan	38.5	34.1
Regional areas		
Barwon South Western	8.5	13.2
Gippsland	6.2	10.9
Grampians	5.1	26.8
Hume	7.4	15.5
Loddon Mallee	6.7	13.1
Total	214.7	284.4

Note: Head Office expenditure reflects payments to the Housing and Community Building Division, DHS (H&CB) for items such as Fire Risk Management (cyclical), infrastructure investment and associated project management costs. Other items include EBA accrual provisions, the allocation of corporate costs and adjustments for depreciation, asset re-evaluation and impact of asset disposals, which have varied over the financial years. An additional variation occurred due to allocation of non-recurring grants of some $75 million for infrastructure investment over the previous two financial years managed through Head Office.

Source: Victorian Government (2008) Data provided to Family & Community Development Committee.

Notably, data collection across the disability and mental health sectors is different. The information for the mental health sector, therefore, is slightly different. During the same year (2007-08), 10 organisations were funded to provide PDRSS residential and supported accommodation services in the mental health sector. CSOs represented almost all PDRSS funding, which in 2007-08 totalled $27.6 million (this funding also covers Home Based Outreach Support services).

It is difficult to generalise about the CSO providers. There are, however, some broad observations that can be made.

Firstly, the range of organisational types means that there is significant diversity in the services provided and how they are delivered. In particular, this may imply different approaches to linking the staffing and provision of support services and accommodation. There is also diversity in staffing models. For example, this issue was raised in a number of submissions to the Committee in relation to wage and award levels in the CSO sector compared with the DHS managed SSA facilities.

Secondly, due to differences in wage structures and service models it is not possible to draw across-the-board conclusions concerning operations or outcomes of CSO provision as a whole. For example, developing figures to compare costs per bed across government managed services and CSOs does not account for costs that are borne by the organisations. There is substantial anecdotal evidence that funds for covering these costs are raised disproportionately through the processes arising from management of service agreements and contract requirements. The diversity across the sector, therefore, results in a meaningless average.

Finally, service provision in the CSO sector has changed. The majority of funding for services is administered by the State Government through DHS and the Department of Health, which fund providers on the basis of service activities. Funding models may be block funding, output based, or individualised. CSO supported accommodation providers are generally funded through output based or individualised funding, which includes an allowance for asset maintenance in the unit price. This has a range of impacts on organisational and service planning. It has in many cases driven the introduction of quality standards frameworks, which sometimes sit alongside an organisation's own quality improvement approaches.

For example, in the disability sector, the introduction of the Quality Framework has included a registration requirement for disability service providers, including CSOs.[94] All registered providers will be independently monitored for compliance with the *Disability Act 2006*. This means that organisations must develop the internal processes to capture, record and report against these requirements.

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[94]   Not all disability funded services are considered providers (for example, National Disability Services in Victoria).

Shifts to output funding also mean that a CSO's budget can now vary more substantially from year to year than under older block funded arrangements. The increasing emphasis on individualised service planning also has implications for an organisation's staff planning, affecting recruitment, training and development decisions.

4.3.2 Government providers

As noted above, the role of government providers relative to CSO providers differs significantly between the two sectors discussed here.

In the case of disability supports, over half SSA facilities/group homes are provided by DHS services. In addition, the remaining residential institutions are operated by the DHS. These services are provided through the DHS regional offices (see Figure 4.3.2–1 below). Group homes may have staff rostered on 24 hours a day.

Government managed supported accommodation facilities are generally block funded, with assets owned by the Department.

In most cases, day programs and other supports for residents in these supported accommodation facilities are provided by external CSOs and local government through HACC.

Figure 4.3.2–1: DHS disability services regions
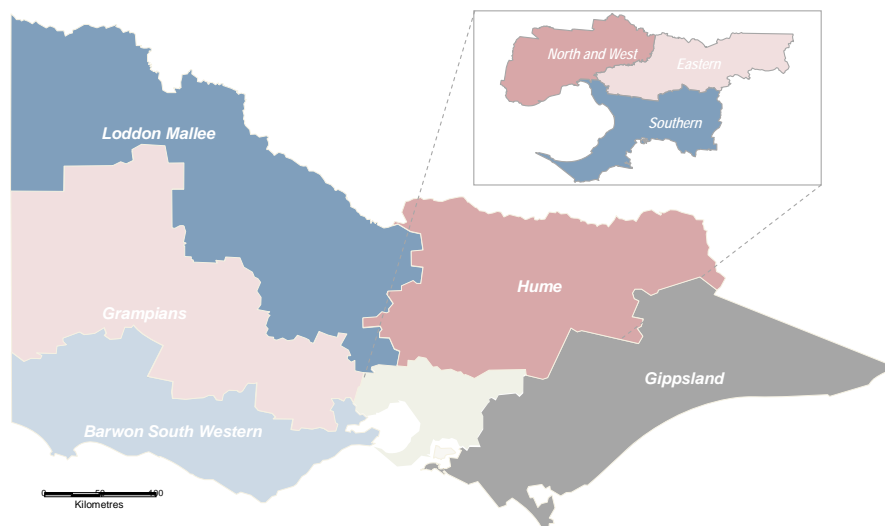
Source: Department of Human Services regional boundaries based on Local Government Australian Standard Geographical Classification 1.

Clinical residential services in the mental health service system are also government provided, with services under the auspices of (and often co-located with) health services, and coordinated through area mental health services (AMHSs). Figure 4.3.2–2 below shows the boundaries of Victorian AMHSs.

Clinical services are predominantly planned on the basis of the population within these catchment areas. PDRS services are planned on the basis of DHS regions.

Figure 4.3.2–2: Department of Health area mental health services

Source: http://www.health.vic.gov.au/mentalhealth/services/maps/index.htm.
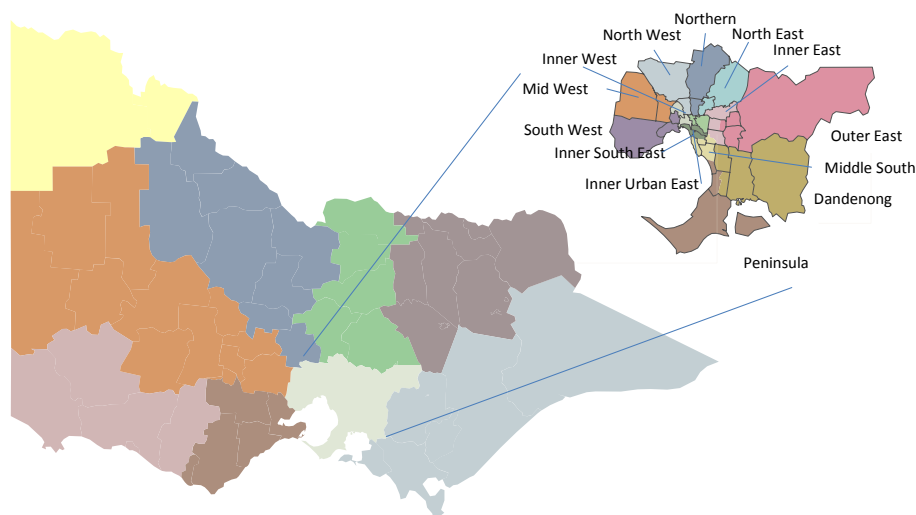
Residential units in the clinical mental health system may be staffed on a 24 hour basis or on a less intensive basis. The workforce generally comprises mixed health and allied health staff. The health services auspicing these clinical residential services have responsibility for the quality of care, although overall service management responsibility is shared with the relevant AMHS.

4.4 Funding of supported accommodation services

There are two important aspects of funding of supported accommodation services. The first is the level of funding. The second is the funding model (that is, the way in which these resources are provided). Funding will vary according to the type or quantity of service provided, or is attached to an individual service user – that is, the funding model. Key models of funding supported accommodation are described in the text box below.

Funding models

Different models of funding programs in the mental health or disability support systems include:

Funding based on variable price and volume

In this model, funding is based on the price and volume of providing an agreed range of services. The service agreement will specify the per-unit

cost of providing a service (which incorporates an overhead provision) and the target number of clients to be provided with the service per annum.

The price and volume model assures the funder of a level of service provision, and also implies greater budget certainty. However, there may be some reduced incentive for service providers to improve the quality of outputs or to reduce costs.

Funding model with fixed plus unit price components

Under this mixed funding model, service providers receive a fixed component which covers overhead costs, as well as a variable, volume-based unit price component.

There are a number of approaches to this variable component. Whether the unit price and level of service is set or negotiated between the funder and the service provider can differ, and this will generally imply that the balance of risk between the two parties varies.

Funding based on outcomes delivered

Under an outcome-based contract, the funder would determine the desired policy outcomes and request proposals from potential service providers to meet the policy objectives. The service provider designs the services and calculates the cost of service.

Under this option the provider has more flexibility to determine the appropriate number of services provided and type of service provided within the agreed terms of the contract.

An outcome-based model may be less prescriptive in terms of the number of services provided and type of service provided, however it is likely that an outcome-based contract would incorporate terms and conditions specifying minimum service levels to be provided.

Activities are typically unit funded or block funded, however arrangements increasingly reflect an individualised funding approach. In most cases the total funding provided by the Victorian Government to a CSO will involve a mixture of block and flexible funding.

Unit pricing allocates funds for activities according to pre-defined units of output, such as bed days, episodes of care, clients etc. The unit prices include components for salaries, operating and other administrative overhead costs. Unit prices are generally adjusted in line with an annual price index.

Block funding, or a fixed amount of funding, is provided in some circumstances where a broad range of services are provided within an activity or for historical

reasons. Some service providers support at least a proportion of block funding, for the certainty of service planning, employment and investment it provides. Others prefer a reduction in this model of funding and increased proportions of individualised funding.

Individualised packages involve a funding amount that is attached to the client and is portable. In Victoria, a range of Disability Services Division activities has been streamlined into ISPs. The underlying objective of attaching support funding to individuals rather than package programs is to allow for more differentiated service use. The intention is a more person-centred approach with no increase in overheads and administration costs. Individualised funding aims to allow for variation in services purchased, depending on the person's needs – whether, for example, they require case management or service brokerage, or have particular respite needs, or a differing mix of personal care and day activity needs.

In March 2009, the Victorian Government commissioned PricewaterhouseCoopers (PwC) to undertake an external review of out of home disability services to determine the costs of service delivery. A number of findings emerged from the review:

- Wide variability in service models, business practices and data quality

- Gap between funding services and the cost of service delivery

- High level of consistency in cost structures

- Sector financial capabilities limited.

In 2009, PwC reported that there is continuing inconsistency in understanding of individualised approaches, including the funding models.[95]

The review identified that in SSA, both government and CSOs face similar cost pressure and challenges. These include, changing client support needs (emerging from the policy shift to support high need residents), staff shortages, award rates and qualification levels, transport, and changing client routines. The CSO services reviewed showed a cumulative deficit of $3.4 million. The PwC unit cost analysis demonstrated that 75 per cent of CSOs reported unit costs greater than current funding. This is further discussed in Chapter Nine.

In addition to these funding models, some one-off project funding may be provided to organisations.

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[95] PricewaterhouseCoopers (2009) 'Department of Human Services: Price Review Out of Home Disability Services Final Report', p.5. Accessed from <http://www.dhs.vic.gov.au/disability/improving_supports /industryplan/pwc> on 20 October 2009.

4.4.1   Funding of disability services

In June 2007-08, $1.16 billion was spent on disability support services. Almost half of this total was on accommodation services. Figure 4.4.1–1 below illustrates the distribution of expenditure across service groups.

Figure 4.4.1–1: Actual DHS disability services expenditure, 2007-08 ($ millions)
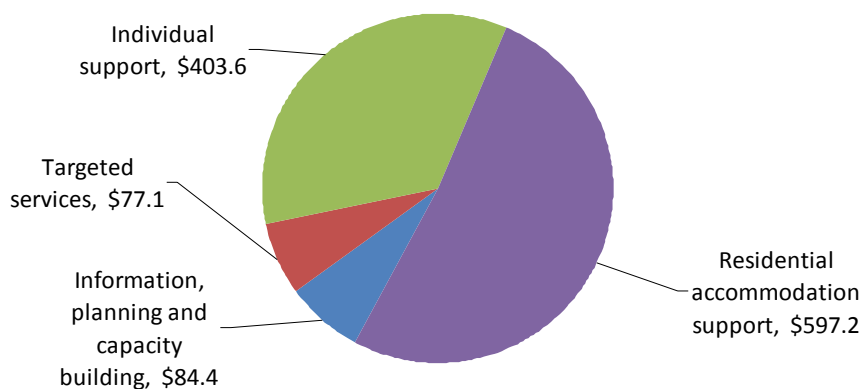
Source: Victorian State Budget 2009-10.

Nationally, the Commonwealth contributed an average 19 per cent to state disability services budgets.[96] The figure below demonstrates the trend for Victoria in funding from the Commonwealth. Mr Arthur Rogers, Executive Director of Disability Services Division, advised the Committee that for historical reasons Victoria compares unfavourably with other states. Figure 4.4.1–2 provides a breakdown of the trends in Victoria for funding, revealing that in 2007-08 Victoria received 13.4 per cent of funding from the Commonwealth.

Figure 4.4.1–2: Funding — National Disability Agreement, Trends 2002/2003 — 2007/2008
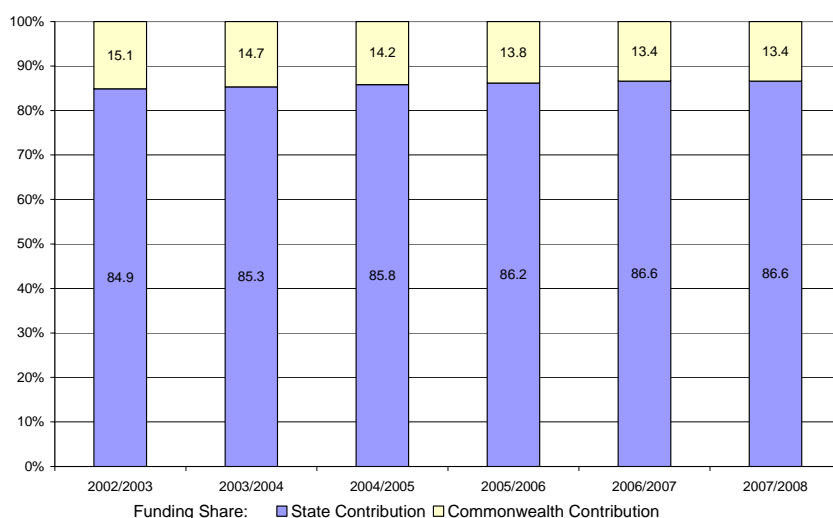
Source: DHS Presentation to Family Community Development Committee Inquiry, 10 Dec 2008.

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[96]   *Committee Transcript*, 10.112.08, p.7 (A. Rogers, Department of Human Services).

Total funding for residential services has shifted during the last five years, illustrating the trend towards supported accommodation in the community rather than based in institutions.

Figure 4.4.1–3: Disability residential services expenditure by type, 2003-04 to 2007-08 ($ million)
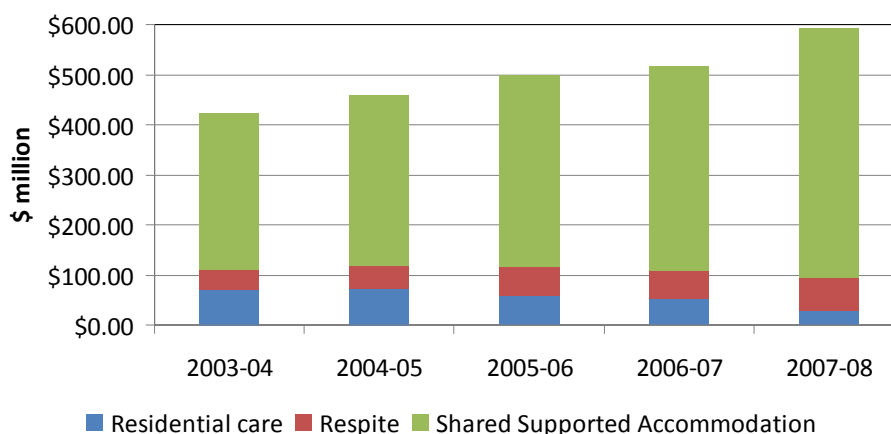
Note: the expenditure trend reflects the reorientation of accommodation services from Residential Institutions to Shared Supported Accommodation.

Source: Victorian Government (2008) Data provided to Family & Community Development Committee.

Funding for the broadly defined residential or supported accommodation services in 2007-08 is summarised in Table 4.4.1–4 below.

Table 4.4.1–4: Funding for supported accommodation services 2007-08

Service type	Funding level ($M)	Basis of funding
Residential facilities	$29.1 million	Block
Shared Supported Accommodation	$499.4 million	DHS: Block CSO: unit pricing
Respite	$29.1 million	Unit pricing

Source: Disability Services Division, *Planning and Funding Policy, 2008-09 Update*.

The two remaining Victorian residential facilities (Colanda and Sandhurst) are DHS-managed, and all resourcing is block funded.

Department-managed SSA funding is based on the agreed service profile of residents in each region. It is adjusted for specific service costs, redevelopment or refurbishing requirements and capacity growth. Internal service costs reflect the rostered support or contact hours provided at a facility in accordance with applicable industry agreements. Variations in funding can occur across facilities due to individual client complexity, which may change over time as clients with different support needs fill vacancies.

CSOs are funded by DHS under service agreements. Service agreements set out the services to be delivered by the CSO, performance measures and targets,

service standards and guidelines and data collection requirements. The unit price is per staff hour or staff shift. The Disability Services Division's *Policy and Funding Plan, 2008-09 Annual Update* does not provide a definition of a 'shift'.

In 2003, the Department introduced an indexed external price as part of a three-year service agreement for non-government organisations in the community services sector. In advice to funded organisations in June 2009, DHS advised that the Policy and Funding Plans 'are currently being revised for the 2009-12 service agreement cycle'.[97] In mid-November 2009, the unit prices in the plan still reflected 2007-09 prices. The current three-year agreement applies till 30 June 2012.

Table 4.4.1–5 below sets out the 2007-08 unit prices.

Table 4.4.1–5: Unit prices for supported accommodation services 2007-08

	Unit	2007-08 price
8 hour worker	1 hour of service	$38.43
24 hour worker (N/A for premises where care is provided to more than 9 residents)	1 shift[98] of service	$416.48
Sleepover	Allowance per annum	$30,637

Source: Disability Services Division, *Planning and Funding Policy, 2008-09 Annual Update*.

Funding is negotiated between DHS regions and the provider agency, and may vary according to individual client complexity relating to the age, behaviour, medical and/or other specific support needs of residents in SSA facilities.

ISP unit pricing varies significantly according to needs, with a range of variables including complexity of needs, level of support required, and whether brokerage or case management is used.

Respite services are similarly provided according to a variable set of unit prices, and are often purchased as part of someone's ISP from the CSO providers.

Table 4.4.1–6 sets out the 2007-08 unit prices for respite services.

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[97] DHS (2009) Letter to all DHS Funded Organisations, 24 June 2009. Accessed from <https://fac.dhs.vic.gov.au/publicfolder/publications/priceindex/Letter-to-NGOs-price-indexation-status-2009-12-Service-Agreements.pdf> on 12 November 2009.

[98] The Disability Services Division's *Policy and Funding Plan, 2008-09 Annual Update* does not provide a definition of a 'shift'.

Table 4.4.1–6: Unit prices for respite services 2007-08

	Unit	2007-08 price
Facility-based/residential service respite		
8 hour worker	1 hour of service	$38.43
24 hour worker	1 shift[99] of service	$416.48
Sleepover allowance	Allowance per annum per facility	$30,637.00
In home/community access respite/ group activities		
Paid direct care staff (3)	1 hour of service	$30.49
Volunteer coordination	1 hour of service	$36.10
Camps/holidays		
Outreach unit cost (3)	1 hour of service	$30.49
24 hour care for paid direct care staff	1 shift of service	$416.48
Volunteer coordination	1 hour of service	$36.10
Community-based weekend respite without public holiday (rate per weekend).	2 staff on duty	$2,230.00

Source: Disability Services Division, *Planning and Funding Policy, 2008-09 Annual Update.*

4.4.2   Funding of mental health supported accommodation services

In 2007-08, $837 million was spent on Victorian mental health support services. Figure 4.4.2–1 below illustrates the distribution of expenditure across service types.

Figure 4.4.2–1: Victorian Government mental health services expenditure, expected outcome, 2007-08 ($ millions)
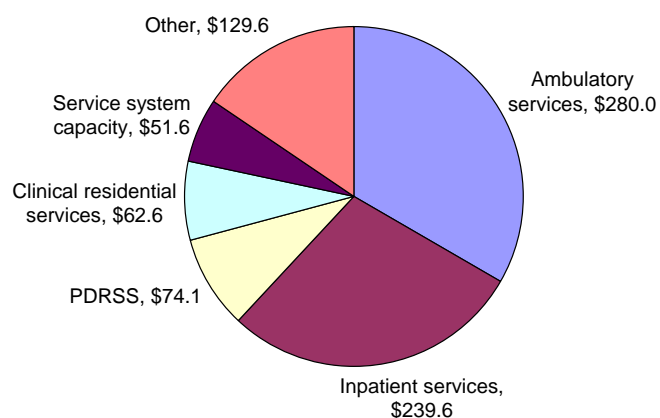
Notes:

Inpatient services – includes services such as Forensicare and SECU

Clinical residential services – includes services such as Community Care Units and PARCS

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99   The Disability Services Division's *Policy and Funding Plan, 2008-09 Annual Update* does not provide a definition of a 'shift'.

Clinical ambulatory services – includes services such as community mental health teams

PDRSS – includes services such as HBOS and residential rehabilitation

Other – includes the Mental Health Review Board and other operational expenses

Service system capacity – includes initiatives such as research.

Source: Department of Human Services, *Public hospitals and mental health services: Policy & funding guidelines 2008-09*.

In addition, in 2007-08 Commonwealth expenditures on mental health services included $173 million on mental health services (the majority of which were claims for psychiatry, psychology and GP episodes of care) and $195 million on PBS-subsidised mental health related pharmaceuticals.

Funding for mental health services is very different from that provided to disability services. Mental health services have never had an agreement informing funding that is comparable with the Special Purpose Payment that formed part of the former CSTDA. State and territory funding for mental health services is received from a range of sources. The Commonwealth contributes funding to Victorian services through the following avenues:

- National Healthcare Agreement (there is no specific allocation of funds to mental health in this Agreement)

- Medicare Benefits Schedule.

The Victorian Government advised the Committee that, unlike disability services, there are no publicly available breakdowns of expenditure of Commonwealth-funded mental health services by jurisdiction.

Funding for Victorian supported accommodation services in 2007-08 is summarised in Table 4.4.2–2 below.

Table 4.4.2–2: Funding for mental health residential services 2007-08

Service type	Funding level ($M)	Basis of funding
CCUs	$36.8 million	Unit pricing (available bed day)
SECUs	$16.3 million	Unit pricing (available bed day)
PARCs	$8.0 million	Unit pricing (available bed day)
Residential rehabilitation	$4.2 million (24 hour) $7.1 million (non-24 hour)	Unit pricing (available bed day)
Supported accommodation	N/A	Unit pricing (available bed day)

Source: Victorian Health Services *Planning and Funding Policy, 2008-09 Annual Update*.

Funds for clinical residential services are based on service type and location (metropolitan or regional). Table 4.4.2–3 below summarises the 2008-09 unit prices for these services.

Table 4.4.2–3: Unit prices, clinical residential services 2008-09

Service type	Metropolitan unit price ($)	Rural unit price ($)
CCUs	326.00	329.00
SECUs	475.00	478.00
PARCs	386.00	386.00

Source: Victorian Health Services *Planning and Funding Policy, 2008-09 Annual Update*.

The bed day rates are based on 100% availability of the funded beds regardless of the actual occupancy, and unit prices are indexed annually.

Similarly, residential services provided by PDRSS are funded on the basis of available bed days. The unit prices for residential rehabilitation services, by type and region, are provided in Table 4.4.2–4.

Table 4.4.2–4: Unit prices for RRSs by type and region 2008-09

	Metropolitan unit price ($)	Rural unit price ($)
RRS 24hr support	$139.45	$139.45
RRS non-24 hr support	$111.48	$111.48

Source: Victorian Government (2008) Data provided to Family & Community Development Committee.

In 2007-08, 264 bed-based RRSs were funded by the government. Of these, 101 were adult facilities while 163 were youth facilities. Funding for residential rehabilitation in the year 2007/08 is tabulated in Table 4.4.2–5 by facility type and region.

Table 4.4.2–5: Total state government funding for residential rehabilitation services by region and service type 2007-08

	RRS (24 hr)	RRS (non 24 hr)
Inner Melbourne	$3,217,415	$5,133,020
Barwon South Western	$494,987	$395,712
Gippsland	—	$395,712
Grampians	—	$395,712
Hume	—	$791,424
Loddon Mallee	$494,987	—
Total	**$4,207,388**	**$7,111,569**

Source: Victorian Government (2009) Supplementary data provided to Family & Community Development Committee.

Like RRS, PDRSS supported accommodation services are funded on available bed days. A daily bed day rate is paid to services.

Table 4.4.2–6: Unit prices for PDRSS supported accommodation services by type and region 2008-09

	Metropolitan unit price ($)	Rural unit price ($)
SAS 24hr support	$108.20 (if >11 beds $37.87)	$108.20 (if >11 beds $37.87)
SAS non-24 hr support	$70.60 (if >11 beds $52.50)	$70.60 (if >11 beds $52.50)

Note: Unit price is for 1-11 beds. For each bed over 11, the unit price is $37.87 (24 hr) and $52.50 (non-24 hr).

Source: Victorian Government (2008) Data provided to Family & Community Development Committee.

In 2007-08, PDRSS supported accommodation services were reviewed. The outcome of the review led to a standard definition for the service, which previously did not exist. As a result, data predating this review accounted for services which do not meet the current definition of SAS. For this reason, data regarding the provision and funding of SAS in Victoria is limited compared to that available for RRS.

Chapter Five:
Need and demand for
supported accommodation

Committee findings

- That understanding need and demand is central to present allocation of and future planning for supported accommodation services. (**Section 5.1.3**)

- That there are alternative methods for determining levels of demand for supported accommodation. (**Section 5.1.1**)

- That available data is insufficient to draw conclusions about unmet demand or about need for people with a disability (**Section 5.3.1**) and/or mental illness (**Section 5.3.2**)

  - in particular, there is little information about the links between demographic characteristics and indicators of service need. (**Section 5.4**)

- That service system planning is essential so that responses can meet current and future need and demand for supported accommodation for people with a disability (**Section 5.5.1**) and a mental illness. (**Section 5.5.2**)

- That there is confusion regarding the purpose and limitations of the Disability Support Register, which has led to concern regarding the transparency of processes. (**Section 5.6.1**)

- That the DSR is only a measure of current need, not of future need. (**Section 5.6.1**)

- That there is a need for tools and processes to enable families in caring relationships to plan effectively for the future. (**Section 5.6.1**)

- That there is no demand register in the mental health sector. (**Section 5.6.2**)

- That to meet need for supported accommodation, the level of resourcing, the allocation of resources and service-provider capacity all need to be taken into account

  - notably, these factors differ across the disability and mental health service sectors (**Sections 5.6 & 5.7**)

- That two key gaps were identified (**Section 5.7**)

    - allocation gaps
      when people with a disability and/or mental illness cannot gain timely access to the services they need due to an imbalance between the levels supplied and those demanded, or as a result of ineffective allocation processes

    - expectation gaps
      when the expectations of services have increased while the system providing these services is still adjusting to meet these new requirements.

U nderstanding need and demand for supported accommodation is important for two main reasons:

- It may enable better allocation of existing services

- It allows more effective planning for future services, so that these are of the right intensity, the right type, and in the right place.

This chapter identifies two broad issues that currently face both the disability and mental health services systems of supported accommodation. The first of these is the gap between met demand and unmet demand; the second is the gap between demand and need.

While these concepts are closely related, there are important distinctions. The following section provides a discussion of definitional differences between these important ideas.

5.1 Definitions of demand

Although the concept of demand for services such as supported accommodation may seem straightforward, there are a number of ways it can be understood. Below are definitions for key terms, which will be used throughout this chapter.

> **Key terms**
>
> **Need:**
>
> - A requirement for a support or service, based on functional restriction because of disability and/or mental illness. Need may be expressed or not.
>
> **Demand:**
>
> - An expressed need for a support or service. Demand may be met, or it may be unmet; if a service is inadequate or inappropriate, demand is considered to be 'partially' met.
>
> **Demand management:**
>
> - Demand management involves modifying the level or nature of demand in order to decrease a gap between supply and demand. It can incorporate a wide range of activities.
>
> **Future need or demand:**
>
> - The level of need or demand in the future will be shaped by a range of factors, including:
>   - Existing levels and patterns of need or demand

- – Demographic shifts which may change the absolute level of need or demand

- – Demographic shifts which may change the patterns of need or demand

- – Shifts in the nature of need or demand which imply a higher level of service need.

In the context of this chapter, need implies a service need. As discussed in Chapter Two, the needs of people with a disability and/or mental illness can be broad and complex. This discussion, however, is confined to needs that may be met by a service (although, importantly, not necessarily one that is provided in the existing service system).

The following sections provide further discussion of three of these concepts:

- ▪ Demand and need

- ▪ Met and unmet demand

- ▪ Future demand.

5.1.1 Demand and need

As a number of submissions to this Inquiry noted, there is a crucial distinction between *demand* for a service and *need* for that service.[100] The Australian Institute of Health and Welfare (AIHW) has noted that the terms are sometimes used interchangeably, and illustrate the importance of maintaining a clear distinction by identifying the different statistical indicators of demand compared to need (see Table 5.1.1–1 below).

Table 5.1.1–1: Statistical indicators of demand and need for services

Demand	Need
People receiving services	People apparently meeting eligibility criteria and not receiving or demanding services
People stating in services, letters and consultations that they have unmet needs – no or inadequate service	People for whom society's goals or 'norms' are not being met, eg housing, literacy or employment or, in some contexts, 'normative' physical and social functioning
People recorded on registers and waiting lists	People or groups who appear disadvantaged in comparison to others
People using services inappropriately, eg. respite care for permanent accommodation	

Source: Adapted from Australian Institute of Health and Welfare (2007) *Current and future demand for specialist disability services*. AIHW cat. No. DIS 50.

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[100] For example, see *Submission* 111, p.25 (I. Spicer).

Although there is overlap between the groups of people who demand and need a service, conceptually they are quite different. In particular, this conceptual distinction will be important to understand when we consider the gaps between services provided, what is demanded, and what is needed. It is likely that the level of expressed demand – that is, people who are either accessing a service or are waiting to have access – is far lower than the level of need.

Assessing the level of demand for disability or mental health support services is relatively straightforward, and is the basis for allocation of funding to providers. By adding together the services provided with the number of people on demand registers or priority lists (such as the Disability Services Register), a fairly reliable estimate of how many people demand a service can be developed. This makes the assumption, however, that all people with a service need (and eligible for a service) will express their demand.

Assessing need, however, is more complex. The Committee heard from a number of participants that there is value in using population data to determine demand. For people with a disability, it is possible to identify who needs services on the basis of eligibility as set out under the *Disability Act 2006*. On this basis, demographic data can be used to estimate the numbers in the Victorian population who are eligible to access disability support services under the Act, which would represent the level of need in the community. Comparing this with the number currently using services, it is possible to identify the gap between existing provision and the underlying need.

In the context of mental health support services there is no parameter of eligibility that can be used to determine the likely level of need. Instead, it is necessary to consider need in terms of the likely incidence of mental illnesses, and therefore the likely rate of need for support. In many circumstances, however, the temporal nature of mental illness means that a person's need for support may not be constant or permanent. Assessing the level of need at any one time, therefore, requires a combination of prevalence data alongside a clinical understanding of when and how much support will be needed.

While data concerning demand is relatively easy to collect, a significant constraint on understanding exactly how big the gap between need and demand might be is that it is often very hard to identify where people possibly have a need for a service but are making no demands. In the absence of this information, it is necessary to estimate the likely level of need in the community using one or a combination of proxies. For example, where different levels or types of service need are assumed to correspond to demographic characteristics or other population indicators, these characteristics/indicators may be used as proxies for the underlying need.

Establishing a distinction between need and demand is also important in ensuring clear expectations of the various parties. For example, submissions to the Committee have pointed out that because eligibility for support is determined by the *Disability Act 2006*, there is a community expectation that the

state is responsible for providing or facilitating services. For example, Mr Max Jackson suggested that the assumption that

> the family home of a person with a disability [is] considered to constitute part of the supported accommodation system should be rejected. Therefore, the Committee should recommend that those families who seek relief from the burden of having to continue to provide supported accommodation for their family member with a disability should not have to do so where the family member is of an adult age.[101]

Similarly, Mr Ian Spicer states that the Victorian Government should revise its policies to 'recognise that a person with disability accommodated with family carers is not living in "their own" home and should not necessarily be classified as being satisfactorily housed'.[102] He goes on to recommend that

> Research should be undertaken by an independent agency to prepare a detailed state-wide assessment of the extent of the "need" for supported accommodation. The data should aim to reflect the need throughout the disability community and not just measure the "demand" for services, which include only those who are existing users of CSTDA funded services and have registered an interest in accessing accommodation. Only through measuring need as against demand can a true picture of the supported accommodation deficit be determined.[103]

As identified by the Victorian Auditor-General's Office in 2008, however, there is some confusion about the extent to which the Department of Human Services (DHS) has a legal responsibility to provide services to those people who may not present for services (i.e. those who may have a *need* but no *expressed demand* for a service).[104]

5.1.2   Met and unmet demand

As well as distinguishing between demand and need, it is important to note that, for both, there can be *met* and *unmet* requirements.

Met demand may be defined as those who want to access services, and who have them provided when and where they wish. In contrast, unmet demand concerns people who want to access services but who do not have them provided appropriately. Met need concerns a slightly different group (though, as noted above, there is some overlap with demand) whose needs for services are being met appropriately. Correspondingly, those with unmet needs do not have their needs met appropriately.

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[101]   *Submission* 78, p.15 (M. Jackson).

[102]   *Submission* 111, p.25 (I. Spicer).

[103]   *Submission* 111, p.25 (I. Spicer).

[104]   Victorian Auditor-General (2008) *Accommodation for People with a Disability*. Victorian Auditor-General's Office, Melbourne, March.

These distinctions point to two areas of concern, which should be considered separately as the implications for change may be different.

First is the issue of *unmet demand*, suggesting that the level or range of services provided is insufficient to meet demand, or else that the processes of allocating services to people are not functioning. Second is the issue of *unmet need*. It is worth noting that, in many cases, need may be unmet even though demands are met. Either of the two issues identified —insufficient provision or inappropriate allocation – may be the cause of unmet demand and unmet need. More significantly, however, this overlap could reflect a deeper misalignment between how service providers and planners are conceiving of demand and need. Some of these potential misalignments are discussed later in this chapter.

5.1.3   Future demand

The final distinction to make in this definition of demand is the difference between *current* and *future* or *potential* demand.

The importance of understanding future and potential demand is that they provide the basis for planning service provision. They involve, however, many of the same data gaps as those identified when considering service need. Indeed, potential demand may include estimates of current need. When assessing future demand, it is generally considered insufficient to simply project forward from today's service use figures. An estimate will include the likely level of need in the future. There is an overlap between how current need is quantified and how future demand is estimated.

There are several factors likely to drive changes between current and future demand for services such as supported accommodation, including:

- General demographic change affecting population composition

- Changing incidence leading to rates of disability and/or mental illness

- Changing expectations of services.

The impacts of demographic change on the need and/or demand for services may be threefold. First, the ageing of large numbers of informal carers may result in higher need for formal support services. Second, as people with a disability and/or mental illness themselves age, it is likely that their need for support services will increase and become more complex. Third, shifts in the demographics of the Victorian community may mean that some disabilities or mental illnesses (in which prevalence is closely linked to demographic factors) are seen more or less, thus affecting the level of need for specific services relating to these conditions.

It is also likely that other factors may lead to shifts in the incidence and/or prevalence of conditions associated with disability or mental illness. For example, it is increasingly recognised that the level of mental illness in the

Victorian community is higher than previously thought, which implies that the need for support services is similarly greater.

Shifts in community expectations of what support services should provide also have implications for the nature and level of services demanded. For example, support paradigms based on individual needs will change the shape of demand considerably compared with previous formations.

5.2   The structure of demand

The definitions above have described various concepts incorporated in the term 'demand'. This section sets out the main subsets of demand for services.[105] It is important to note that demand for supported accommodation is not singular. Demand comprises a diverse range of needs, which vary according to the nature, intensity, duration, and flexibility of services required. These dimensions represent the range of factors essential for an adequate service.

The *nature* of services demanded refers to the type of service provided or required. That is, it can refer to support, accommodation or both. In both the disability and mental health support systems, these services are defined relatively consistently, and are the basis of funding provided to Community Service Organisations (CSO) or DHS managed facilities delivering the services.

The *intensity* or *level* of service demanded refers to how much of the service is required – how frequently and with what intensity. In the Victorian system, the level of service is generally prescribed, along with the service type, in the set of funded services. It is likely, however, that an increasing emphasis on individualised support will imply greater variation in how people may choose to combine service types and service levels.

The *duration* of services demanded is likely to differ across groups within the population of people with disability and/or mental illness. For many people with a disability, it is likely that support will be needed constantly over their lifetime, although the nature and level of services required may vary over time and may not always include supported accommodation. On the other hand, for at least some people with a mental illness, the need for supported accommodation may be episodic, and may be relatively short-term.

Each of these variations in demand for services means that the provision of these services must be differentiated, and must be flexible enough to change over time.

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[105]   This differentiation can equally be applied when considering someone's need for services. In this section, demand is used interchangeably with need.

5.3   Demand and need for supported accommodation

This section outlines the level of demand for supported accommodation services in the disability and mental health support systems, based on national and state data. While there is no single dataset identifying the hidden aspects of demand – where existing services only partially meet needs, or where people need but do not demand services – some approaches to estimating the level of this underlying need are discussed.

5.3.1   Disability

This section discusses what is known about the level of need for supported accommodation services for people with a disability, assesses data on demand for these services, and identifies where there are gaps between the two. Managing the gap between the two is discussed later in the chapter.

Table 5.3.1–1 below summarises the data identified.

Table 5.3.1–1: Summary of need and demand for supported accommodation, Victoria

		Number	Data source
Need	People with a disability	992,300	SDAC/ ABS
	People with a disability who may need supported accommodation *	46,200	SDAC/ABS
Demand	People using disability services	85,506	CSTDA/AIHW
	People using supported accommodation	13,900	CSTDA/AIHW
	People in residential institutions	199	DHS
	People in shared supported accommodation (SSA)s	4,784	DHS
	People requesting an SSA place (2007-08)	244	DHS

* i.e., those with a profound or severe core activity limitation, due to intellectual and developmental disorders, congenital and perinatal disorders, injury, poisoning and other external causes. Note that the definitions used at the national level can correlate differently to those used in Victoria.

Sources: AIHW (2009) *Disability support services 2006-07*; ABS (2004) *Survey of Disability, Ageing and Carers*. ABS cat. no. 4430.0; DHS data (2008) provided to Family and Community Development Committee.

Need for disability supported accommodation services

Identifying the level of underlying need in the community for supported accommodation services involves several concepts. Firstly, it is necessary to understand the size of the population who have a disability. Secondly, the proportion of this group considered likely to need supported accommodation or an equivalent service must be defined.

There are two possible ways of thinking about this:

1) To consider the group of people who have a disability (and, under Victorian legislation, are eligible for disability support services)

2) To consider the group of people who have a functional limitation.

In Victoria, there are detailed datasets about each group. Each group, however, has some significant constraints.

The first approach makes it easier to identify who in the population should be considered, and there is likely to be more information about what services are currently being used. It doesn't, however, reveal whether someone might require a support that they are not using.

The second part makes it possible to assess who in the population might have the underlying need. Because it doesn't link this need to the presence of a disability (and any information about existing service use), however, it does not help understanding of the limitations of existing services.

In reality, it is likely that a combination of the two approaches will be required.

The ABS *Survey of Disability, Ageing and Carers* in 2003 identified that approximately 42,400 Victorians had an intellectual disability, 8,900 had a congenital or perinatal disorder, and 73,400 Victorians had a disability due to injury, poisoning, or other external causes.

This group then must be narrowed down in order to identify the group of people in the community who, because of a permanent disability, frequently (three or more times a day) need assistance with a core activity, and who therefore may potentially be considered to need in-home support, supported accommodation, or respite. The ABS survey also asks people to report whether they need assistance with a range of activities, and whether their limitations are profound, severe, moderate or mild. These responses are also grouped according to the nature of the disability – whether it is due to ageing or to another cause.

Table 5.3.1–2 summarises the potential level of underlying need for supported accommodation in Victoria. However, because it is not possible from this dataset to identify whether the people involved are eligible for disability support services (for example, assessing whether a functional disability is due to age), it is necessary to use broad proxies such as the category of disability reported.

Table 5.3.1–2: Summary of underlying need for supported accommodation, Victoria

	Intellectual and developmental disability	Congenital and perinatal disorders	Injury, poisoning and other external causes
People with a disability	42,400	8,900	73,400
People with a disability who may need supported accommodation*	21,400	5,700	19,100

* ie, profound or severe core activity limitation, intellectual and developmental disorders, congenital and perinatal disorders, injury, poisoning and other external causes.

Source: Australian Bureau of Statistics (2003) *Disability, Ageing and Carers: Summary of Findings*. ABS, cat. no. 4430, Table 11.

Demand for disability supported accommodation services

The level of demand for supported accommodation services can be identified through service data collected by DHS through the Commonwealth State and Territory Disability Agreement (CSTDA) National Minimum Data Set (MDS).

The CSTDA MDS is a relatively robust indication of how many people are using services, based on information collected from approximately 10,000 service providers around Australia.

Support services funded through the CSTDA/National Disability Agreement (NDA) are grouped into seven broad categories. Among these, *accommodation support* is defined as:

> Services that provide accommodation to people with a disability and services that provide the support needed to enable a person with a disability to remain in his or her existing accommodation or move to a more suitable or appropriate accommodation.[106]

All supported accommodation services provided by the Victorian Disability Services Division, as well as some in-home support, fall into this group.

The AIHW reports that, of CSTDA service users in 2006-07, approximately 16 per cent used accommodation support services (representing around 47 per cent of total expenditure). In Victoria, this translates to just over 13,900 people with disabilities accessing some form of accommodation support. Of these, a significant proportion (around 70 per cent) also used services. In particular they used community support (such as case management, early intervention, or individual therapy) and community access services (such as life skills development and recreational programs). DHS data suggest that around 4,780 people live in SSA facilities, and around 200 in congregate care. This implies that

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[106] Australian Institute of Health and Welfare (AIHW) (2008) *Disability support services 2006–07: national data on services provided under the Commonwealth State/Territory Disability Agreement*. Cat. no. DIS 52. Disability series. AIHW, Canberra.

the remaining 9,000 people are living in a private residence but accessing support services in order to stay at home.[107]

CSTDA MDS data, however, does not provide insight into the level of need or of unmet demand (as defined in section 1.1 above). Some indication about unmet demand can be identified through DHS data concerning requests for SSA places. DHS reports that there has been a downward trend in new requests for SSA places over the years 2003 to 2008 (see Figure 5.3.1–3 below). These figures do not provide any indication of those people who have a need for a service, yet do not express their demand. The Committee heard that some people do not express their need for a range of reasons.

Figure 5.3.1–3: New requests for SSA by age, 2003-04 to 2007-08
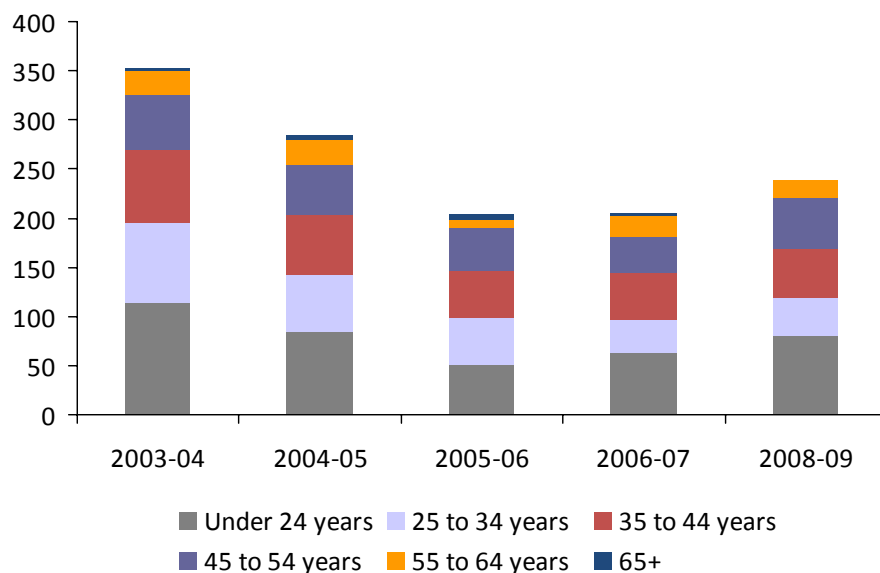
Notes:

Excludes applications that were withdrawn, rejected or not yet verified/finalised by the end of the financial year

Excludes applications from existing SSA residents seeking a location transfer

Data prior to April 2006 are from the Service Needs Register (SNR)

Data from April 2006 are from the Disability Support Register (DSR)

Data for 2005-06 may be incomplete due to transition from SNR to DSR

Figures prior to April 2006 may not be comparable due to changes in registration methodology.

Source: Victorian Government (2008) Data provided to Family and Community Development Committee.

Gaps between need and demand for disability supported accommodation

As already noted, data about the number of people who have used or formally asked for services provides only a partial picture of the need for disability support.

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[107]   Victorian Government (2008) Data provided to Family & Community Development Committee.

For instance, the CSTDA dataset does not capture whether people are using the most appropriate services for their needs. Because of this information gap, it is impossible to identify where there is partially met or unmet demand among existing service users.

A potentially much larger issue is that the figures about service use do not say much about the underlying level of need for supported accommodation among people with a disability if they are not currently accessing these services. There is no single or definitive measure of this need, however the AIHW has produced a series of studies examining the nature of demand and the extent of unmet demand/need for specialist disability services. [108]

The AIHW use population data about levels of disability, functioning, and need for assistance to estimate the likely gap between existing service use and actual need. The researchers estimate that the national level of unmet demand for accommodation and/or respite services in 2005 was approximately 27,800 people (the methodology used is described below). In the 2003 *Survey of Disability, Ageing and Carers (SDAC)*, Victorians with a severe or profound core activity limitation aged younger than 65 represented just over 26 per cent of the national total. This corresponds to approximately 7,300 with unmet need for these services.

AIHW methodology for estimating unmet demand for disability services

The approach to this study is based on disability and functioning levels as reported in the most recent (2003) ABS *Survey of Disability, Ageing and Carers (SDAC)*. The central challenge was to translate survey data – which asked questions about peoples' needs for assistance with daily activities – into estimates of whether supported accommodation services would be appropriate to meet these needs.

This study therefore only estimates the number of people who are potentially in need of in-home support, supported accommodation and/or respite. It is assumed that, at a population level, any of these services may substitute for another; it is only possible to assess which of these alternatives is most appropriate at an individual level.

The survey found that there were 661,400 people in Australia who:

- Were aged under 65 years
- Had a severe or profound core activity limitation
- Were not living in cared accommodation.

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108   Australian Institute of Health and Welfare (AIHW) (2007) *Current and future demand for specialist disability services. Disability series.* Cat. no. DIS 50. AIHW, Canberra; Australian Institute of Health and Welfare (AIHW) (1997) *Demand for disability support services in Australia: size, cost and growth.* AIHW Cat. no. DIS 8. AIHW, Canberra.

> Among this group, those reporting assistance needs in certain areas were considered to be probable candidates for supported accommodation or one of the alternative services. The types of assistance required can include help with:
>
> ▪ General tasks and demands (guidance, property maintenance, mobility, paperwork)
>
> ▪ Communication
>
> ▪ Mobility and transport
>
> ▪ Self-care and health care
>
> ▪ Domestic life (housework, meal preparation).
>
> 26,700 people who needed assistance with one or more of these activities three to five times a day were considered likely to need supported accommodation or an alternative support. This estimate was adjusted for population growth to an expected 2005 level of 27,800 in Australia (or 7,300 in Victoria).

5.3.2 Mental health

This section discusses what is known about the level of need for supported accommodation services for people with a mental illness, assesses data on demand for these services, and identifies where there are gaps between the two.

Need for mental health supported accommodation services

Assessing the level of potential need for residential support among people with mental illnesses in Victoria involves considering the level of mental illness in the community, and identifying the proportion of these people who may need external support in accommodation.

Mental illness is one of the more prevalent conditions affecting the Australian population. The Australian Bureau of Statistics (ABS), in the 2007 *National Survey of Mental Health and Wellbeing* estimated that around 18 per cent of Australian adults had experienced a mental illness in the 12 months preceding the survey.[109]

There is no single measure that would indicate the proportion of people, among those with a mental illness, who might need supported accommodation services. Therefore, to assess the potential unmet need and demand a range of proxies must be used.

Because there is no comparable survey among people with a mental illness to the SDAC, which collects information about the need for functional assistance

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[109] Australian Bureau of Statistics (ABS) (2007) *National Survey of Mental Health and Wellbeing*. ABS cat. No. 4326.0. Accessed from <http://www.abs.gov.au/AUSSTATS/ abs@.nsf/mf/4326.0> on 30 September 2009.

among people with disabilities, the same approach to assessing hidden demand and need for supported accommodation as that used in the context of disability services cannot be used. While the SDAC does include some people considered to have a psychiatric disability, this is only a subset of the population of those who may require support (in particular where this need for assistance is episodic).

In place of this approach, there are a number of strategies that may be used to develop a quantitative estimate corresponding to the substantial amount of anecdotal evidence of unmet demand and unmet need.[110] These include:

- Identifying the prevalence of mental illness in the community and forming a clinically based judgement about the likely proportion of people in this group who need supported accommodation or an alternative service

- Identifying population indicators of potential unmet need[111]

- Identifying populations of obviously unmet need.

The first approach involves a number of assumptions, about prevalence as well as about how this translates into need. To give a sense of scale of the possible extent of unmet need in Victoria, the text box below describes some estimates.

Implied service need due to mental illness in the Victorian population

One way of thinking about the potential need for supported accommodation among Victorians with a mental illness is to use a prevalence approach. This considers how many people in the community have a major mental illnesses, then assesses what proportion of these are considered likely to require assistance such as supported accommodation. This approach to estimating need has many similarities with burden of disease assessments.

In 2007, the ABS *National Survey of Mental Health and Wellbeing* reported that approximately one-fifth of Australians had experienced mental illness during the last year. This corresponds to around 800,000 Victorians. Among this group, just over 40 per cent (around 320,000 Victorians) reported that their core activity limitations represented a severe to profound level of disability and over a week each year 'out of role'.[112]

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[110] Similarly, in its Inquiry into Mental Health Services in 2008, the Commonwealth Senate Standing Committee on Community Affairs heard evidence indicating the shortage of accessible supported accommodation for people with a mental illness across Australia.

[111] See, for example, Parslow, R. & Jorm, A. (2001) 'Predictors of partially met or unmet need reported by consumers of mental health services: an analysis of data from the Australian National Survey of Mental Health and Wellbeing'. *Australian and New Zealand Journal of Psychiatry*, Vol.35. Parslow and Jorm found that, while few sociodemographic factors were associated with unmet need, there were a number of factors – having less education, being male, living alone, being unemployed, having seen a GP for mental health reasons, and having an anxiety disorder – associated with increased unmet need for different types of mental health help.

[112] ABS (2007), *National Survey of Mental Health and Wellbeing* [see Footnote 109].

Accurately assessing the proportion of these people that may need services such as supported accommodation is not possible based on existing data. There are, however, a range of approaches that provide at least an order of magnitude for this potential need. One possible estimate is described below.

'Burden of disease' weightings provide an estimate of the impact on health and wellbeing arising from various conditions; these weightings are generally divided into three groups reflecting a mild, moderate and severe manifestation of the condition.[113] Using a similar approach in its 2006 report for the Victorian Government, the Boston Consulting Group estimated that at a population level, the proportion of people with a mental illness falling into these three groups was:

- Mild: 12 per cent

- Moderate: 4 per cent

- Severe: 3 per cent

- **Total: 19 per cent.**

If it is assumed that those people considered to have a severe core activity limitation from a mental illness are those who need supported accommodation or a substitute service, this suggests that in the order of 24,000 individuals have at least one annual episode.

With the total number of beds reported by DHS to have been fewer than 500, a conservative estimate suggests that in order to accommodate these people, the average length of stay (across all service types) would have had to be less than eight days.

Based on DHS and AIHW estimates, this is far shorter than any residential service type, suggesting that the number of beds available is significantly fewer than the level of community need.

Demand for mental health supported accommodation services

Unlike disability support services, most of which are funded through the CSTDA/NDA and are therefore captured in the national dataset, mental health support services are significantly fragmented, and data about the level of service demand reflects this.

The AIHW aggregates information into three broad groups: ambulatory mental health care, admitted and residential mental health care, and mental health-related pharmaceuticals.

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[113]   Stouthard, M.E.A., Essink-Bot, M.L., Bonsel G.J., Barendregt, J.J., Kramer P.G.N., van de Water, H.P.A., et al (1997) *Disability weights for diseases in the Netherlands.* Rotterdam:,Department of Public Health.

Victoria provides data to the National Residential Mental Health Care Database (NRMHCD), which provides information about episodes of care in government-funded residential mental health services in Australia, except in those targeting aged people under the *Aged Care Act 1997*. These services include rehabilitation, treatment or extended care in a residential setting, and so include all services described in Chapter Four – that is, residential clinical services (CCUs, SECUs, PARCs) and PDRSS residential rehabilitation and supported accommodation.[114]

This data suggests that in 2006-07 there were a total of 659 residential mental health services beds in Victoria, equivalent to 12.8 per 100,000 population.[115]

Information provided to the Committee by DHS reports that there were a total of 743 bed-based PARC, SECU, CCU and residential rehabilitation services funded in 2006-07. In addition, PDRSS-funded SAS (approximately 100) were not included in this count due to classification changes and non-comparability.

There is a range of potential reasons for the difference in national (659 beds) and state (743 beds) figures. The Committee sought clarification from the Department of Health regarding the discrepancy in the figures, but did not receive a response.

This information about the level of service use suggests there is a very significant gap between the level of need for residential support and services provided in the community.

5.4   Data collection

What is known about the level and nature of need and demand for disability and/or mental health supported accommodation services is inferred from data about the demographic characteristics of people with a disability and/or mental illness, and from data describing use of existing services. The implicit assumptions behind these datasets, therefore, affect the ways need and demand are identified.

It is important to note that knowledge about need and demand is substantially driven by the shape of existing services, which is where most data collection occurs. Services in both the disability and mental health systems are frequently fragmented and de-centralised, and those collecting information on the ground may not keep records in a way that is consistent across the country, across the

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[114]   Note that information concerning non-government-operated and non-24 hour staffed facilities is optional for the NRMHCD, however Victoria appears to have provided at least some of this information. See Australian Institute of Health and Welfare (AIHW) (2009) *Mental health services in Australia 2006–07*. Mental health series no. 11. Cat. no. HSE 74. AIHW, Canberra.

[115]   This figure excludes services targeting people aged over 65 years. AIHW, *Mental health services in Australia, 2006-07*. AIHW cat. no. HSE 74.

state, even across an organisation. At the system level, fragmentation of a different kind occurs. Depending on whether reporting is to the state or federal level, or whether services are part of the disability support, mental health services, or other systems, different sectors may have very different records management systems.

Some of the challenges of data collection are reflected in the very partial information that is available. For example, in Victoria little is known about key demographic and service need characteristics of significant proportions of current disability service users. Table 5.4–1 below compares the proportion of 'not stated' responses to questions about demographic characteristics and service need indicators from Victorian service users against the national averages.

Table 5.4–1: Not stated responses, disability services users, Victoria, 2006-07

	Victoria % not stated	Australia TOTAL % not stated
Age	0.0	0.0
Sex	0.5	0.2
Indigenous status	12.5	5.0
Country of birth	11.9	5.5
Need for interpreter services	24.9	9.5
Method of communication	21.6	11.7
Living arrangements	13.8	10.8
Residential setting	21.1	11.0
Primary disability group	23.8	9.2
Existence of carer	23.3	8.2
Frequency of support or assistance needed:		
▪ Self-care	35.9	18.0
▪ Mobility	35.0	17.4
▪ Communication	34.7	17.0
▪ Domestic life	43.0	22.4

Source: Australian Institute of Health and Welfare (2008) *Disability support services 2006-07*. AIHW cat. no. DIS 52.

What is unknown about those who are currently using services reflects the greater unknown, about those who are not currently 'in the system'. It is likely that there are substantial numbers of Victorians with a disability and/or mental illness who are not currently accessing formal supported accommodation services or their equivalents, but who may in reality need this level and type of assistance.

The relatively high proportion of service users for whom key demographic characteristics – such as indigenous status, or culturally and linguistically diverse (CALD) background – are unknown is reflected in the DHS data about residents in SSA facilities. Some possible reasons for gaps in data about Aboriginal and Torres Strait Islander (ATSI) people are described below from the perspective of Rumbalara Aboriginal Corporation.

> **Rumbalara on information gaps about ATSI people with disabilities**
>
> The unmet complex support needs of ATSI people with disabilities and their carers were the subject of the 2005 DHS funded report *Analysis of the Needs of ATSI People with Disabilities and Their Carers within the Shepparton Area*, which identified:
>
> - Many gaps in data on ATSI people with complex disabilities
> - Significant underreporting
> - Minimal engagement with the mainstream service system and
> - A dearth of support services for this group of people, impacting heavily on them, their carers and service providers.
>
> The report included extensive consultations with: mainstream and ATSI organisations, Elders and parents caring for children with disabilities. It identified people in their 20s to late 40s, too young for aged care packages, as often having numerous disabilities such as an Acquired Brain Injury (ABI) or an intellectual disability (often undiagnosed). The report suggested there could be 300 ATSI people with severe or profound disability in the Shepparton area, out of an ATSI population of an estimated 6,000.
>
> Source: Rumbalara Aboriginal Cooperative.[116]

Issues relating to the lack of information about the needs of people from indigenous and CALD backgrounds are discussed in greater depth in later chapters.

The Committee found that the Victorian Government recognises the importance of receiving accurate and informative data about the nature and level of service needs in communities in order to understand demand, and plan for and provide such services.

5.5 Collecting data about need and demand: issues and initiatives

The challenges of establishing accurate datasets to understand both current and future demand as the basis for planning disability and mental health services are well known. This section briefly outlines some of the key responses to these challenges at the state and national levels.

5.5.1 Disability

The need for better approaches to developing data about existing unmet need/demand as well as future need was noted in a number of submissions to

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[116]   *Submission* 134, p.2 (Rumbalara Aboriginal Cooperative).

the Committee. For example, St Laurence recommended to the Committee that 'Government work with key stakeholders and community service organisations to develop new initiatives to gather reliable data about unmet need, particularly in the area of accommodation (shared supported and 'independent')'.[117] Similarly, the Association for Children with Disability argued that DHS needs to 'develop a mechanism for tracking unmet demand and future accommodation needs of people with a disability'.[118] Gippsland Carers Association also recommended

> That the Victorian Government takes immediate steps to establish a detailed Disability Accommodation and Support Service Needs Register in order to record accurately the current and future demand for specialist disability services.[119]

The Committee heard a consistent message that the Victorian Government needs to improve its understanding of future and potential need.

Recommendations made by participants in the Inquiry regarding the need for DHS to project future demand are consistent with recommendations made by the Victorian Auditor-General in early 2008. In its review on supported accommodation services in the disability sector, the Victorian Auditor-General's Office stated that:

> If the present shortcomings in demand measurement persist, it is unlikely that DHS will be prepared to meet future demand. As a consequence, residential service recipients will suffer and the system will continue to be crisis driven…
>
> Estimating the cost of providing accommodation and support for all people listed on the DSR would assist DHS in better understanding its future resourcing requirements.[120]

The auditors therefore recommended that DHS should:

> Expand its demand management strategies and explore options for accelerating the implementation of existing demand management strategies (Recommendation 5.1)
>
> Systematically measure projected need and develop strategies, such as alternative delivery mechanisms and a workforce management strategy, to meet future resourcing requirements (Recommendation 5.2).[121]

In evidence provided to the Inquiry, Disability Services Division advised that it has committed to addressing the need for improved measurement of current

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[117] *Submission* 104, p.4 (St Laurence).

[118] *Submission* 91, p.5 (Association for Children with Disability).

[119] *Submission* 52, p.3 (Gippsland Carers Association).

[120] Victorian Auditor-General (2008) *Accommodation for People with a Disability*. Victorian Auditor-General's Office, Melbourne, March, pp.45-50.

[121] Victorian Auditor-General, *Accommodation for People with a Disability,* pp.50, 52.

and future demand in partnership with its counterparts in other states. The Committee heard that this is a priority under the NDA. Mr Arthur Rogers, Executive Director of Disability Services Division, stated that:

> All ministers of disability, community services, health and ageing have agreed to contribute to improving the next collection of data to that survey, which is obviously conducted by the Australian Bureau of Statistics. [122]

Activities currently being undertaken to improve data about demand and enable improved planning for service activity include:

- Developing more complete information about the total population of people with severe or profound disability. This involves a range of strategies to improve the SDAC including

    – Increasing the sample size to improve jurisdiction level data

    – Modifying the survey questions to better identify patterns of current and future service use.

The Committee was advised that work to be released in late 2010 includes:

- Planning based on knowledge of future potential demand. This involves national work to develop a projection model, which develops estimates of potential demand based on current met and unmet demand

- Development of a nationally consistent methodology and data collection for measuring unmet expressed demand. [123]

While these projection models are being developed, the Committee was advised that in the interim the Disability Services Division has developed a demand management model to assess the impact of various scenarios on future demand for a range of disability services, including supported accommodation. [124] The Victorian Government advised that in the absence of reliable population-level data on the support needs of people with a disability, the Disability Services Division currently uses scenario modelling (based on variable annual demand growth rates of between 3 and 5 per cent) to assess the potential future demand for disability services.

Mr Arthur Rogers also advised the Committee that an additional priority for the Department is the development of a model of population planning for disability services at a national level. The Victorian Government is collaborating with other states in this work. He explained that in the context of service planning:

> One of the other priorities is about national population benchmarks. There has been some work happening around what that might mean. State, territory and commonwealth ministers have agreed that there needs to be a more rational approach to national population benchmarking for disability services. We are

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[122] *Committee Transcript*, 10.12.08, p.8 (A. Rogers, DHS).

[123] *Committee Transcript*, 10.12.08, p.8 (A. Rogers, DHS).

[124] Victorian Government (2008) Data provided to Family & Community Development Committee.

> currently assessing options for benchmarking frameworks. Much has been said about the aged care frameworks and benchmarks, and that is an option that has being looked at as well as other options. There is a view that we do not particularly want to be tied to having the same service type for everybody because we are looking at individual approaches, but we do need some approach to benchmarking, so that work will progress.[125]

The Committee supports the commitment of the Victorian Government to progress work on improving data to enable potential demand to be more effectively understood. The Committee understands that progress has continued in regard to improving data on unmet demand and undertaking a national population benchmarking exercise. Furthermore, the Committee recognises that the Victorian Government will work with other jurisdictions to develop more robust projection methods once data from the survey is released in late 2010.

In addition to identifying the importance of good data on unmet demand and need, a number of submissions noted the importance of ensuring available data is fed into service planning. In particular, the need for a longer-term perspective in service planning was consistently identified.

Recommendations

5.1   That the Victorian Government acts to ensure that improved national data collection to be released in 2010 is used to inform the establishment of a consistent, coherent planning framework across all dimensions of supported accommodation for people with a disability to enable short, medium and long-term planning.

5.2   That the Victorian Government publicly releases an interim plan prior to the release of the national data, to determine future need and demand for disability supported accommodation in Victoria based on its current use of scenario modelling.

5.5.2   Mental health

The Committee was advised that Mental Health and Drugs Division undertakes a range of activities to collect information on demand for services. This includes routine data collection on service utilisation such as information on numbers of people using services, how long they are in services, when they arrive and when they are discharged, informal surveys of clinical and PDRSS providers through to large pieces of work that result in the development of reports that are used to inform future service planning and delivery.

The Executive Director of Mental Health and Drugs Division also explained that several programs, such as the Integrated Care Recovery and Rehabilitation

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[125]   *Committee Transcript*, 10.12.08, p.9 (A. Rogers, DHS).

Program, have been established based on work that identified unmet demand in this area.

However, while data concerning service use is relatively comprehensive, information about unmet or partially met demand (ie, where people are accessing services but these are inappropriate or insufficient to meet their actual needs) as well as unmet need (the underlying requirement for supported accommodation or a comparable support) is very limited. As a consequence, current and future need is not a significant factor in determining service planning.

The Committee heard that improved data is needed. Participants told the Committee they have significant expectations of the mental health reform strategy in the context of data collection. The strategy, *Because Mental Health Matters*, notes that

> Victoria does not systematically apply a planning model that links service responses to prevalence of mental health problems across defined areas. Nor do we currently link benchmarked levels of provision to expected benefits at a population level.[126]

The strategy suggests, however, that there is 'a compelling argument for Victoria to investigate a population-based service planning model of this kind. Such a linking of investment, evidence based service provision and measurable outcomes should progressively become a key part of the way we develop our service system'.[127]

Participants in the Inquiry highlighted the importance of data systems that effectively measure service need, both current and future. For example, Carers Victoria stated that:

> The development of data systems that adequately measure the housing needs of people with mental illness is essential. It is hoped that governance and accountability reforms through the Victorian Government's Mental Reform Strategy will address this problem.[128]

Recommendations

5.3   That the Victorian Government measures met and unmet demand for accommodation in the Victorian mental health service system both from people in bed-based mental health services and people with a mental illness who live in the community and need access to these services.

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[126]   Department of Human Services (DHS) (2009) *Because mental health matters. Victorian mental health strategy, 2009-19*. Mental Health and Drugs Division, DHS, Melbourne, p.35.

[127]   DHS, *Because mental health matters*, p.36 [see Footnote 126].

[128]   *Submission* 61, p.21 (Carers Victoria).

	Recommendations
5.4	That the Victorian Government improves data collection relating to service need to assist with service and systems planning in the Victorian mental health sector.

5.6 Meeting demand for supported accommodation

Providing enough supported accommodation to meet the needs of all people in the community with a disability and/or mental illness is always likely to be a challenge, not least because there are almost always constraints on supply.

In addition, it is also frequently a challenge to ensure that the system can meet demand (that is, where people have expressed that they have a need for a particular service).

This section outlines some of the challenges and approaches involved in meeting need and demand for supported accommodation.

As the definitions of demand provided earlier in this chapter suggest, there are diverse subsets of demand/need among the group of people with a disability and/or mental illness who require supported accommodation. Ensuring that these demands/needs are met, therefore, does not just involve having a sufficient level of service provision. In addition, services must be available and accessible when and where they are needed and have capacity to meet specific and diverse needs of people with a disability and/or mental illness.

This process of matching can be modified in two major ways:

- Demand side management: that is, shifting individual needs (in relation to service capacity) through processes of prioritisation, risk assessment, and (for example, in the context of water or energy) demand modification
- Provision side management: that is, shifting service capacity (in relation to individual needs) through structural changes which shift what is provided, and when or where this occurs.

This section describes key features of the processes used to match supply with demand for the disability and mental health service systems. It is important, however, to note that there are some service provision factors that may prove to be limits on demand management.

5.6.1 Meeting demand for disability supported accommodation

Currently, the major prioritisation and allocation mechanism in Victorian disability services is the Disability Support Register (DSR). The DSR is a system that records current need for ongoing disability supports, which includes supported accommodation and also day programs and individual support

packages. It allocates services on a system of prioritisation. The DSR was introduced in April 2006 and replaced the Service Needs Register (SNR) with the intention of reflecting the shift in practice following the introduction of individualised planning and support.

The Victorian Government suggests that the DSR has resulted in improvements to

- The outcome of an individualised planning process
- Recording current need only
- One application per person
- Annual review of applications
- Priority status criteria.

Through the DSR, applications for support are intended to be the outcome of an individualised planning process that identifies the type of support required (for example, supported accommodation and part-time group activities, or support to move from DSD accommodation). The support type, along with demographic information, indicates the funding level required. This application is made through the Regional Intake and Response team. When an appropriate resource becomes available, this team develops a shortlist of applicants, prioritising some applications according to circumstances. Figure 5.6.1–1 below summarises the prioritisation process.

Figure 5.6.1–1: Developing a shortlist of DSR applicants

Support becomes available → Initial shortlist developed by regional intake team → Shortlisted applications assessed according to priority status → If there are additional supports once all priority status applicants have been allocated resources, or if there are fewer supports available than there are priority applicants, Priority for Access Panel assesses applications and allocates supports.

Source: Disability Support Register (DSR) (2008) Resource Coordination & Allocation Guidelines. DHS.

Following a decision about resource allocation, the applicant and their family or other carer or case manager is advised of the outcome. A case note, identifying the outcome and reasons for the panel decision are entered into the data management system, the Client Relationship Information System (CRIS). People with a disability, their carers, the community, and disability support providers may make appeals and complaints about allocation decisions.

DSR applications are reviewed annually and updated where a person's needs have changed.

A number of submissions to the Committee raised issues of transparency concerning the DSR, including the allocation of resources, the processes of prioritisation and the review or appeals processes. The Committee heard that considerable confusion exists amongst participants in the disability service system regarding the purpose of the DSR. The transition from a system of registering future need (the SNR) to registering current need (the DSR) appears to have caused uncertainty.

The Committee found that this confusion about the changed system appears to have led to a view amongst Inquiry participants that the DSR process isn't transparent. Linked to this perceived lack of transparency is a view expressed to the Committee that decision making is not independent.

The following perspective from two service providers gives an overview of some of the concerns raised.

Two service providers' perspectives:

Karingal and Gateways Support Service – experience of the DSR

Access to supported accommodation for people with a disability is through the Department of Human Services (DHS) Disability Support Register (DSR). In our experience this process lacks transparency and independence of decision-making.

DHS Disability Services is responsible for making a decision to register the applicant on the DSR. This includes the recommendation for Priority Status. There are no service users or community representatives included in the decisions relating to registering a request on the Disability Support Register and determining 'priority status'.

People with disabilities, their families and service providers are advised that a person has been accepted on the DSR but are not advised if they have been determined as having priority status. This leaves no mechanism to appeal this decision.

The Disability Priority Status Criteria does not include homelessness or as is more often the case, 'hidden homelessness'. Priority is given to people wishing to move from funded Shared Supported Accommodation to independent living. It is not given to people wishing to move from inappropriate, more restrictive living situations such as Supported Residential Services, Residential Aged Care (over 50's) or 'makeshift' living situations such as motels, caravans etc or those living long term in respite.

It is extremely difficult for families to gain access to the supported accommodation system. People may be listed on the DSR for many months and even years waiting for an individual support package or a

> shared supported accommodation placement. The demand management strategy through the DSR puts up multiple barriers and many people simply give up. Gateways and Karingal attempt to support families by assisting them to complete the necessary documentation whilst also providing emotional support and interim support even though we are not funded to do this.
>
> Other families see no choice but relinquishing care by leaving their son or daughter in respite, as they come to the conclusion that this is the only way they can gain a place in a crisis-driven system.
>
> Because the DSR only measures immediate need, it does not promote or support long term planning.[129]

To assist in improving the concerns with the DSR, St Laurence suggested to the Committee that:

> Government and key stakeholders work to develop clearer timeframes and access to information regarding a DSR application as a 'priority needs' application, including a process of appeal or review to be given so that more accurate planning can occur and people with a disability and their families can make timely informed decisions.[130]

Karingal suggested that the 'DSR be reviewed and revised to ensure timely access for people requiring support, transparency of process, priority status and funding allocations'.[131] One family recommended that 'families receive annual confirmation of their register/waiting list status'.[132]

It should be noted that unlike the SNR, the DSR is only a measure of current need. With no priority status criterion relating to 'length of time waiting', there is no queue as such. Allocation decisions are made on a point in time basis. Hence, there is not anything to know until a resource becomes available and the short-listing process begins.

Evidence presented to the Committee suggests that people on the DSR often give up waiting for accommodation placement or an individual support package. Yooralla suggested to the Committee that:

> the move from the 'Service Needs Register (SNR)' to the 'Disability Support Register (DSR)' has dramatically reduced capacity to collect data leading to effective strategic planning. The SNR had capacity to capture future need and interest in specific services. While limited in the way it collected this information, at least it had some predictive capacity. The newer DSR is specifically limited to those with a current need. This has eliminated data collection and analysis on those who know what they will require in the future

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129   *Submission* 16, p.4 (Karingal and Gateways Support Service).
130   *Submission* 104, p.4 (St Laurence).
131   *Submission* 16, p.5 (Karingal and Gateways Support Service).
132   *Submission* 73, p.5 (Name withheld).

but who will be able to remain in their family home for the next 3 to 5 or more years. On this basis, we will only know about those who need accommodation 12 months or less before it is required.

The evidence received by the Committee demonstrates concern regarding the shift to a process that focuses only on current need and prioritisation of need. Participants in the Inquiry suggested the Victorian Government implement a system that enables the future needs of people with a disability to be registered in some form.

Notably, this type of planning differs from the broader system of planning that can be based on populations. It relates more directly to people's individual experiences and need to plan and to have some certainty about the future.

The Committee identified that while the DSR is a valuable tool for measuring, prioritising and allocating in the context of current demand, it does not provide a tool for measuring future or potential need. As noted in the sections above, this is a critical issue on a systems level to ensure the availability of services. The Committee found that it is also a critical issue on an individual level for families in caring relationships seeking some certainty about what will happen to their family member when they are no longer in a position to provide support. Furthermore, prioritising and allocating on current demand does not allow for transitional planning for people with a disability who might find the transition from the family home to other living arrangements extremely stressful.

The Committee found that in addition to the need for the Victorian Government to plan for future systems needs, there is a need for planning tools to be established to assist families in caring relationships to plan more effectively for inevitable transition.

This issue is discussed further in Chapter Ten

Recommendations

5.5	That the Victorian Government commissions an external evaluation to assess the effectiveness of the implementation of the Disability Support Register, particularly relating to processes of decision-making and appealing decisions.
5.6	That the Victorian Government communicates the purpose of the DSR to more accurately distinguish its intention as a tool for prioritising and allocating services on the basis of current demand.
5.7	That in addition to population-based planning, the Victorian Government develops and promotes a mechanism for registering future service need to assist people with a disability and families to plan effectively for the future.

5.6.2   Meeting demand for mental health supported accommodation

Issues regarding appropriate allocation and matching in the context of mental health services differ from those seen in disability support. In evidence provided to the Committee, a key issue raised was that the absolute levels of support available are simply insufficient to meet need.

At the same time, this shortfall is exacerbated by 'blockages' at various points in the system, which mean that the limited number of places provided may not be available when and where they are needed.

The set of clinical and PDRS services provided for people with a mental illness involve different levels of treatment and support depending on someone's need at a given time and at a given point in the rehabilitation cycle. This implies that it is crucial to have an appropriate flow through the various services. One of the issues consistently identified is that when someone cannot access appropriate services (and therefore uses an inappropriate service), this multiplies through the system, reducing availability at each point. Where there are not enough services, it is likely that some people will remain with an inappropriate one rather than moving to a (possibly not available) service providing a different level of support.

In the mental health support system, there is no formal register such as the DSR. The Victorian Government has advised the Committee that in the context of mental health services, it does not collect data on waiting lists. This data sits within waiting lists and demand data collected by hospitals and health services.

Allocation to residential services appears to be, at least formally, on the basis of clinical guidelines in conjunction with a set of prioritisation criteria. The Victorian Government did advise, however, that it is developing a state-wide triage scale to promote greater consistency in the assessment of consumers and the identification of the most appropriate mental health response.[133]

Recommendations

5.8   That the Victorian Government develops a method to measure demand for mental health services separately from general heath services.

5.9   That the Victorian Government develops a central mental health services register for medium to long-term accommodation/resident services.

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[133]   Victorian Government (2009) Supplementary data provided to Family & Community Development Committee.

5.6.3   Matching service provision with demand

Effectively matching service demand or need with provision has significant implications for the ways service provision is structured, in terms of planning, funding, allocation, staffing and delivery.

There are two dimensions to the matching of services provided with those needed, and both require service systems that have the capacity to support this. Firstly, it is necessary that appropriate services exist. Secondly, there must be effective allocation processes so that people have access to the appropriate services.

Evidence presented to the Committee suggests that currently there are some shortfalls in both dimensions in the disability and the mental health support service systems.

To ensure that people are able to access the appropriate services, several things are needed:

- Provider structure and capacity to meet the different kinds of demand/need
- Funding models which allow for services to be provided in a responsive way as well as supporting provider capacity
- Appropriate and functioning allocation processes.

5.7   Key gaps in demand for and provision of supported accommodation

This section describes two key gaps between demand or need for supported accommodation, and the capacity of organisations to provide the services required. It emphasises that such gaps do not only arise because there is not enough service provision (although this may be a factor). The nature and level of demand, or need for a service, interacts with the system of service provision in subtly different ways. Notably, these interactions differ between the disability and mental health support service systems.

The first gap identified is a mismatch between the services available and the nature, timing and level of demand for these services. The different timing of flows through the disability service system compared to the mental health service system is highlighted.

The second gap described takes a longer-term perspective, and considers the misalignment between how service need (and therefore the nature and level of demand) is understood by people requiring the services, and the structural capacity of the provision system to meet this need and demand.

5.7.1   Allocation gaps

There are important differences between the disability and mental health services systems in how supported accommodation is distributed among people according to their demand or need for these services. In particular where there are gaps in allocation – that is, where the services provided do not match what is required – these factors are an area of concern across a wide range of people who submitted evidence to the Committee. Differences in the nature, level and duration of demand (and need) for services are the underlying drivers of these differences.

In the disability support system, mismatches between need and provision have been identified. The resulting gaps include inadequate matching of services with individualised needs, preferences and aspirations. This arises from the diversity of the needs of people with a disability, in terms of intensity and nature of services required, and is one of the main objectives of shifts towards more individualised service provision in Victoria and elsewhere in recent years. This was discussed in Part A.

There are also gaps arising from inadequate matching of services with needs as they change over a lifetime. While there have been some policies and programs to address this issue, submissions to the Committee suggest that the scale of these gaps is considerable. It is also likely that, compared with other support services, supported accommodation services may be less flexible and slow to change. Because supported accommodation services for people with disabilities are generally not short-term, significant shifts in needs are likely to arise as the person and their families or carers move through different life stages, and require different accommodation arrangements.

While there are services available, it is unclear whether the gaps between provision and need are arising because of inappropriate matching of services with peoples' needs, or because the levels of service overall are inadequate. Evidence to the Committee suggests that both factors play a role, and indeed interact to a substantial degree. The following recommendations were suggested to the Committee:

> Housing and support options, particularly shared supported accommodation, must be funded in a way that support can be adapted to the changing needs of people with intellectual disabilities as they age, to enable ageing in place.[134]

> Develop a whole-of-life assessment tool which can be reapplied as people's needs change. The assessment process should be used to translate information relating to people's support needs into a funding model, with capacity for ongoing monitoring and review.[135]

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[134] *Submission* 106, p.4 (STAR-VALID-Reinforce-AMIDA).
[135] *Submission* 105, p.11 (Wesley Mission).

> [That the Committee] commission experienced individuals and organisations to develop 'whole of life' planning services that would guide the family and government in the provision of services at appropriate times throughout the life of the person with disability.[136]

> Development of a Planning for Future Housing Support Service to work over time with ageing parents, the person with a disability and other family members to plan and develop individual and group plans for future shared and supported accommodation or community housing. Selected providers would be contracted to develop the variety of housing options required.[137]

In contrast to the disability support field, where the time frame for an individual's needs are largely longer-term and relate to life stage, a significant proportion of gaps between service need and provision in the mental health service system occur through a lack of continuity of care between clinical and non-clinical services and the capacity to sustain accommodation. This is evidence of the different underlying models in the two service systems. The objectives of mental health services in the context of recovery and rehabilitation are very different to the aims of disability supports.

Broadly characterised, the gaps between supported accommodation provisions and need for people with a mental illness occur in two places: firstly, when there are insufficient available places in the clinical/PDRSS continuum of recovery-oriented services; and secondly, when there are insufficient accommodation options outside these recovery-oriented service systems. While concerns were raised about misallocation and the inappropriate use of existing services, the key issue appeared to rest with the level of supply.

5.7.2   Expectation gaps

In addition to the straightforward gaps between the services provided and those demanded or needed, described above, there is another dimension of the gap between provision and demand. This is a gap that has arisen between changes in expectations and the capacity of the system to undergo the structural changes to enable these expectations to be met.

This suggests that shifts in expectations of what support services deliver – shifts in paradigms of support as well as the policies that implement this – may sometimes outpace the structural requirements that make the provision of these services possible. For example, in the case of disability support services, it is evident that a fundamental move towards individualised and person-centred support has occurred in recent years, at least in how people with disabilities, their families and carers, service providers and policy makers think about support. It is also evident, however, that such a fundamental shift in expectations implies significant practical and structural re-alignments, as

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[136]   *Submission* 111, p.27 (I. Spicer).
[137]   *Submission* 61, p.13 (Carers Vic).

government and non-government providers alike alter how they fund, monitor and manage services, and how they relate to each other and to the people with disabilities they serve.

A number of submissions to the Inquiry pointed to the gaps that can arise between what is expected, and what is provided, during this adjustment process.

Chapter Six:
Supported accommodation
in other states

Committee findings

- That Victoria provides a greater number of disability services than other Australian states. **(Section 6.2.1)**

- That Victoria receives less Commonwealth funding for disability than other Australian states and territories. **(Section 6.2.1)**

- That Victoria provides the highest number of mental health beds per capita. **(Section 6.2.2)**

- That Victoria's mental health expenditure is below the national average. **(Section 6.2.2)**

- That the process of closing institutions has been slower in other states than Victoria. **(Section 6.3.3)**

- That other states have developed innovative programs, such as the Housing and Support Initiative, that have been proven successful programs in providing long-term accommodation and psychosocial rehabilitation support to people with a mental illness. **(Section 6.4.1)**

I n the course of the Inquiry, the Committee has considered how Victorian supported accommodation compares with best practice in other state jurisdictions.

Supported accommodation has evolved across states in very different ways. Different historical circumstances, policy frameworks and driving forces have resulted in diverse systems of policy and practice. Making comparisons across states can shed light on how Victoria is progressing in regard to its policy and program development in supported accommodation for people with a disability and/or mental illness. Looking to other states can also provide opportunities for learning. On the other hand, such comparisons could provide an artificial benchmark due to differences across a range of factors in each state.

This chapter looks at the following aspects of supported accommodation in other states:

- Funding arrangements
- Policy and program developments relating to supported accommodation
- Alternative approaches to supported accommodation.

While it explores all states in funding comparisons, the chapter examines the policy and program development of three states in particular – NSW, SA and Qld. The Committee has focused particularly on these states because of their supported accommodation provisions and comparable population with Victoria. Additional information about policy and legislative developments in other jurisdictions can be found in the Appendix.

6.1 Perspectives on Victoria in comparison with other states

During the course of the Inquiry, participants told the Committee about service provision and policies in other jurisdictions and how they perceive Victoria's current accommodation and support provision in comparison to other jurisdictions.

The Committee heard that Victoria compares favourably with other states in some aspects of its provision of supported accommodation and less favourably in other areas.

For example, the Health and Community Services Union suggested that Victoria leads the way across Australia in both disability and mental health services.[138] The Health and Community Services Union (HACSU) told the Committee that:

> The services in Victoria, whilst they have their problems, overall are of good quality and good structure, particularly our mental health services. The level of

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[138]   *Committee Transcript*, 5.11.08, p.12 (HACSU).

community support and structure around those services, and how it is an integrated and connected, model is a good model.[139]

Carers Victoria suggested that Victoria is more advanced than other states in terms of the closure of institutions and having a network of community housing.[140] The organisation expressed its view that:

> In Victoria there are patches of brilliance in some of the models that are on the ground, like the notion of being an elite tenant for some people with disabilities, and … where you have people living in ordinary community housing supported by a person who lives in the same community and provides offsite support to them. Those sorts of models are very good and have great potential.[141]

Young People in Nursing Homes suggested that Victoria has done better than other states with regard to meeting demand for supported accommodation, but that the issue of demand remains a challenge. It explained that:

> while Victoria has certainly done better than many states in responding to this growing demand, we still have a disability system that lacks sufficient funding to respond in a timely and effective manner to the needs of Victorians with a disability. As a result, our existing system is driven more by the delivery of services according to budgetary constraints than to the needs of the people requiring support.[142]

While there was positive reflection on Victoria's progress in the development of disability policy and the provision of disability services, some participants also suggested a need to be cautious in being self-congratulatory. For example, Yooralla advised the Committee that while Victoria may be regarded as doing better than other states, 'we need to ask what more we can do, because if our maturity as a state and as a community is measured by how well we support our citizens with disabilities, then we still have a very long way to go'.[143]

The Committee heard that Victoria has made greater progress in the development of alternative accommodation options, such as those provided by housing associations. Housing Choices Australia stated that Victoria is more advanced than other states with regard to the regulation of housing associations and the provision of accommodation and support. It told the Committee that 'we have really charged ahead with developing business disciplines, developing a balance sheet, while remaining totally committed to social housing and to meeting needs of people with disabilities'.[144]

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[139]   *Committee Transcript*, 5.11.08, p.12 (HACSU).
[140]   *Committee Transcript*, 22.10.08, p.10 (Carers Victoria).
[141]   *Committee Transcript*, 22.10.08, p.10 (Carers Victoria).
[142]   *Committee Transcript*, 5.11.08, p.2 (Young People in Nursing Homes).
[143]   *Committee Transcript*, 22.10.08, p.5 (Yooralla).
[144]   *Committee Transcript*, 30.04.09, p.2 (Housing Choices Australia).

A number of organisations expressed a view that Victoria had led the way with the Housing and Support Program (HASP) for people with a mental illness prior to the tapering off of the program. VICSERV and Carers Victoria agreed that HASP provided leadership for other states in providing housing and support for people with a mental illness. VICSERV stated that Victoria had a housing and support program which 'funded about 1200 properties and support placements. It was based on an assumption that people would either move through the properties or that other properties would be provided, and it was a roaring success'.[145]

Likewise, Carers Victoria stated that Victoria

> led the way in terms of other states in Australia in providing housing support for people with mental illness, including people who had spent many years in institutions. There are some very good learnings from that program. It was highly successful and almost a victim of its own success, because when people with long-term psychiatric disabilities were in secure housing of their own with support, they actually got better and then needed less support.[146]

The Housing and Support Program is discussed further in Chapter Eight.

Some participants suggested that practices and models in states other than Victoria were providing better services in the disability and mental health sectors. National Disability Services told the Committee that Victoria has led the way in terms of policy but other states are delivering disability services in more effective ways, such as in Tasmania and ACT where services have been transferred from government to the non-government sector.[147]

Similarly, with regard to mental health, Victorian Mental Illness Awareness Council argued that whilst Victoria has pockets of good practice, Queensland is currently faring better in the mental health service provision as a result of increased financial resources.[148]

6.2   Distribution of Commonwealth funding

Commonwealth funding for services is significant in determining the resources available to Victoria. How Victoria compares with other states in regard to its share of the Commonwealth funding pool provides some insight into what can and cannot be achieved with the existing funds available.

In comparison with other jurisdictions, the discussion below indicates that Victoria's allocation of Commonwealth funding for disability services is less

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[145]   *Committee Transcript*, 30.04.09, pp.5-6 (VICSERV).

[146]   *Committee Transcript*, 22.10.08, p.10 (Carers Victoria).

[147]   *Committee Transcript*, 5.11.08, p.8 (NDS).

[148]   *Committee Transcript*, 30.04.09, p.8 (VMIAC).

than other jurisdictions and that Victoria provides more supported accommodation for people with disability than other states.

With regard to mental health services, Victoria's mental health expenditure was just below the national average in 2006-07. The data suggests that Victoria's community residential mental health services are more extensive than other Australian states.

6.2.1   Disability Services

Mr Arthur Rogers, Executive Director of Disability Services, informed the Committee that Victoria provides approximately 30 per cent of the national number of supported accommodation facility based services.[149] He stated that 'if you take both in-home accommodation support and group homes and other places such as institutions, we provide 37 per cent of the total broad accommodation support in Australia'.[150]

The Figure below shows the number of disability service users by accommodation type in all Australian states and territories. It illustrates clearly that Victoria provides a greater number of services for these types of supported accommodation than the other states.

Figure 6.2.1–1: Number of users by accommodation type 2006–2007
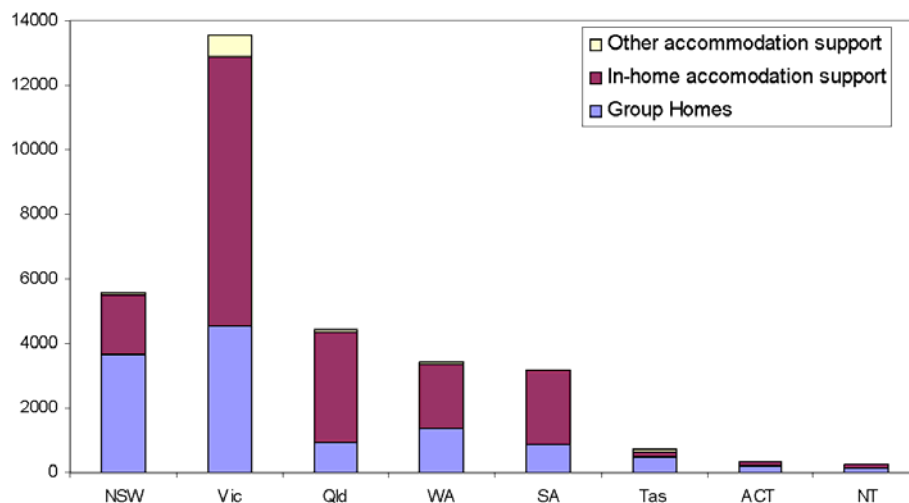
Source: Committee Hearing. 10.12.08 (Arthur Rogers, Executive Director, Disability Services).

Mr Rogers told the Committee that 'Victoria has fared poorly in terms of its share of Commonwealth investment in Victoria'.[151] He explained that the average Commonwealth funding for all other states and territories is 19 per cent with 81 per cent provided by the state or territory. In comparison, Victoria receives 13 per cent from the Commonwealth and the state contributes 87 per

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149   *Committee Transcript*, 10.12.08, p.7 (A Rogers).

150   *Committee Transcript*, 10.12.08, p.7 (A Rogers).

151   *Committee Transcript*, 10.12.08, p.7 (A Rogers).

cent. This figure has been reduced from the 15.1 per cent cited in 2002-03.[152] Mr Rogers suggested that this was 'a historic issue, probably from the first agreement, where there were swaps and exchanges of services. There has not been a review through the different agreements of the equity of that arrangement to Victoria's satisfaction'.[153]

Figure 6.2.1–2: Comparative investment in disability contributions from interstate jurisdictions 2003-2004 to 2007-2008
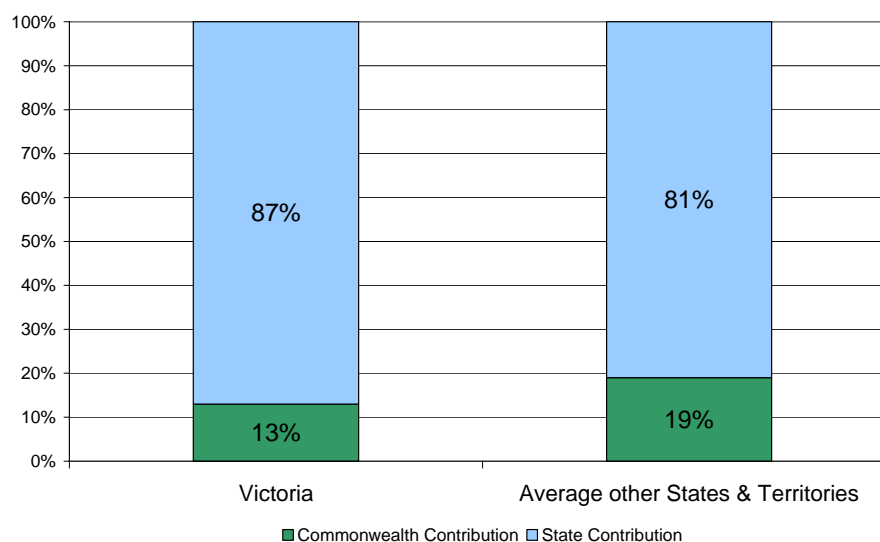
Source: Committee Hearing. 10.12.08 (Arthur Rogers, Executive Director, Disability Services).

6.2.2   Mental Health Services

Ms Gill Callister, Executive Director of Mental Health and Drugs Division, advised the Committee that Victoria has the highest number of beds per capita and has been a leader in the reform of mental health services and provision of community-based services.[154] For this reason, Ms Callister suggested that other jurisdictions have looked to Victoria for direction.

The following information regarding mental health expenditure across states and territories was provided by the Department of Human Services (DHS). The data provides a national comparison of Victoria's mental health funding.

Table 6.2.2–1: Real estimated recurrent expenditure per person at the discretion of States and Territory governments, excluding other revenue, 2006-07 (in dollars)

	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Aust
2002-03	110	121	101	137	115	103	114	98	114
2003-04	112	124	103	141	120	107	127	119	117
2004-05	115	132	105	154	134	112	139	130	123

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152   *Committee Transcript*, 10.12.08, p.7 (A Rogers).
153   *Committee Transcript*, 10.12.08, p.7 (A Rogers).
154   *Committee Transcript*, 10.12.08, p.19 (G Callister).

	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Aust
2005-06	128	136	111	160	138	133	137	133	131
2006-07	136	135	122	164	153	152	156	148	138

Source: Department of Human Services (2009) Letter from A/g Executive Director Mental Health and Drugs Division in response to question on notice taken on 10 December 2008, Received 10 June 2009.

The figures above suggest that the real expenditure per person has increased over time in all states and territories. Victoria's expenditure was slightly below the national average for the period 2006-07.

DHS informed the Committee that Victoria's community residential mental health services are more extensive than other states and territories.[155] In Victoria, community residential mental health services comprise both clinical services and residential rehabilitation services managed by psychiatric disability rehabilitation and support (PDRS) agencies. The table below shows the extent of Victoria's community residential services compared to other states and territories.

Table 6.2.2–2: Number of 24 hour staffed general adult community residential beds per 100,000 population at 30 June

	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Aust
2001	3.6	10.6	2.6	1.5	2.1	14.3	9.4	–	5.1
2002	2.9	10.3	3.4	1.8	2.1	13.2	10.7	–	5.0
2003	2.7	10.5	3.3	1.7	2.1	13.0	12.9	–	5.0
2004	2.6	11.1	3.3	1.7	2.1	11.5	13.8	–	5.1
2005	2.4	11.2	3.2	1.6	3.1	11.4	13.7	–	5.1

Source: Department of Human Services (2009) Letter from A/g Executive Director Mental Health and Drugs Division in response to question on notice taken on 10 December 2008, Received 10 June 2009.

These figures suggest that Victoria compares favourably with other states and territories in the provision of 24 hour staffed adult community residential beds than. This figure is significant when linked to the figures provided in Table 6.2.2-2 indicating that Victoria provides more residential health services with less expenditure than most other jurisdictions in Australia.

6.3 Disability and supported accommodation policy in other states

The Committee's Terms of Reference ask it to consider policy and practice relating to disability supported accommodation in other Australian jurisdictions. Comparisons with other states assisted the Committee in its consideration of disability policy and practice in Victoria and alternative accommodation approaches being explored in other states.

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[155] Department of Human Services (2009) Letter from Executive Director Mental Health and Drugs Division in response to question on notice taken on 10 December 2008, received 10 June 2009.

As the evidence suggests, policy developments in other jurisdictions are at varying stages, particularly in the context of closing or redeveloping institutions. Other states have been slower than Victoria in moving people with a disability from institutional care into accommodation and support facilities in the community. In this context, the Committee heard that Victoria has led the way in the development of disability policy and practice.

As the discussion outlines, disability policy and service provision in other states is evolving in similar ways to Victoria, with an emphasis on self-directed and person-centred approaches to service delivery. Other states are also experiencing issues in meeting demand, with some (such as South Australia) establishing strategies to address these challenges.

The table below provides the number of users accessing Commonwealth State and Territory Disability Agreement (CSTDA) funded services by service type in Victoria, NSW, Queensland and South Australia. The table demonstrates that Victoria has a particularly strong emphasis on in-home support, which is support only and does not include the provision of accommodation.

Table 6.3-1 - Users of CSTDA-funded services, service type by state and territory, 2006-07

Service Type	Vic	NSW	Qld	SA
Large residential/institutions	355	1,623	319	840
Small residential/institutions	-	84	542	20
Hostels	181	103	-	14
Group homes	4,551	3,681	939	883
In-home accommodation support	8,326	1,814	3,413	2,277
Attendant care/personal care	325	329	637	928
Alternative family placement	10	14	94	78
Other accommodation support	**666**	79	**95**	1
Total accommodation support	**13,962**	**7,532**	**5,817**	**4,677**

Source: Australian Institute of Health and Welfare (AIHW) (2008) *Disability Support Services 2006-07: National data on services provided under the Commonwealth State/Territory Disability Agreement*. Canberra, October, p.10.

6.3.1   New South Wales

In New South Wales, the Department of Ageing, Disability and Home Care (DADHC) provides various services for people with a disability. DADHC makes a significant investment in accommodation and support services and funds three main models for the delivery of these services. These are:

▪   Group homes

▪   Large residential centres

▪   In-home support.

While these models meet the support needs of many people with a disability, the Government determined that the system did not have the flexibility required to meet the continually changing needs of people with a disability.

In 2005, the NSW Government recognised that it needed to respond to a number of pressures with regard to supported accommodation services. These included:

- The growing demand for accommodation and support as a result of increasing age of carers, people moving from large residential centres and an increasing number of people with a disability seeking supported accommodation

- The need for greater flexibility in the range of supported accommodation and the capacity of these to change over time as individual needs change

- The need to identify options that will achieve community participation for people with a disability.[156]

In 2006, the NSW Government launched a 10-year plan, *Stronger Together: A New Direction for Disability Services in NSW 2006-2016,* which aims to increase support and options for people with a disability to live at home and to increase the range of specialist accommodation services.[157] The majority of people with a disability in NSW are cared for by family and friends. There are five components of *Stronger Together.* These are:

- Fair and more transparent access

- Services linked to need

- Assisting people to remain in the home

- More options for out-of-home support

- A sustainable care system.[158]

Stronger Together makes a commitment to closing large residential centres. In 2006-07, an AIHW report stated that in NSW 1,623 people with a disability continued to live in large residential institutions.[159]

The policy framework recognises the lack of options for people with a disability and the need to explore new and different ways with which to support people with a disability in the community. A range of different specialist accommodation facilities will be developed to meet individual needs, locations and changing circumstances. The support provided in these facilities will be consistent with contemporary accommodation and care standards and will comply with the *NSW Disability Services Act 1993.*

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[156] New South Wales Government (2005) *Roundtable on Accommodation and Support for People with a Disability.* Discussion Paper No 2, August, p.2.

[157] New South Wales Government (NSW) (2006) *Stronger Together: A new direction for disability services in NSW 2006-2016.* Sydney, May, p.3.

[158] NSW Government, *Stronger Together,* pp.3-5 [see Footnote 157].

[159] AIHW, *Disability support services 2006-07,* p.10 [see Footnote 106].

The *NSW Disability Services Act 1993* is the legislative framework for funding and providing disability services, and sets out the terms and conditions on which non-government organisations receive funding. A review of the Act is being conducted to determine the validity of the policy objectives of the Act and the appropriateness of the terms of the Act in securing these objectives.

6.3.2   Queensland

Disability Services Queensland provides accommodation and support services for people with a disability in this state. In the past decade significant changes have occurred in Queensland's disability sector with the development of new service approaches and an emphasis on community engagement.

In recognition of the changes, the *Disability Services Act 2006* was introduced to create a new legislative framework for services. The Act replaces the *Disability Services Act 1993* and seeks to acknowledge the rights of people with a disability by promoting their inclusion in community life and ensuring that disability services funded by the Queensland Government are safe, accountable, and responsive to the needs of people with a disability. In addition, the Act acknowledges that there are limited resources for disability services and that these resources need to be allocated equitably.[160]

The Queensland Government developed a four-year reform program, *Growing Stronger: Investing in a better disability service system (2007-2011)*, to deliver better specialist disability services.

A strong focus of the document, similar to Victoria's focus, is the introduction of a person-centred approach to delivering specialist disability services through tailored service responses informed by assessment outcomes.

A key goal of the policy is to consolidate funding programs. Under this system, services will be offered according to a tailored service response designed to maintain or improve a person's capacity. Since the development of *Growing Stronger*, a single application form to access disability services has been released.

The Disability Services Queensland accommodation support service provides accommodation and units where adults with an intellectual disability share support services and facilities in a community setting, with the support of paid Disability Services Queensland staff.

A typical household comprises three to five people who have an intellectual disability and are supported by a group of five or six Residential Care Officers (RCOs).

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[160]   Disability Services Queensland (2007) 'A guide to the *Disability Services Act 2006*: Safeguarding rights and improving services', Queensland Government, Brisbane, November, p.6.

Houses are generally rented either from public housing, the private market or through Disability Services Queensland-owned housing, and include approximately 221 shared or single houses, flats and units which accommodate approximately 580 people.[161]

6.3.3   South Australia

The South Australian Government, through the *State Strategic Plan,* is committed to expanding the supply of community-based accommodation for people with a disability. The *State Strategic Plan* states that by 2014 the SA Government aims to appropriately house and support double the number of people with a disability in community based accommodation.[162]

In 2006 the SA Government released the *Supported Accommodation Strategy* in order to improve supported accommodation options for people with a disability and their families. The strategy sits alongside the *Housing Plan for South Australia,* which aims to increase the supply of housing and accommodation opportunities for people including those with a disability.[163]

The strategy aims to improve the management, coordination, assessment and provision of supported accommodation to South Australians with a disability by creating:

▪   A single waiting list

▪   A single system of service coordination through Disability SA to help
        people navigate services

▪   A requirement for all service providers to meet service standards

▪   Services based on people's support needs, not diagnosis

▪   A new Accommodation Act to better ensure that all service providers meet
        acceptable standards (buildings, food services and support).[164]

The *Disability Services Act 1993* sets out the principles that are to be applied with respect to a person with a disability, provides for the funding of disability services, sets out objectives for providers of disability services and ensures that disability services are provided and carried out in a manner that applies those principles and meets those objectives.[165]

Disability SA provides three types of supported accommodation services to people with a disability. These are:

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[161]   Disability Services Queensland website. Accessed from
        <http://www.disability.qld.gov.au/support-services/dsq/als.html> on 20 November 2009.
[162]   South Australian Government. *State Strategic Plan,* Accessed from
        <http://saplan.org.au/content/view/100/test#d> on 1 November 2009.
[163]   Disability SA (2006) *Supported Accommodation Strategy.* Government of South Australia,
        December, p.15.
[164]   Disability SA, *Supported Accommodation Strategy*, p.6.
[165]   See the *Disability Services Act 1993(SA).* Accessed from
        <http://www.austlii.edu.au/au/legis/sa/consol_act/dsa1993213/s2.html> on 1 November
        2009.

- ▪   Campus-based residential care services

- ▪   Community group homes

- ▪   In-home support.

Access to government provided services is through referrals from Disability SA Regional Community Services to the Accommodation Placement Panel, with priority given to people in most urgent need.

Non-government operated supported accommodation services complement government services.

6.4   Mental health and supported accommodation policy in other states

This section provides an overview of supported accommodation policy and programs for people with a mental illness in New South Wales, Queensland and South Australia.

Mental health policy and plans in other jurisdictions indicate a commitment to increasing the range of accommodation and support options for people with a mental illness.

Like the former Housing and Support Program in Victoria, there are a number of accommodation and support models for people with a mental illness existing in other states that are successful and effective. Programs in NSW, Queensland and South Australia have been effective in enabling people to live in their own homes with support and in reducing the number of hospital admissions. These accommodation and support models are discussed below.

Table 6.4–1: CSTDA-funded residential service users with a psychiatric disability, by residential service type, states and territories, 2006-07

Service Type	Vic	NSW	Qld	SA
Large institutions	70	432	43	223
Small institutions	0	8	54	6
Hostels	38	22	0	13
Group homes	914	860	99	177
Total accommodation support	**1,022**	**1,322**	**196**	**419**

Notes:

Large institutions – provide 24 hour residential support in a setting of more than 20 beds

Small institutions – provide 24 hour residential support in a setting of 7 to 20 beds

Hostels – provide residential support in a setting of usually less than 20 beds and may or may not provide 24 hour residential support

Group homes – provide combined accommodation and community-based residential support to people in a residential setting and are generally staffed 24 hours a day. Usually, no more than 6 service users are located in any one home.

Source: AIHW (2009) *Mental Health Services in Australia 2006-07*. Canberra, 27 August, p.111.

6.4.1   New South Wales

In 2006, the NSW government released the five-year plan *NSW: A new direction for Mental Health*. The plan aims to achieve change in four areas. These are:

- Promotion prevention and early intervention across the lifespan

- Improving and integrating the care system

- Participation in the community and employment, including accommodation

- Better workforce capacity.

Under this plan, there has been an increase in funding to build specialist inpatient and community programs across the public and NGO mental health sectors with particular reference given to the Housing and Accommodation Support Initiative.

In 2007, the *Mental Health Act* was passed and maintains the same principles of the *Mental Health Act 1990*. Additional objectives were applied to the new Act with regard to the provision of care and treatment. These include:

- Care and treatment should be designed to assist people with a mental illness or mental disorder, wherever possible, to live, work and participate in the community

- Every effort that is reasonably practicable should be made to involve patients in the development of treatment plans and plans for ongoing care

- The role of carers for people with mental illness or disorder and their rights to be kept informed should be given effect.

Housing and Accommodation Support Initiative

In the Inquiry, participants drew the Committee's attention to the Housing and Accommodation Support Initiative (HASI) in NSW. HASI is a state government program that aims to improve housing stability and community participation for people with a mental illness, by means of community based accommodation and coordinated support services.[166] HASI provides support in three areas to people with a mental illness – housing, accommodation/disability and clinical. Community housing providers and the Department of Housing supply accommodation for clients. This housing is linked to clinical and disability support. Case managers in local area mental health services assist people clinically and three NGOs provide a range of psychosocial rehabilitation interventions that include domestic, emotional and community support.[167]

A number of organisations provided evidence to the Inquiry that highlighted the HASI model. The Office of the Public Advocate and Carers Victoria suggested

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[166]   Social Policy Research Centre (SPRC) (2006) *Housing and Accommodation Support Initiative*. New South Wales Health, Sydney, p.iii.

[167]   SPRC, *Housing and Accommodation Support Initiative*, p.3 [see Footnote 166].

that the HASI model is worth noting as it provides a level of tenure security and choice in housing to tenants.[168] The Mental Illness Fellowship stated that the HASI program has resulted in two significant improvements to people with a mental illness. More than two-thirds of the residents experienced improvements in their Global Assessment of Functioning Scores[169] and reduced frequency and duration in hospitalisation and emergency admissions related to their mental illness. There was also an improvement in community involvement and increased participation in employment, education and social networks.[170]

In a longitudinal evaluation of HASI, the Social Policy Research Centre maintains that:

> HASI mediates some of the effects of mental illness for many people in the program. It provides a networked system of support from housing providers, AMHS and NGO accommodation and community support providers. This enabled some people to maintain their tenancies, increase their participation in the community and develop and strengthen social and family networks.[171]

Both research and evidence received for this Inquiry recommend that the HASI model be considered as a worthy housing and support approach for people with a mental illness.

The NSW Ombudsman has reported on another NSW service for people with a mental illness, the Joint Guarantee of Service for People with Mental Health Problems (JGOS). The service was established in 1997 so that NSW Health and Housing NSW could collaborate to address accommodation and support needs for people with a mental illness.

In 2003, additional organisations became involved, including the NSW Aboriginal Housing Office.

The Ombudsman's investigation found that the program had not been successful due to the patchy and inconsistent implementation of the JGOS. The report suggests that the program did not meet the needs of people with a mental illness due to several weaknesses in the JGOS agreement and governance arrangements, including inconsistencies and a lack of accountability mechanisms and systems to support the effective implementation of the service.[172]

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[168]   *Submission* 100, p.25 (OPA); *Submission* 61, p.20 (Carers Victoria).

[169]   The Global Assessment of Functioning Scale is a standardised clinical scale that is used by clinicians to measure and monitor an individual's clinical level of functioning.

[170]   *Submission* 98, p.8 (Mental Illness Fellowship Victoria).

[171]   Muir, K. (2008) 'Housing Support for People with Mental Illness', *Social Policy Research Centre Newsletter.* No. 98, March, p.5.

[172]   NSW Ombudsman (2009) *The implementation of the Joint Guarantee of Service for People with Mental Health Problems and Disorders Living in Aboriginal, Community and Public Housing.* November, p.v.

Mr Bruce Barbour, the NSW Ombudsman, stated that a shortage of supported accommodation still exists for people with a mental illness who require support to live independently in the community in NSW.[173]

6.4.2 Queensland

Queensland Health delivers public mental health services in the 20 Queensland Health Districts. These services include specialised assessment, clinical treatment and rehabilitation services to people who experience severe forms of mental illness and behavioural disturbances and those who may fall under the provisions of the *Mental Health Act 2000*.

The *Mental Health Act 2000* replaces the *Mental Health Act 1974* and has been drafted to reflect contemporary clinical practice, international, national and state policy directions and broad community expectations. The Act contains provisions for initiating involuntary assessment, authorising involuntary treatment, independent review of involuntary treatment and patient rights. It provides processes for admission of mentally ill offenders from court or custody and decisions about criminal responsibility where the person has a mental illness or intellectual disability.[174]

The key policy document for mental health services in Queensland is the *Queensland Plan for Mental Health 2007-2017*. The plan outlines the Queensland Government's aim to reform and improve mental health services over a 10-year period. Under the plan, the Queensland Government commits to expanding the continuum of supported housing and accommodation available to individuals with a mental illness in the community.

The Resident Recovery program delivers services to people who have a moderate to severe mental illness and focus on empowering people with a mental illness to work towards recovery and independence within the community. The target group is adults over 18 years who are about to be discharged from inpatient mental health care to boarding house or hostel accommodation or who are being actively case-managed while living in a boarding house or hostel accommodation. Eligibility criteria include an individual agreement to fully participate in a recovery-based support program to work towards achieving their goals.

The support provided by the program is flexible and the duration and level of support depends on individual needs. The support is progressively decreased over time as recovery-goals are achieved.

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[173] AAP Australian General News (2009) 'Scheme to support mentally ill a failure, says Ombudsman'. *AAP News Wire*. Wednesday 11 November.

[174] Queensland Health website. Accessed from <http://www.health.qld.gov.au/mha2000> on 20 November 2009.

Project 300

Carers Victoria drew the Committee's attention to Project 300 in Queensland. Project 300 supports people with a psychiatric disability to transition from Queensland Health extended treatment facilities and integrate back into the community. This is achieved through a collaborative partnership between Disability Services Queensland, Queensland Health and the Department of Housing.

NGO service providers are funded by Disability Services Queensland to support people who have transitioned into the community.

The program acknowledges that people may need a range of supports during recovery and aims to provide support to strengthen people's capacity to adequately respond to planned and unplanned changes in their lives.[175]

People are able to receive support through Project 300 if they:

- Have a psychiatric disability
- Are aged between 18 and 65 years
- Are living in a Queensland Health extended treatment facility
- Want to live in the community with support
- Are assessed as able to leave the extended treatment facility.[176]

Carers Victoria told the Committee that the program provides long-term secure housing, a supportive landlord, clinical support, psychosocial rehabilitation, and a 'joined up approach' to link all functions of the program.[177] While people involved in Project 300 experienced favourable outcomes in maintaining housing and reducing hospital admissions, Carers Victoria stated that social inclusion outcomes such as community and workforce participation were less favourable.[178]

In 2001, an evaluation of the project suggested that the mental health of people involved in the project had improved. It found that after 18 months, only three of the 213 people discharged had returned to long-term care. After seven years, only 13 people out of 181 studied were re-admitted to long-term care. [179]

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[175] Disability Services Queensland website. Accessed from <http://disability.qld.gov.au/support-services/mental-health/project-300/> on 20 November 2009.

[176] Disability Services Queensland website [see Footnote 175].

[177] *Submission* 61, pp.20-21, (Carers Victoria).

[178] *Submission* 61, pp.20-21, (Carers Victoria).

[179] Meehan, T. O'Rourke, P. & Drake, S. (2001) *Final Report Project 300 Evaluation December 2000*. Queensland Health, Brisbane, p.26.

6.4.3   South Australia

The Mental Health Unit of the Department of Health is responsible for policy development, facilities planning, and advancing mental health reform throughout the state.

The Department of Health has released a draft of South Australia's *Mental Health and Wellbeing Policy 2009-2014*. With particular relevance to supported accommodation, the policy identifies the implementation of a stepped system of care in order to provide integrated, recovery-oriented mental health care in line with consumer needs. This will be carried out by:

- Increasing the number of supported accommodation places available
- Developing Community Rehabilitation Centres for support rehabilitation and recovery
- Investing in facility and non-facility based intermediate care
- Ensuring best possible acute hospital and secure care.[180]

In June 2009, the Mental Health Bill 2009 was assented to as an Act by the Governor in Executive Council. The Act will be proclaimed on 1 July 2010. The *Mental Health Act 2009* provides a new legislative framework that more explicitly articulates the rights of people with a mental illness and aims to facilitate their recovery and participation in community life.

The Act introduces into South Australian legislation for the first time:

- The concept of recovery
- A definition of 'relative' that accommodates the kinship rules of Aboriginal and Torres Strait Islander people
- Provision to work collaboratively with traditional healers.[181]

Housing and Accommodation Support Partnership

The South Australian Government initiative, the Housing and Accommodation Support Partnership program, is being developed to increase supported accommodation places for people with a mental illness through partnerships between SA Health and the non-government sector. The program is a partnership between not-for-profit housing providers, not-for-profit mental health support providers, and clinical mental health services, to provide additional supported accommodation in metropolitan Adelaide.[182]

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[180]   Mental Health Unit. *Draft South Australia's Mental Health and Wellbeing Policy 2009-2014*. South Australian Government Department of Health, p.9.

[181]   SA Health (2009) *Information Bulletin No. 1: Mental Health Act 2009*. Government of South Australia, Adelaide.

[182]   SA Health website. Accessed from <http://www.health.sa.gov.au/ mentalhealth/Default.aspx?tabid=119> on 1 November 2009.

The program is part of the Stepping Up reform of the mental health sector. The main objective of the partnership program is to support the accommodation of people in long-term safe, secure, and affordable housing with appropriate support so they can improve their skills and capacity to live independently in the community.[183]

The program will provide accommodation and psychosocial rehabilitation and support services which will be delivered by organisations experienced in working with people with severe and enduring psychiatric disability. Non-clinical support may be provided up to 24 hours a day, depending on individual needs. Public mental health services will provide clinical support.

A recent media report suggests, however, that South Australia requires at least 1000 more mental health facilities in order to provide appropriate accommodation and support to people with a mental illness.[184]

The table below provides information regarding the number of people with a mental illness accessing CSTDA funded residential services in specific states.

6.5   Comparing Victoria

The discussion above regarding disability and mental health service provision in different jurisdictions shows that states in Australia are at different stages of developing and providing accommodation and support in the community for people with a disability and/or mental illness. Some states, such as New South Wales and South Australia, have been slow to move people with a disability and/or mental illness from institutional care to community accommodation in comparison with Victoria.

It is also evident that policy development in each state is at different junctures and developing slower with regard to the aims and vision of supported accommodation for people with a disability and/or mental illness. In comparison with the states discussed above, the evidence suggests that Victoria's policies relating to disability and mental illness services have progressed ahead of other states.   Clearly all states are moving towards a stronger focus on rights and person-centred approaches and are aiming to provide greater opportunities for recovery for people with a mental illness.

The Committee heard that other states are developing new and innovative services and programs. Evaluations of some of these programs demonstrate beneficial outcomes for people with a disability and/or mental illness. The HASI program in New South Wales, for example, provides security and choice in housing for people and improvements in the lives of people with a mental illness. Similarly, the collaborative partnership program, Project 300 in

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[183]   SA Health website [see Footnote 182].

[184]   Shepherd, T. (2009) '1000 new mental health premises needed'. *The Advertiser,* Wednesday 11 November, p.10.

Queensland, has provided a recovery based approach to people with a mental illness through flexible accommodation and support.

The evidence indicates, therefore, that a number of accommodation and support programs provided in other states have proved successful in ensuring that people with a disability and/or mental illness are able to access accommodation and support options that enable them to live in the community.

It is evident from the above discussion, however, that all states struggle with the challenges associated with meeting levels of demand and need with regard to the provision of supported accommodation.

Recommendation

6.1   That the Victorian Government examines innovative and best practice models operating in other jurisdictions and determines whether they can be made operational and add diversity to supported accommodation options in Victoria.

Part C:

Experiences & Perspectives

Chapter Seven: Experiences of supported accommodation – disability services

Committee findings

- That there is support for new developments in service direction outlined in the State Disability Plan, 2002-12. **(Section 7.1)**

- That expectations of the Victorian Government have increased regarding the delivery of supported accommodation for people with a disability. **(Section 7.1)**

- That two broad models of disability support have evolved for people with a disability – shared supported accommodation (SSA) and an emerging alternative, individual support packages (ISPs). **(Section 7.1)**

- That the model of SSA remains a preferred option for some people with a disability and their families or other carers. **(Section 7.2.1)**

- That the level of demand for SSA exceeds the level of service availability. **(Section 7.2.1)**

- That ISPs represent an emerging alternative option to supported accommodation. **(Section 7.2.2)**

- The Committee heard that there is broad support for the model of ISPs as an alternative to SSA for some families providing accommodation for people with a disability **(Section 7.2.2)**

- That there is concern regarding the level of availability of ISPs and their capacity to meet demand. **(Section 7.2.2)**

- That the further development of ISPs cannot occur in isolation from the accommodation needs of people with a disability. **(Section 7.2.2)**

- That the SSA has traditionally focused on responding to the needs of people with an intellectual disability. **(Section 7.3)**

- That the disability support sector faces challenges in meeting high, complex and changing needs in SSA. **(Section 7.3)**

- That ISPs tend to meet the needs of people with low support needs. **(Section 7.3)**

- That different disabilities often require specialist responses associated with the disability in ways that complement person-centred approaches. **(Section 7.4)**

- That disability is understood differently in indigenous communities and there is potentially significant levels of unmet need. **(Section 7.5)**

- That people with a disability from culturally diverse backgrounds potentially do not access the service system to the extent they need. **(Section 7.6)**

- That there is an uneven dispersal of SSA across the state that leaves gaps in some rural and regional areas. **(Section 7.7)**

T his chapter examines and reports on the findings of evidence provided to the Committee regarding the adequacy and range of supported accommodation services in Victoria for people with a disability. It also considers the response to new directions the Victorian Government is pursuing in the disability sector that emphasise self-directed and person-centred approaches. These changes are not only related to supported accommodation but also to individual support packages, which are emerging as an alternative to shared supported accommodation.

In the Inquiry, participants expressed support for new directions, but also highlighted concerns relating to the level of availability of current services. The Committee also found that since the expansion of eligibility for disability services, the nature of need in disability services has broadened, presenting new challenges. The Victorian Government has initiated a number of new developments to address these issues, yet Inquiry participants were not always familiar with these. In addition, some uncertainty was expressed regarding the Victorian Government's capacity to deliver due to resource constraints.

7.1   New service directions

As highlighted throughout this report, since 2002 the approach to the provision of disability support services in Victoria has undergone significant change underpinned by the *State Disability Plan, 2002-12.* The Victorian Government has ambitious objectives in its commitment to re-orient disability services and to achieve its vision for Victoria to be

> a place where diversity is embraced and celebrated, and where everyone has the same opportunities to participate in the life of the community, and the same responsibilities towards society as all other citizens of Victoria.[185]

The Plan states that to achieve this vision a key objective of Disability Services Division (DSD) is to 'reorient disability supports so that they are more responsive and more focussed on people's individual needs and choices, and to the needs of their families and carers'.[186] Many individuals and organisations expressed support for the developments and new directions outlined in the *State Disability Plan.*[187] Furthermore, expectations of what the Victorian Government will deliver in regard to services have increased to equal its large-scale objectives.

Both the State Disability Plan and the *Disability Act 2006* provide the foundations for the change agenda that is currently re-directing the way

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[185]   Department of Human Services (DHS) (2002) '*Victorian State Disability Plan, 2002-12.* Disability Services Division, DHS, Victorian Government, Melbourne, p.5.

[186]   DHS, *Victorian State Disability Plan, 2002-12*, p.9.

[187]   For example, see *Committee Transcript*, 21.10.08, p.8 (Gippsland Carers Association); *Committee Transcript*, 23.10.08, p.10 (Barwon disAbility Resource Council); *Committee Transcript*, 5.11.08, pp.4-5 (NDS); *Committee Transcript*, 6.11.08, p.3 (Sunraysia Residential Services); *Committee Transcript*, 18.11.08, p.3 (Goulburn Valley Centre Disability Services).

disability support and accommodation is provided. In 2002, the *State Disability Plan* stated that it 'outlines a new approach to disability', and that it is 'the first disability plan in the history of Victoria… to address the needs of people with a range of different types of disabilities; that is, people with intellectual, physical and sensory disabilities, acquired brain injury, and neurological impairments.'[188]

This, in turn, has led the Victorian Government to reach the view that 'the emphasis on the CRU [community residential unit] has meant that there have been limited opportunities for alternative, flexible housing and support arrangements for people with a disability'.[189] In addressing these limited opportunities, the Victorian Government states that it has 'taken steps towards the provision of a more flexible support system through expansion or introduction of a range of individual support packages, including Support & Choice'.[190]

From its perspective, the Victorian Government sees its key challenge as being to 'assist people with a disability who do not currently have suitable or preferred housing, to locate and receive their support in their own accommodation'.[191] The Executive Director of Disability Services Division, Mr Arthur Rogers, confirms this, stating that 'the biggest service movement direction in terms of policy is towards self-directed individual support. Quite a high proportion of new funding in the last few years has been moved to that area to provide a different balance in the service system'.[192]

A key outcome of these new directions is that two broad models have evolved in the disability support sector:

- Traditional supported accommodation – when people with a disability live in specialist accommodation facilities (either residential care or shared supported accommodation, previously known as community residential units or CRUs)

- Individual support packages (ISPs), which represent an alternative to shared supported accommodation (SSA) with an increased focus on in-home support or support to live independently in the community. This involves people with a disability making an application to receive an individualised support package that enables them to secure the appropriate supports for their individual needs.

The evidence received by the Committee revealed support for both SSA and ISPs, which are both considered critical components of the services provided by the disability sector.

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[188] DHS, *Victorian State Disability Plan, 2002-12*, p.1.

[189] Department of Human Services (DHS) (2006) *Future directions for housing and support in Disability Services.* Disability Services Division, DHS, Victorian Government, Melbourne, p.1.

[190] DHS, *Future directions for housing and support in Disability Services*, p.2.

[191] DHS, *Future directions for housing and support in Disability Services*, p.2.

[192] *Committee Transcript*, 10.12.08, p.3 (A. Rogers, DHS).

SSA can be in small group homes of less than five residents or large group homes of more than five residents. The majority of facilities in Victoria are small group homes. DSD advised the Committee that at the end of August 2008 there were 905 small group homes and 17 large group homes. There remained three congregate care facilities.

The nature of support provided in SSA differs from that provided through ISPs. Support services within SSA are linked to the accommodation facility. According to the DSD Policy & Funding Plan in 2008-09, 'these supports are not attached to, or transferable with, any individual'.[193]

ISPs, on the other hand, provide options for individuals to direct the planning process and make their own choices about supports. People with a disability living in SSA are not eligible for individualised funding packages. The Committee heard that support in SSA is often provided in a group model.[194]

The *Disability Act 2006* provides new guiding principles for planning within SSA that requires it to be person centred. As will be discussed in Chapter Nine, however, service providers expressed some concerns regarding their ability to deliver person-centred approaches within SSA in view of staffing levels and workforce capacity.

In view of the changing paradigms within the disability sector regarding provision of support and accommodation options, the Committee has considered both SSA and ISPs in its inquiry into the adequacy, range and standard of supported accommodation in Victoria for people with a disability. As the Executive Director of Disability Services Division, Mr Arthur Rogers advised the Committee, 'individual support does actually provide support to people to maintain sustainable tenancies or sustainable living arrangements in different forms of accommodation'.[195]

7.2   Level of service availability

While participants expressed support for the SSA model, the Committee heard that there is a shortage of services to meet the levels of demand in the SSA sector. In addition, many suggested that concern is emerging that ISPs will not have the capacity to meet the levels of demand. The Committee found that frustration with service availability was often redirected towards the prioritising process introduced with the Disability Support Register (DSR). These three issues are outlined in this section.

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[193]   Department of Human Services. *Disability Services Policy and Funding Plan: 2008-09 Annual Update*, p.139. Accessed from <<http://www.dhs.vic.gov.au/policyplans.htm> on 9 September 2009.

[194]   For example, see *Committee Transcript*, 22.10.08, (Kew Cottages Parents Association); *Committee Transcript*, 5.11.08, (NDS); *Committee Transcript*, 20.11.08 (H. & T. Tregale).

[195]   *Committee Transcript*, 10.12.08, p.3 (A. Rogers, DHS).

The role of families in caring relationships is also critical to understanding ISPs and SSA. This is explored further in Chapter Ten.

7.2.1 Shared supported accommodation

The Committee heard that SSA remains a preferred model of support for many in the disability sector. In particular, due to the lack of alternatives when a person with a disability has high, changing and/or complex needs, SSA is seen to provide the levels of staffing and support that cannot be accessed in the community. Sunraysia Residential Services, for example, suggested that 'for some families the CRU model is what they want',[196] and Yooralla stated that:

> For many people, the traditional shared supported accommodation model is still a service of clear preference. If we accept that people need to have the right to choose the service option of their choice and the style of service they would like, then we have to respect that choice.[197]

The self-advocacy network comprising the organisations STAR, VALID, Reinforce and AMIDA state that 'shared supported accommodation is not a defunct model but one that holds significantly more potential than is currently realised in Victoria'.[198]

Throughout its consultations with the public, the Committee heard the view of participants that there is not enough SSA to meet the demand of people with a disability seeking such accommodation.[199] HACSU captured this view in the evidence it provided:

> In the last five years there has been no funding allocated to increase community residential unit stock, which continues to be identified by families as their preferred option, particularly where clients have ageing parents.[200]

In its 2009 price review of out of home disability services, PricewaterhouseCoopers (PwC) noted that 'there has been no change and growth in the SSA budget base beyond indexation since the number of SSA places was capped in 2003/04, with the introduction of Support and Choice initiatives and community housing options'.[201]

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[196]   *Committee Transcript*, 6.11.08, p.7 (Sunraysia).

[197]   *Committee Transcript*, 22.10.08, pp.3-4 (Yooralla).

[198]   *Submission* 106, p.17 (STAR-VALID-Reinforce-AMIDA).

[199]   For example, see *Submissions* 10, p.1 (A. Read); 21, p.3 (P & K Moate); 35, p.2 (U. Harrington); 36. p.1 (Southern Way Direct Care Services); 45, p.1 (Gellibrand Residential Services); 49, p.1 (MacKillop Family Services); 66, p.1 (East Gippsland Shire Council); 73. p.1 (Name withheld); 74, p.2 (VDAC); 78, p.9 (M. Jackson); 96, p.3 (VCOSS); 97, p.6 (Scope); 100, p.13 (OPA).

[200]   *Committee Transcript*, 5.11.08, p.7 (HACSU).

[201]   PricewaterhouseCoopers (2009) 'Department of Human Services; Price Review Out of Home Disability Services Final Report'. Accessed from <http://www.dhs.vic.gov.au/disability/improving_supports /industryplan/pwc> on 20 October 2009, p.28.

In its evidence to the Committee, National Disability Services (NDS) drew attention to the pressure on ageing parents in caring relationships, noting that as the population ages, the capacity of family members to provide support will diminish. NDS acknowledged the recent Federal Government's Disability Assistance Package, but expressed its view that this is unlikely to resolve the problem of the shortage of accommodation.[202]

The Committee heard that the Disability Assistance Package will create 100 new supported accommodation places for individuals with a disability being cared for by older people, most commonly family members. Victoria received $24.58 million in Commonwealth capital funding for 70 accommodation places and the Victorian Government has added an additional funding for 30 beds under this initiative. The Committee was advised that these places will be built by June 2011.

In addition, the Commonwealth and State have provided joint funding of $60.5 million over five years for supported accommodation through the *my future, my choice* initiative. A total of 22 new service developments will be established under the *my future, my choice* initiative, providing accommodation and support for about 100 younger people living in, or at risk of entry to, residential aged care. This includes the first home for six younger people with acquired brain injury that opened in Balwyn in 2008. The remaining 21 houses and unit developments are at various stages of design and construction.

The Committee was also advised by the Victorian Government that 45 innovated housing options are being developed that will provide intensive support to residents and are an alternative to residential places. These places are not categorised under the SSA area.

In addition, the Victorian Government has also committed $15 million to refurbish existing SSA stock. The Committee was advised that 105 group homes will have been replaced with modern, purpose-built facilities by the end of 2011.

Table 7.2.1–1: Number of additional accommodation places at construction, design or planning stages, by DHS region, August 2009

Region	Shared Supported Accommodation	Innovative Accommodation	*my future, my choice*	Total Places
Metropolitan Areas				
Eastern Metropolitan	9	4	18	31
North & West Metropolitan	29	14	21	64
Southern Metropolitan	24	11	22	57
Regional Areas				
Barwon South Western	10	5	8	23
Gippsland	9	4	6	19
Grampians	5	1	4	10
Hume	5	2	6	13

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202   *Submission* 120, p4 (NDS).

Region	Shared Supported Accommodation	Innovative Accommodation	*my future, my choice*	Total Places
Loddon Mallee	9	4	5	18
State-wide[1]	0	0	10	10
Total	**100**	**45**	**100**	**245**

[1] Includes facilities which have places available for clients drawn from across the State.

Source: Victorian Government (2009) Supplementary data provided to Family & Community Development Committee.

Recommendations

7.1 That the Victorian Government invests in additional supported accommodation beds to meet current demand registered on the DSR.

7.2 That the Victorian Government increases the availability of SSA in line with population based trends informing the projected growth in numbers of people with a disability.

7.2.2 Individual Support Packages

While participants stressed the importance of SSA as an option, many also reflected positively on the new directions of person-centred support, and ISPs particularly. An ISP is an allocation of funding to a person with a disability that seeks to assist them to purchase supports that will best meet their ongoing disability support needs.

NDS indicated that there is widespread support across the disability support services sector for person-centred approaches to service delivery, despite some of the challenges that come with a new model of support provision.[203] For example, Barwon disAbility Resource Council expressed support for the new initiative of ISPs and suggested that there is scope for expanding the model to people outside disability services:

> Further work on this kind of initiative would result in better outcomes for people with disabilities and their families, with greater choices. This kind of initiative could be applied also to residents of SRSs [supported residential services], to perhaps make better and more appropriate accommodation available to those people.[204]

The Regional Information and Advocacy Council also expressed support for ISPs, noting that there is room for investing greater resources into making them more available:

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[203] *Committee Transcript*, 5.11.08, p.3 (NDS).

[204] *Committee Transcript*, 23.10.08, p.3 (Barwon disAbility Resource Council).

> Brilliant initiative but for everybody to actually truly have an individual plan, to truly have the choices, there probably needs to be a little bit more money out there for them to be able to do it. [205]

Similarly, Ms Sue Hermans, the Planning and Support Services Manager at Sunraysia Residential Services, reflected that 'on a personal and professional level I embrace this opportunity to see people as individuals and not block-fund huge amounts of money that is not necessarily devoted to the needs of an individual once planning is completed'.[206]

Despite the broad support for the concept of individualised support, some participants suggested to the Committee that there are limitations to the current model. In particular, concerns that limitations to the size of the packages have implications for the level of support a person with a disability can access to live independently in the community with support. In its submission, Yooralla made the following observation in regard to ISPs:

> We cannot disregard the fact that such 'individual packages' average a far lower level of funding than the average funding provided for accommodation. For many people, these packages are far from sufficient and rely substantially on informal supports such as family and carers that may not be available into the future, further fuelling current and future demand for shared supported accommodation.[207]

Service providers advised the Committee that despite the positive directions that individualised support appears to offer, it should not be considered a 'panacea'. Yooralla has cautioned against raising expectations that personal planning will resolve system issues when there is a general shortage of accommodation.[208] Karingal made a similar point, stating that 'the most aspirational and detailed plans are of little value without the resources necessary to implement them. Terms like "support" and "choice" can be very misleading. This initiative promised much, but packages have been limited and not large enough to meet the needs of recipients'.[209] Sunraysia Residential Services also expressed the need to exercise caution around managing expectations, stating that:

> The model of planning for individuals is a wonderful philosophy. The resources required for plans to be rolled out as they were written needs to be very seriously discussed so that people have got an idea of limitations when they are planning for the future.[210]

The Committee found that underlying many concerns relating to ISPs is the issue of access to accommodation. For ISPs to work effectively, a person with a disability needs access to adequate accommodation. The Committee heard that

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[205]   *Committee Transcript*, 18.11.08, p.8 (RIAC).

[206]   *Committee Transcript*, 6.11.08, p.3 (Sunraysia Residential Services).

[207]   *Submission* 77, p.2 (Yooralla).

[208]   *Committee Transcript*, 22.10.08, p.3 (Yooralla).

[209]   *Committee Transcript*, 23.10.08, p.7 (Karingal).

[210]   *Committee Transcript*, 6.11.08, p.3 (Sunraysia Residential Services).

in many instances, this accommodation is provided by families in caring relationships. At the same time, however, participants drew the Committee's attention to the reality that some people with a disability have no family or social support networks. For people in these circumstances, accessing adequate accommodation to enable them to receive an ISP is more challenging. Furthermore, the Committee recognises that this raises issues relating to the coordination of ISPs for people with no family or social support networks.

The Committee therefore found that the further development of ISPs must encompass the accommodation circumstances of people with a disability. Alternative accommodation options are discussed further in Chapter Twelve.

Recommendations

7.3 That the Victorian Government provides case coordination for people with a disability to link ISPs with appropriate accommodation options.

7.4 That the Victorian Government funds additional ISPs for allocation to people with a disability registered on the DSR.

7.5 That the Victorian Government develops a support framework to assist people with a disability to live independently from family in the community in their own accommodation.

7.3   Meeting high, complex and changing needs

In addition to concerns regarding the lack of availability of both SSA and ISPs, the Committee heard concerns about the inability of the disability support system to respond to the diverse needs of people with a disability, particularly those people with high, complex and changing needs. Those who provided evidence made frequent reference to the increasing complexity of the needs of people with a disability.[211] For example, Sunraysia Residential Services in Mildura told the Committee that 'the complexity of the needs that we are being asked to meet has in the last two years increased dramatically'.[212]

The issues raised were different for SSA than those raised in regard to ISPs. The Committee heard that ISPs tend to work effectively in meeting the needs of people with low support needs, yet don't cater well for people with high and complex needs. SSA, on the other hand, was often described as a form of accommodation for people with degrees of disability requiring more intense support. In view of changes to eligibility for SSA, outlined in Chapter Three, the Committee heard that services providing SSA do not always meet the needs of people with high, complex and changing needs.

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[211] For example, see *Committee Transcripts*, 22.10.08 (Kew Cottages Parents Association); 23.10.08 (Karingal); 23.10.08 (Gateways Support Services); 6.11.08 (Sunraysia Residential Services).

[212] *Committee Transcript*, 6.11.08, p.2 (Sunraysia Residential Services).

The nature of resident needs in SSA varies considerably. The Committee heard that services can experience capacity issues in responding to people with intense, complex and/or changing needs. Kew Cottages Parents Association, for example, explained that providers don't always have the capacity to respond to people with a 'severe or profound intellectual disability with attendant high support needs, challenging behaviour, complex medical conditions, psychiatric diagnoses or communication and/or decision-making impairments'.[213] Similarly, Karingal noted that 'we often find that there is an inadequate ability [amongst the staff] to respond to the complex health care relating to an individual's diagnosis within particular services'.[214] Similarly, the Acting CEO of Goulburn Valley Centre Disability Services, John Clements, explained that:

> People with more complex needs are now presenting for support accommodation placement and require more medical model rather than a basic care model of service. Staff do not have the skills necessary to provide the level of care required and the rate of pay does not attract nursing staff and therefore the level of care sometimes is inadequate.[215]

The Committee heard that the expansion of disability support services to provide support to people with a disability other than an intellectual disability has been well received by many. The reality, however, is that different disabilities present with a range of different issues that require diverse expertise and skill sets. The evidence heard by the Committee relating to the diversity of needs associated with different disabilities is discussed below.

One possible development that might be considered in Victoria is to introduce the nurse practitioner (NP) model into the disability sector to respond to complex and changing health needs of people with a disability. Victoria was one of the first states in Australia to introduce the NP role and the Victorian Government has been supporting the development and implementation of the NP role since 1998. A nurse practitioner is a registered nurse educated and authorised to function autonomously and collaboratively in an advanced and extended clinical role. The NP role includes assessment and management of clients using nursing knowledge and skills and may include, but is not limited to, the direct referral of patients to other health care professionals, prescribing medications and ordering diagnostic investigations. NPs have been introduced into a range of sectors in Victoria such as palliative care and stroke care. More recently, proposed models have been either funded or further researched in mental health, alcohol and other drugs and oncology services.[216]

It is noteworthy that the issues raised by participants in this Inquiry have been acknowledged in previous reviews. The Victorian Auditor-General commented on capacity issues in the system in meeting diverse, individual needs, noting that

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213   *Committee Transcript*, 22.10.08, p.2 (Kew Cottages Parents Association).
214   *Committee Transcript*, 23.10.08, p.5 (Karingal).
215   *Committee Transcript*, 18.11.08, p.2 (GV Centre Disability Services).
216   See Department of Health website. *Nursing in Victoria: Nurse Practitioner*. Accessed from
       <http://www.health.vic.gov.au/nursing/furthering/practitioner> on 26 November 2009.

'DHS does not have a suite of alternatives to deal with the complexity of people's individual circumstances',[217] suggesting that resourcing was not adequate to provide the person-centred responses the service system aspires to achieve. Since the Auditor-General's report into supported accommodation for people with a disability, the Victorian Government has allocated $3 million to disability service providers to assist them to transition to more individualised support and flexible service models.

As noted in Chapter Two, many service providers are increasingly confronted with greater complexity of needs. Gateways Support Services, for example, revealed that 'in general the people we support have quite complex needs: 55 per cent of our residents have behavioural needs; 30 per cent have autism; 30 per cent have complex physical needs; and 50 per cent have complex medical needs.'[218] Sunraysia Residential Services told the Committee that it is supporting at least four people with a disability who meet the criteria for the Multiple and Complex Needs (MACN) program, but that they are unable to access the program for these people.

The Victorian Government has acknowledged the issues relating to multiple and complex needs and has initiated programs to respond to these. In the disability sector, regionally based behavioural intervention support (BIS) teams are funded to provide a range of specialist intervention services to individuals displaying behaviours of concern, such as severely aggressive, self-injurious or anti-social or withdrawn behaviours. BIS teams consist of a small team of professionals who have experience in behaviour management. They work with disability providers and people with a disability and their families or other carers around particular treatment and interventions programs. The teams aim to help people manage behaviours of concern so they can live sustainability in a home or in SSA. The Committee heard from participants that there are not enough BIS teams available to meet demand.

The MACN program mentioned above is an additional program for people with multiple and complex needs. It aims to promote collaborative cross-program planning and support at the local level to improve individual outcomes wherever possible. In addition, it provides a specialist intervention for 50 new referrals each year that aims to:

- Pursue planned and consistent therapeutic goals for each person
- Provide a platform for long-term engagement in the service system
- Stabilise accommodation, health, social connection and safety issues.

To be eligible for the MACN program under the *Human Services (Complex Needs) Act 2009*, a person (over 16 years) must

- Have a combination of two or more of the following:

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[217] Victorian Auditor-General (2008) *Accommodation for People with a Disability*. Victorian Auditor-General's Office, Melbourne, March, p.47.

[218] *Committee Transcript*, 23.10.08, p.2 (Gateways Support Services).

1.   a mental disorder within the meaning of the *Mental Health Act 1986*;

2.   an acquired brain injury;

3.   an intellectual impairment;

4.   or be an alcoholic or drug-dependent person within the meaning of the *Alcoholics and Drug-dependent Persons Act 1968*; and

- Have shown violent and dangerous behaviour that has caused serious harm to themselves or others, or show behaviour which is reasonably likely to place them or another person at risk of serious harm; and

- Be in need of intensive supervision and support, and would derive benefit from receiving coordinated services in accordance with a care plan (including, welfare, health, mental health, disability, drug and alcohol treatment or housing and support services).

The Committee heard that while the MACN program has had success in responding to people with multiple and complex needs, it is difficult to gain access to the program. The Office of the Public Advocate (OPA) recommended to the Committee that the program needed to be expanded. As this section and later chapters note, however, individual service systems need to improve their capacity to respond to complex and emerging need through workforce capacity building and restructuring. The purpose of the MACN program reiterates this, stating explicitly that it aims to complement, not replace, existing services or systems of support for individuals with multiple and complex needs.

Recommendations

7.6   That the Victorian Government creates support and coordination packages that meet the specific needs of people in the disability service system with complex needs.

7.7   That the Victorian Government introduces multidisciplinary staff teams in shared supported accommodation with the capacity to meet the needs of people with complex, changing and high needs.

7.8   That the Victorian Government introduces a nurse practitioner model in shared supported accommodation to meet the health needs of people with high and complex medical requirements.

7.9   That the Victorian Government expands the Multiple and Complex Needs program to enable greater access for people with a disability and/or mental illness who require complex and intensive case management.

7.4   Specific disabilities, specific needs

The new *Disability Act 2006* has been developed to create greater opportunities for people with a diverse range of disabilities beyond intellectual disability. The

Committee supports the Victorian Government's intentions to make disability services more widely accessible to people with a range of disabilities.

This represents a significant shift in service approach to people with a disability. A key strategy in responding to this greater range of disability has been the introduction of person-centred approaches. The Committee found, however, that while person-centred approaches are a positive development, there is value in considering the specific needs associated with disability type. Participants told the Committee that service responses need to be developed in ways that enable person-centred approaches to complement disability-specific knowledge.

While the following sections discuss some specific aspects and types of disabilities, the Committee notes that these do not comprise all disabilities.

7.4.1   Ageing and early onset dementia

The Committee heard that there are specific support and accommodation issues experienced by people with a disability who are ageing. Australian policy in the aged care sector has tended to reflect the centrality of the concept of 'ageing in place'. Ageing in place relates to opportunities for people to remain in their own home regardless of increasing care needs.[219] In the context of disability services, researcher Christine Bigby suggests that ageing in place for people with a disability will require financial resources, an adaptable environment and proximity of health services.[220]

In the disability sector, the CSTDA has emphasised the need to strengthen access to generic services and cross-government linkages for people with disability. However, the National Strategy for an Ageing Australia has noted that people ageing with life-long disabilities face difficulties in obtaining the level and type of services they need. The Strategy suggests special arrangements would be required to meet the needs of this group.

According to Victorian policy statements, however, where a person's support needs change to such an extent that his or her existing SSA service 'can no longer provide adequate support within existing resources, there may be a requirement to move to another service'.[221] A network of disability self-advocates, STAR-VALID-Reinforce-AMIDA, advised that Victoria has work to undertake in developing and implementing a policy to support ageing in place for the disability sector. The network also suggested that funding be adaptable to take account of changing needs as residents in SSA age.[222] The submission

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[219]   Bigby, C. (2008) 'Beset by obstacles: A review of Australian policy development to support ageing in place for people with intellectual disability. *Journal of Intellectual and Developmental Disability,* Vol. 33(1), March, p.77.

[220]   Bigby, 'Beset by obstacles' [see Footnote 219].

[221]   Department of Human Services (2006) *Vacancy coordination policy and practice: Guidelines for shared supported accommodation.* DHS Disability Services, Melbourne.

[222]   *Submission* 106, p.27 (STAR-VALID-Reinforce-AMIDA).

states that moving to other services may mean relocation from the local community, and a loss of natural support networks.

The network of disability self-advocates draws particular attention to the need to distinguish between age-related and disability-related needs, and the issues surrounding provision of services to people with an intellectual disability who are ageing, whose needs reflect a complex combination of disability and age-related changes.[223] In its submission, STAR-VALID-Reinforce-AMIDA expressed the view that neither the disability sector nor the aged care sector in Victoria adequately addresses the needs of older people with an intellectual disability.[224]

The network also suggests that some people with an intellectual disability may be unable to access accommodation support and consequently move into residential aged care. From the perspective of these organisations, nursing homes are highly restrictive forms of accommodation, and can be inappropriate for many people with an intellectual disability. The network highlights the particular problems faced by 'younger old people' (ie those less than 65 years) with an intellectual disability, who are inappropriately placed in residential aged care.[225] Being younger than other residents, they can have difficulty forming relationships with other residents and participating in activity programs. A further problem is that residential aged-care staff often lack the expertise to support people with an intellectual disability. This highlights the need for greater awareness of the needs of people with a disability in the aged-care sector.[226]

A particular issue experienced by people with a disability who are ageing is early onset dementia. Early onset dementia is a term used to describe people under the age of 65 with any form of dementia, which includes a range of diseases affecting memory and thinking in people. Research suggests that dementia is significantly higher for adults with Down's Syndrome than for other adults.[227] Early onset dementia is also prevalent among adults with an intellectual disability, due to the premature ageing that occurs in this population group. Subsequently, younger people with a disability and dementia have unique and complex issues in terms of accessing appropriate services that meet their needs. This includes appropriate support and accommodation.[228]

A report by Alzheimer's Australia states that young people with a disability and early onset dementia can experience difficulty in accessing health and disability sectors.[229] Goulburn Valley Centre Disability Services reiterated this point, with

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[223]   Bigby, 'Beset by obstacles', p.76 [see Footnote 219].

[224]   *Submission* 106, p.27 (STAR-VALID-Reinforce-AMIDA).

[225]   *Submission* 106, p.27 (STAR-VALID-Reinforce-AMIDA).

[226]   Bigby, 'Beset by obstacles', pp.76-86 [see Footnote 219].

[227]   Alzheimer's Australia. (2007) *Exploring the Needs of Younger People with Dementia in Australia*, p.55. Accessed from <http://www.alzheimers.org.au/upload/YoungerOnset.pdf> in March 2009.

[228]   Alzheimer's Australia, *Exploring the Needs of Younger People with Dementia in Australia*, p.4.

[229]   Alzheimer's Australia, *Exploring the Needs of Younger People with Dementia in Australia*, p.5.

specific reference to health and accommodation needs, and the issue of early onset dementia for people with Down's Syndrome:

> As the age of people with a disability has increased, the instance of early onset dementia has increased among people with Down Syndrome. What was previously a very suitable accommodation placement can quickly become inadequate and the level of care required to keep these people healthy and safe [changes].[230]

In research on issues for people with a disability who are ageing, Christine Bigby states that the issues for individuals with a disability and dementia are complex:

> The issues for this group extend beyond just having a place to live, to a lack of choice or control over housing and support options. They arise from the inherent need for people with ID [intellectual disability] for support as well as housing, their pattern of support and housing in young adulthood, the high level of unmet need for accommodation services, and the unresolved tensions of the interface between disability and aged care service systems.[231]

She goes on to highlight the importance of partnerships between the disability and aged care systems. Currently the support required by people with a disability who are ageing or who have early onset dementia comes from disability service providers with limited resources and expertise.[232]

The Committee found, therefore, that there is a need for further policy development relating to the needs of people with a disability who are ageing, particularly in the context of age-related disabilities that are more prevalent for those with an intellectual disability. The Committee is aware that the Victorian Government is currently developing an Ageing in Victoria strategy. The discussion paper released in May 2008, however, does not demonstrate that older people with a lifelong disability will be given specific attention in this policy.

At the Commonwealth level, the Senate Standing Committee on Community Affairs is undertaking an Inquiry into Planning Options and Services for People Ageing with a Disability. The Committee is due to table its report on 2 September 2010.

Recommendations

7.10   That the Victorian Government develops a strategy for the provision of supported accommodation for older people with a disability to avoid premature and inappropriate admission to residential aged care.

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230   *Committee Transcript*, 18.11.08, p.2 (GV Centre Disability Services).
231   Bigby, 'Beset by obstacles', p.77 [see Footnote 219].
232   Bigby, 'Beset by obstacles', p.78 [see Footnote 219].

Recommendations

7.11   That the Victorian Government works with the Commonwealth to develop the capacity of geriatric and aged care services to respond to the needs of older people with a lifelong disability to promote 'ageing in place'.

7.12   That the Victorian Government's Ageing in Victoria strategy gives specific attention to the needs of older Victorians with a lifelong disability and the service responses required.

7.13   That the Victorian Government builds partnership across disability support services and aged care services to improve responses to people with a disability who are ageing.

7.14   That the Victorian Government invests in specific individual support packages for people with a disability who want to age in place in shared supported accommodation.

7.4.2   Acquired Brain Injury

The Committee heard that the experiences of people with an acquired brain injury (ABI) are distinct and lead to supported accommodation requirements that are not always available in traditional SSA models.

ABI generally refers to disability arising from any damage to the brain occurring after birth. The causes can vary, including trauma (such as traffic accidents or blows to the head), hypoxia (lack of oxygen), infection, substance abuse or degenerative neurological disease. Occasionally brain injury acquired at birth is also included in the scope of ABI, however where brain injury is acquired before, during or shortly after birth, service providers and representative organisations tend to regard this as falling within intellectual disability.[233] The AIHW reports that causes of ABI also increase in prevalence among older people. For example, stroke, Parkinson's disease, dementia, neurodegenerative conditions, alcohol-related brain injury and falls may be age-related causes of ABI.[234]

The consequences of ABI for individuals can also be varied and complex. Physical effects range from headaches, to visual or hearing disturbance, chronic pain, seizures or paralysis. Cognitive effects may range from poor memory and concentration, reduced planning, information processing or problem solving abilities, or a person may have psychosocial/emotional and behavioural problems. ABI may therefore impact on an individual's relationships and everyday activities, resulting in a variety of temporary or permanent restrictions on their ability to participate fully in education, employment and other aspects

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[233]   Australian Institute of Health and Welfare (AIHW) (2007) 'Disability in Australia: acquired brain injury'. *Bulletin 55*, Cat. no. Aus 96, AIHW, Canberra.

[234]   AIHW, 'Disability in Australia', p.15 [see Footnote 233].

of life. Furthermore, people with ABI will often have multiple disabilities, which may or may not be related to the person's ABI.[235]

In 2001, the Victorian Government launched an *ABI Strategic Plan* detailing the direction for the provision of ABI services and a range of initiatives, and acknowledging the complex and diverse needs of people with ABI. The plan integrated and coordinated services for people with an ABI, their families and carers. The relationship of the *ABI Strategic Plan* to the *Disability Act 2006*, however, is unclear.

The inclusion of ABI in the *Disability Act 2006* entitles individuals with an ABI to access support systems in the same way as other individuals with a disability. Participants highlighted the value in providing responses that are specific to ABI. Karingal, for example, suggests that 'transitional community accommodation facilities, [and] live-in, slow-stream rehabilitation facilities are also needed in the area of acquired brain injury'.[236] The organisation also told the Committee, however, that:

> people with acquired brain injury are not getting past the intake and response points. If they need case management, they are not getting past intake and response to get to case management. That is still very intellectual disability focused in this particular region, and hopefully that will change.[237]

Furthermore, people with an ABI do not have equitable access to services. Access to services often depends on the nature of the injury acquired.

Separate service systems have developed for those with ABI in Victoria, according to whether individuals are 'compensable' or 'non-compensable'. Compensable individuals are those whose ABI was the result of a road traffic or work related accident and who receive funding from the Victorian Transport Accident Commission (TAC) or Victorian WorkCover Authority (VWA) as a consequence. Non-compensable individuals are those whose ABI was the result of some other trauma or condition. They will not be eligible for TAC or VWA funding.[238]

Compensable individuals tend to have access to higher levels of funding and are often provided with a greater range of accommodation and support choices. Legislative requirements determine the allocation of funding to each individual recipient, rather than to a service operator, and compensating bodies must meet the lifetime care and support needs of the person.[239]

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235   AIHW, 'Disability in Australia', p.15 [see Footnote 233].

236   *Committee Transcript*, 23.10.08, p.7 (Karingal).

237   *Committee Transcript*, 23.10.08, p.6 (Karingal).

238   Victorian Coalition of ABI Service Providers (VCASP) (2007) *Final Report of Accommodation Project*, p.14. Accessed from <http://www.vcasp.org.au/site/items/2009/05/88761-upload-00006.pdf> on 30 July 2009.

239   VCASP, *Final Report of Accommodation Project* [see Footnote 238].

Non-compensable clients may be eligible to access a range of government funded support packages or programs. These include

- ABI Slow To Recover (STR)

- Home First Program

- *my future, my choice*

- ABI Assisted Community Living (ACL)

- Home and Community Care (HACC)

- Support and Choice Program, Linkages

- Victorian Aids and Equipment Program

- Disability Services Flexible Support options.

However, the Melbourne City Mission submission suggests there is a disjointed system regarding accommodation vacancies for people with ABI across private, Disability Services funded and Community Housing options and a disconnect between this housing and provision of support.[240]

The ABI Slow to Recover (STR) program, for example, provides case management and brokerage assistance to enable people to purchase a flexible range of supports and slow-stream rehabilitation, irrespective of their living arrangements. By providing 'portable' rehabilitation services, the ABI STR program has enabled individuals to move from intensive acute care services to less restrictive environments, sometimes from acute to nursing homes but with a planned transition to a community-based option. This has been reported as being a positive initiative to assist young people who are non-compensable to have the opportunity of rehabilitation; however, there is a waiting list for this program due to high demand and the intensive support provided by the program is often time-limited to two years.[241]

In Victoria, approximately 160 clients per year are referred to the ABI Behaviour Consultancy for assessment and treatment of challenging behaviour.[242] The Consultancy is a community-based outreach behaviour management service. Most clients live in a range of home-based settings (own home, family home, hostels, supported residential services (SRSs), public housing), and the remainder live in aged care facilities (about 15 per cent) or other facilities (about 10 per cent in community residential units, hospitals, rehabilitation units, and even prison). It is common for this group to face eviction from accommodation, a range of legal consequences for their behaviours, loss or refusal of services, and significant interpersonal difficulties. However, the Consultancy service cannot manage cases of severe behaviour disorder in the existing service system.[243]

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[240] *Submission* 124, p.5 (Melbourne City Mission).

[241] *Submission* 79, p.6 (Inability Possability); VCASP, *Final Report of Accommodation Project*, p.47.

[242] Kelly, G. & Winkler, D. (2007) 'Long-Term Accommodation and Support for People With Higher Levels of Challenging Behaviour'. *Brain Impairment*, Vol. 8(3), p.264.

[243] Kelly & Winkler 'Long-Term Accommodation and Support for People With Higher Levels of Challenging Behaviour', p.264.

The Victorian Coalition of ABI Service Providers (VCASP) provided the Committee with its *Accommodation Project Final Report* (2007) which described the types of accommodation and support options in Victoria for people with an ABI or neurological disease.[244] These include:

- SSA as the major model of accommodation in both the public and private sector for people with ABI. However, though providing a long-term accommodation option, this may lack the level of specialisation to accommodate people with higher levels of challenging behaviour. According to Kelly and Winkler, there are fewer than 10 ABI-specific SSA services in Victoria for people who are publicly funded[245]

- SRSs provide another option, however such accommodation does not provide the level of personal care or behaviour assistance that many ABI clients require. This is discussed further in Chapter Eleven

- Wintringham provides access to specialised and long-term or permanent housing and support to frail aged homeless people, often with ABI, including a full range of non-clinical and non-institutional style services with specialised care strategies[246]

- Residential Aged Care facilities are often the only option for people with ABI, particularly for young people with a severe ABI and requiring a high level of care.[247] This is discussed further in Chapter Eleven

- The Royal Talbot Rehabilitation Centre – Brain Disorders Unit (Mary Guthrie House) has a secure unit for people with the dual diagnosis of an ABI and a mental illness. It provides 10 rehabilitation beds for up to 12 months for this group[248]

- Many people who have an ABI also remain in hospital after their injury for considerably longer than is medically necessary because there are no suitable accommodation options available.[249] St Vincent's Hospital reported difficulties in securing accommodation after discharge from hospital, where people had no previous history with a disability service.[250]

In addition, DHS advised the Committee that it funds the ABI Behaviour Consultancy, a state-wide behaviour consultancy service for people with an ABI provided by Epworth Healthcare. This program receives $410,000 annually to assist 160 individuals.

For people with an ABI, there is frequently a need to access a range of health services. To achieve this, VCASP's report on supported accommodation for people with ABI suggests that partnerships between health and disability

[244]   VCASP, *Final Report of Accommodation Project* [see Footnote 238].

[245]   Kelly & Winkler, 'Long-Term Accommodation and Support for People With Higher Levels of Challenging Behaviour', p.269 [see Footnote 243].

[246]   *Submission* 119, p.9 (NorthWestern Mental Health).

[247]   *Submission* 124, p.11 (Melbourne City Mission).

[248]   VCASP, *Final Report of Accommodation Project*, p.33 [see Footnote 238].

[249]   *Submission* 99, p.3 (VCASP).

[250]   *Submission* 130, p.7 (St Vincent's Hospital).

services are essential.[251] The report states that successful service delivery is dependent on a complex network of partnerships that ensure services required by individuals with an ABI are provided. VCASP explained to the Committee that some people with ABI have severe physical and sensory disabilities combined with high health care needs.[252] The organisation states that this group of individuals require 24 hour specialised nursing, specialised therapy and medical oversight.

> They have an extremely narrow margin of health and this puts them at serious risk in any environment that is not fully responsive and attuned to their clinical, therapeutic and support needs.[253]

As noted earlier in this chapter, the NP model has been progressively introduced throughout Victoria to provide specialist healthcare to people with a range of complex healthcare needs, including stroke care and oncology services. The Committee considers that there is potential to explore the value of this model for people with an ABI in view of their often intense and complex healthcare needs.

Recommendations

7.15   That the Victorian Government improves partnerships across disability services and health services that provide support for people with an acquired brain injury, including the introduction of the nurse practitioner model in each region.

7.16   That the Victorian Government increases the availability of supported accommodation options available for people with a non-compensable acquired brain injury.

7.4.3   Autism spectrum disorder

In December 2008, people with autism spectrum disorder became eligible to access disability services when the Victorian Government acknowledged its recognition of autism spectrum disorders (ASDs) as a neurological impairment under the *Disability Act 2006*.

ASDs are neurodevelopmental disorders that cause substantial impairments in social interaction and communication and are associated with unusual behaviours and interests. Although not officially defined in any international medical classification code, the phrase 'autism spectrum disorder' is commonly used to encompass a range of related disorders. ASDs are described according to a spectrum, with varying degrees of pervasive impairment that range from mild to severe.

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251   VCASP, *Final Report of Accommodation Project*, p.11 [see Footnote 238].

252   *Submission* 99, p.10 (VCASP).

253   *Submission* 99, p.10 (VCASP).

Due to the complex nature of autism, some organisations and individuals told the Committee that specialist accommodation and support are necessary for individuals with autism in order to meet their high support needs. The Office of Public Advocate recommended that funding be increased to 'enhance the availability of specialist accommodation and high level support for people with … autism'.[254]

The Committee heard that there is a need for increased understanding for and awareness of ASD and how to most appropriately respond within disability services. People in caring relationships with a person with autism have experienced difficulty accessing appropriate supported accommodation due to the high support needs of people with autism.[255] Due to limited ongoing, suitable supported accommodation, one family providing care for a family member with autism told the Committee that they care for their son '24 hours a day assisting him with all daily needs, with constant supervision for his safety'.[256] Furthermore, the Committee heard that even when people with autism have secured a placement in SSA, the capacity of staff to work with their needs may be limited. This is discussed further in Chapter Nine, particularly in relation to the use of restrictive interventions.

Importantly, in May 2009 the Victorian Government released the *Autism State Plan*. The plan aims to support all people with ASD and their families and carers to improve their quality of life. The plan has six priority areas. These are:

- Make it easier to get support

- Strengthen the ASD expertise of the workforce

- Extend and link key services and support, especially during times of transition

- Enhance and provide appropriate educational opportunities

- Facilitate successful participation in the community

- Develop a robust evidence base about ASD. [257]

The Plan is a broad strategy that aims to improve outcomes for people with autism through their various stages of life over a 10-year period. The Plan contains some broad statements about how the above priorities can be achieved, with no clear timeframes.

The plan provides a comprehensive overarching strategy for addressing the lifetime needs of people with ASD. There are three particularly relevant goals in the plan for people with autism receiving support from the disability sector – strengthening the expertise of the workforce, extending key services and support, and facilitating successful participation in the community.

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[254]   *Submission* 100, p.31 (OPA).

[255]   *Submission* 89, p.1 (M & R Tonissen).

[256]   *Submission* 89, p.1 (M & R Tonissen).

[257]   Department of Human Services (DHS) (2009) *Autism State Plan.* DHS, Victorian Government, May, p.20.

In regard to facilitating successful participation in the community, the Plan indicates that a way to achieve this goal for people with ASD will be to 'strengthen accommodation and support models to better meet the needs of people with an ASD'.[258] It is unclear, however, how the Victorian Government will strengthen accommodation and support models to achieve this statement. Furthermore, there is no statement that suggests when this will occur.

Similarly, in regard to strengthening the ASD expertise of the workforce, the Plan notes that this could be achieved by implementing 'a cross-sector workforce development strategy that includes training, secondary consultation and mentoring'.[259] The Plan does not indicate how or when this strategy will be implemented. Recently, Disability Services Division has released a tender for the development and delivery of an ASD training package for disability case mangers. This has four goals:

- To enhance the knowledge and understanding of ASD, including its main features, diagnostic pathways and functional impacts
- To increase the understanding of the key issues impacting on people with ASD and their families, carers and siblings
- To ensure that disability case managers can implement a range of strategies to support this client group effectively within a self-directed approach
- To enhance the understanding of the services available for people with ASD, including the linkages between the disability service system and other service systems.

In addition to this training initiative, other strategies include access to training provided by Disability Services on behaviour intervention for case management staff, and training, workshops and consultation provided by the Office of the Senior Practitioner for disability support workers, families and other carers to assist with support strategies to reduce behaviours of concern.

The Committee found that the Victorian Government has acknowledged the need for increased workforce capacity in relation to supporting people with ASD in the disability sector. The Committee also identified the need for developments in the accommodation options available to people with autism. While the Victorian Government has acknowledged its intentions to address this issue through the Autism State Plan, it has not developed an implementation with specific timelines and accountabilities.

Recommendation

7.17   That the Victorian Government releases an implementation plan with timelines specifying how and when accommodation and support models will be improved to better meet the needs of people with ASD, in line with the Autism State Plan.

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[258]   DHS, *Autism State Plan*, p.32.
[259]   DHS, *Autism State Plan*, p25.

7.4.4   Dual and multiple disabilities

Participants in the Inquiry told the Committee of challenges in accessing appropriate supported accommodation and services for people with multiple disabilities and dual diagnosis. In particular, the Committee heard about difficulties in accessing necessary services that cross service systems.

Multiple disabilities refer to a combination of two or more limitations, impairments or restrictions occurring at the same time, which can include a range of disabilities and ABI. The dual diagnosis of people with an intellectual disability and suffering from mental illness has also been referred to as 'dual disability'. In their 2004 research, Chan, Hudson and Vulic state that there is increasing evidence to support the high prevalence of mental illness in adults with intellectual disability.[260]

While there have been recent changes to disability policy and new directions in support service delivery, the Committee heard that both ISPs and traditional SSA models are limited in their capacity to provide the flexibility required to respond to dual and multiple disabilities. Karingal suggests that a continuum of options is required to improve the situation:

> We need a continuum of options to be available in that area as personalised as the individuals themselves. That could be their own home with individual support packages, right through to shared support accommodation options. There is a need for active night support; sleepover support is often not adequate for those with high and complex support needs. There is a requirement for access to medically qualified staff within disability support services. That might mean what I call in-reach models from hospitals.[261]

Chan, Hudson and Vulic support this approach. [262] Their research highlights the difficulty for individuals with dual disabilities in accessing appropriate support across service provision sectors. While the authors acknowledge the complexity of providing such services, they argue that it is crucial for appropriate support services to work in partnership in order to meet the complex needs of individuals with dual or multiple disabilities.[263]

The Executive Director of Disability Services Division, Mr Arthur Rogers, advised the Committee that the Department is currently working towards increasing the continuum of services that provide disability support. In regard to people with dual and multiple disabilities, he explained that:

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[260]   Chan, J., Hudson, C. & Vulic, C. (2004) 'Services for adults with intellectual disability and mental illness: Are we getting it right?' *Australian e-Journal for the Advancement of Mental Health (AeJAMH),* Vol. 3(1), p.1.

[261]   *Committee Transcript*, 23.10.08, p.7 (Karingal).

[262]   Chan et al, 'Services for adults with intellectual disability and mental illness', pp.1-6 [see Footnote 260].

[263]   Chan et al, 'Services for adults with intellectual disability and mental illness', p.5 [see Footnote 260].

> For people with mental illness and coexisting disability — that is, dual disability — the department funds the Victorian dual disability services, primarily through the mental health and drugs division. That is auspiced by St Vincent's. Mental health and disability services jointly fund an enhanced regional service response in the north and west, where there is a higher concentration of people with mental illness and coexisting disability, because of the size of the population. That provides assessments and secondary consultation.[264]

Based on the evidence heard by the Committee, this service cannot meet the level of demand for services.

Karingal and Gateways informed the Committee that individuals with a dual disability have difficulty in gaining access to recognised assessment services. They explained that

> Gaining access to the mental health system for people with a disability may take months or even years and access to behaviour services is also a lengthy process. It is very likely that in the meantime the person's living situation will break down.[265]

Participants also stressed the importance of staff having the relevant expertise to respond to people with complex needs and multiple disabilities. Ms Judi Hollingsworth told the Committee that:

> It is important that staff are provided who have experience according to the needs of the residents and therefore staff recruitment must be carried out specific to the residents that the person will be working with.[266]

Similarly, Karingal suggested that staff are a key link in providing relevant and individualised support to individuals with a dual disability.

> We are finding that staff are not skilled or equipped to work with people with dual disabilities, and that may be someone with a mental illness who also has an intellectual disability and/or autism.[267]

The Committee is aware that the Victorian Government has protocols between disability and mental health services in an effort to overcome the cross-sectoral barriers. The evidence suggests, however, that these barriers continue to persist.

The following story told to the Committee reveals the challenge experienced by one family seeking access to an appropriate supported accommodation placement for their family member with multiple disabilities.

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[264] *Committee Transcript*, 12.10.08, p.6 (A. Rogers, DHS).

[265] *Submission* 16, p.3 (Karingal & Gateways Support Services)

[266] *Submission* 5, p.2 (J. Hollingsworth).

[267] *Committee Transcript*, 23.10.08, p.5 (Karingal).

One family's experience

Kate's story:

Hello. I cannot remember all of my old house; I have forgotten things, but I do remember some things. I was not allowed to talk to staff when they went outside to have a coffee. There was no one to talk to in the house. The others were not able to talk.

I did not have a key to my room. I had to ask a staff person to let me in all the time. I had to go to the staff every time I wanted to get out of my house, because the door was locked all the time. I was not allowed to use the TV. I had to ask staff to use it when I wanted to watch it. I was not allowed to use the telephone because staff might need it. There was no fun. I was bored a lot. There was nothing to do on the weekends. I am very happy in the new house. Staff help a lot. It is good to be able to talk to people. Everyone is happy there.

Kate's mum's story:

To give a little bit of background, Kate is 29. She suffers from intractable epilepsy, which has resulted in a brain injury and some psychiatric difficulties. So her needs are complex…

I got her a position in a rehabilitation centre run by mental health. She was to be placed there for 12 months. She made huge gains with their occupational therapy and she had the support of all the staff in the day programs. She lived there for three years, and finally they turfed her out because no place was available for Kate to live. She actually used up someone else's rehab spot for two years. The disability services department would not pick her up…

The director of DHS is responsible for both mental health and disability services. But the two departments have such a completely different approach …

Initially, then, when disability services finally did pick Kate up — in response to a cardiologist saying that a member of our family just could not continue in this [carer's] role any longer — the finding that was offered to Kate initially was to support her in a place of her own. The department was then unable to say how many hours of support each week would be offered. So we were not really able to consider the offer…

Fortunately, eventually, a good home did become available after years of never giving up on complaining. Is this how it should be?[268]

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268   *Committee Transcript*, 23.10.08, pp.4-5 (Gateways Support Services).

While the Committee acknowledges that the Victorian Government has services in place for people with dual and multiple disabilities, it found that the barriers for people in these circumstances persist in view of existing protocols. This suggests there is merit in reviewing those protocols with a view to improving collaboration across mental health and disability services.

Recommendations

7.18   That the Victorian Government increases the supported accommodation options available for people with dual and multiple disabilities.

7.19   That the Victorian Government reviews the protocol between Disability Services Division and Mental Health and Drugs Division to remove barriers for people with dual and multiple disabilities seeking to access supported accommodation.

7.4.5   Huntington's Disease

Huntington's Disease is an inherited, neurological disorder that causes the gradual deterioration of physical, cognitive and emotional abilities. As with other high and complex disabilities, individuals with Huntington's Disease are limited by the lack of suitable supported accommodation options. As the Committee heard, many people with the disease end up being inappropriately placed in accommodation that is unable to meet their support needs.

The OPA told the Committee that individuals with Huntington's Disease have a complexity of service provision needs which require the availability of a wide range of services and individualised programs across multiple sectors.[269] The Committee heard that due to the extended period of the disease and its complexities, family capacity to provide continued support is often reduced. The outcome is that not all individuals with Huntington's Disease can remain at home for the duration of the disease.[270] Adding to the stress of carers is the challenge in securing suitable placement options.[271]

Ms Ruth Hertan, the CEO of the Australian Huntington's Disease Association (ADHA), told the Committee that despite the rarity of the disease, people with Huntington's are disproportionately represented with regard to individuals who fall between the service gaps.[272] Huntington's Disease is individual in the way it affects people; some people will have motor symptoms, cognitive problems, serious behavioural problems, or a combination of any or all of these symptoms. Because of the individualised and complexity of an individual's symptoms, Ms Hertan maintained that finding supported accommodation is very difficult.

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[269]   *Submission* 100, p.47 (OPA)

[270]   *Submission* 100, p.47 (OPA)

[271]   *Submission* 100, p.47 (OPA)

[272]   *Committee Transcript*, 5.11.08, p4 (Young People in Nursing Homes National Alliance).

> There is no facility anywhere to put someone young, in their 40s, who has got younger onset dementia like Huntington's … Psychiatric units do not consider that Huntington's is a psychiatric condition because it is a medical condition. It is a disease and not a psychiatric condition and one of those very fine lines of delineation…[273]

The OPA highlighted the need for increasing specialist accommodation that provides intensive support that meets the support needs of individuals with Huntington's Disease.[274]

Wesley Mission provides a 30-bed congregate care facility, Arthur Preston Residential Services (APRS), for people with Huntington's Disease and other complex progressive neurological disorders and physical disability. There can be a number of people with Huntington's Disease and a dual diagnosis of mental illness living at the facility at any time.[275]

The Committee heard that behaviours concerned with Huntington's Disease can mean that some supported accommodation services are reluctant to accommodate people with the condition. With limited placements in facilities such as APRS, the alternative options, such as SRS and hostels, are often not capable of managing the associated support needs and behaviours of concern that can arise. The OPA informed the Committee that it has worked with many people in the middle stages of the disease who are caught moving between acute mental health units and SRS for lengthy periods when they cannot access specialised options that provide appropriately structured, supportive accommodation.[276]

Ms Ruth Hertan, AHDA, informed the Committee that the Royal Talbot Rehabilitation Centre has been another option for people with Huntington's Disease:

> We currently have five people in the Royal Talbot Rehabilitation Centre and we have had to be really strong advocates to get them in there because that is a rehabilitation facility. People are meant to stay there for a few months with an acquired brain injury and then move on back into the community. Our people need to be there for several years until their physical deterioration stops them from being able to be a risk to themselves or others, so the rehab centre is very reluctant to take on any more. We are occupying half of one of their houses at the moment.
>
> What we find, though, is that in a place like that where there is a rigid structure, a really great timetable, staff who really know what they are doing, the behaviours improve enormously because people feel secure and they can cope with those sorts of things.[277]

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[273]   *Committee Transcript*, 5.11.08, p.5 (Young People in Nursing Homes National Alliance).

[274]   *Submission* 100, p.8 (OPA).

[275]   *Submission* 105, p.2 (Wesley Mission).

[276]   *Submission* 100, p.48, (Office of the Public Advocate).

[277]   *Committee Transcript*, 5.11.08, p.5 (Young People in Nursing Homes National Alliance).

The OPA supports the view that people with Huntington's Disease respond best to a structured and supportive environment.[278]

> In care settings that confront, restrict and punish, the person often responds by getting more resistant and unmanageable. OPA works with many people who have spent years of their lives in the middle stages of the disease, moving between acute mental health units and SRS because no specialised appropriately structured and supportive accommodation is available.[279]

In view of the specific complexities of people with Huntington's Disease and the suggestion that they are over-represented in the number of people who fall through service system gaps, the Committee identified a need to further investigate the options available in these circumstances.

Recommendations

7.20   That the Victorian Government investigates the extent to which people with Huntington's Disease are over-represented in service system gaps.

7.21   That the Victorian Government increases the specialist support and accommodation options available for people with Huntington's Disease.

7.5   Supported accommodation and people from indigenous backgrounds

The Committee heard from organisations representing indigenous people with a disability and/or mental illness and sought views of mainstream services regarding options for indigenous communities. The evidence clearly pointed to gaps in service provision for people with a disability from an indigenous background.[280] Notably, however, most organisations representing the needs of people from an indigenous background with a disability and/or mental illness gave considerable attention to the issues of those with a mental illness. The Committee was fortunate to receive a comprehensive submission from Rumbalara Aboriginal Cooperative that highlighted some of the key issues.

Rumbalara Aboriginal Cooperative explained the significant cultural differences that potentially shed light on how disability is understood in indigenous communities and the implications for the needs of the indigenous population with a disability:

> The words disability/disabled do not have meaning in the ATSI community; individuals with special needs are not segregated or considered not normal, so

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[278]   *Submission* 100, p.48 (OPA).

[279]   *Submission* 100, p.48 (OPA).

[280]   See *Submission* 46, p.3 (West Wimmera Health Service); *Submission* 124, p.14 (Melbourne City Mission); *Submission* 121B, p.28 (HACSU).

families do not necessarily seek out a diagnosis or disability services. This is true not only for families/consumers but also for staff working in the field.[281]

From Rumbalara Aboriginal Cooperative's perspective, this contributes to a significant degree of unmet need for those people with a disability from indigenous backgrounds. While services might not be sought, the Committee's attention was drawn to the stress experienced by family and kinship networks providing support.

Rumbalara Aboriginal Cooperative informed the Committee that in 2005 it completed a report that analysed the needs of indigenous people with a disability and their carers in the Shepparton area. The findings of the DHS funded report identified significant under-reporting, minimal engagement with the mainstream service system, a dearth of support services for this group of people and gaps in data on indigenous people with complex disabilities. The report revealed that a key outcome of this unmet need is that families and extended kinship networks were experiencing the stress of providing support to their family member with a disability, who often has complex needs.[282]

As indicated by Rumbalara Aboriginal Cooperative, there is a lack of relevant information and data about the needs of Aboriginal communities and their experience of disability. This makes it difficult to understand their needs.

DHS data relating to the number of indigenous people in shared supported accommodation and the number of new requests for SSA made by people with a disability from indigenous backgrounds confirms this lack of available information. According to this information, the indigenous status of 16 per cent of residents in SSA (excluding residential institutions) is unknown. In regard to what is known, at 30 June 2008 there were only 32 residents from an indigenous background (of a total 3,854 residents); that is, 0.7 per cent.[283]

From Rumbalara Aboriginal Cooperative's perspective:

> Mainstream organizations are given encouragement to deliver services to ATSI people, but their whole construct means ATSI individuals with a disability are largely missing out.[284]

Rumbalara Aboriginal Cooperative suggested that a key challenge for people with disability from indigenous backgrounds seeking access to disability services relates to them not being registered with Disability Services in DHS. The reasons for this include not meeting the specific diagnostic or eligibility requirements due to the difficulties they frequently have in completing the process. Their families or other carers may lack the literacy skills to complete

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281 *Submission* 134, p.3 (Rumbalara Aboriginal Cooperative).
282 *Submission* 134, p.2 (Rumbalara Aboriginal Cooperative).
283 Victorian Government (2008) Data provided to Family & Community Development Committee.
284 *Submission* 134, p.3 (Rumbalara Aboriginal Cooperative).

the necessary forms or to seek specialist assessments. The Committee was told that many are also distrustful of a process they find intrudes into their personal and private circumstances.[285]

The issue of trust is clearly an important one, as was raised by the Regional Information and Advocacy Council (RIAC), based in Mildura. The organisation's approach to responding to indigenous communities in the field of disability has been to appoint an Aboriginal worker. RIAC suggests that this worker has been successfully building trust by engaging with the communities. The outcome has been that more people from indigenous communities are willing to access the service. RIAC stated that it strives to make its service responsive to the individual needs of Aboriginal people who access their service.[286]

Rumbalara Aboriginal Cooperative has sought to increase its understanding of need in the indigenous community in Shepparton through surveying their needs. In late 2008, it found that:

> 7 people with an immediate SAP [supported accommodation program] need were identified, with the majority having an ABI, ID [intellectual disability] and/ or a neurological disorder. There were a further 25 whose disability may or may not have been fully diagnosed, but included a mental health disability. At least 2 were identified as living in RACFs [residential aged care facilities] (this is not exhaustive), 15 were at home with aging carers/no carer, living in transition care or were homeless. Very few were registered with Disability Services or had undergone formal assessments. This data was accumulated without going through RAC [Residential Aged Care] Health Services data or going outside of RAC's program areas. This is known to be a severe underestimation of actual need.[287]

Rumbalara Aboriginal Cooperative provided information about a range of solutions it has sought to introduce. These include the appointment of a skilled worker in disability to facilitate agreements and protocols across services, to facilitate the development of data systems within Rumbalara Aboriginal Cooperative and also between it and mainstream organisations, and to facilitate cultural awareness training for disability services providers. These strategies are consistent with suggestions made by other organisations that gave evidence to the Committee.[288]

Recommendations

7.22   That the Victorian Government develops protocols for working with Aboriginal services to meet the needs of people with a disability from indigenous backgrounds.

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285   *Submission* 134, p.3 (Rumbalara Aboriginal Cooperative).

286   *Committee Transcript*, 18.11.08, p.9 (RIAC).

287   *Submission* 134, p.4 (Rumbalara Aboriginal Cooperative).

288   For example, see *Committee Transcript*, 22.10.08, p.4 (Yooralla).

Recommendations

7.23   That in collaboration with indigenous communities, the Victorian Government researches the needs of people with a disability from indigenous backgrounds and implements the findings from this research.

7.24   That the Victorian Government undertakes cultural awareness training for disability service providers in collaboration with Aboriginal services.

7.25   That the Victorian Government provides an Aboriginal disability liaison worker across all regions to facilitate improved responses to people with a disability from indigenous backgrounds.

7.6   Cultural diversity and supported accommodation

Supported accommodation options for people with a disability from culturally and linguistically diverse (CALD) communities has been one of the Committee's key areas of inquiry The Committee heard that specific options for people with a disability and/or mental illness from CALD are important.[289] NDS stated that:

> local supported accommodation solutions that reflect the needs of particular cultural groups where there are clusters of people from those groups in communities are very critical.[290]

Action on Disability within Ethnic Communities (ADEC) identified a number of specific issues relating to suitable and appropriate support and accommodation options, including how disability services engage with CALD communities, the available data relating to people from CALD and the extent to which CALD communities are aware of, need and access disability services.

The Committee heard that it is important to understand the unique and individual needs of people with a disability from CALD to facilitate appropriate provision of services. ADEC highlighted the challenge in accessing relevant data on the needs of people from CALD backgrounds and their use of services. This is also evidenced by DHS data provided to the Committee, which reveals that the cultural background of 62.7 per cent of residents in SSA (excluding residential institutions) was unknown at 30 June 2008. Of the 37.3 per cent known, only 1.8 per cent (or 84 residents) are from a CALD background. Issues relating to data collection were discussed in Chapter Five.

In addition to the issues of needs and data collection, research suggests that Victorians with a disability and/or mental health issue from CALD backgrounds are often unaware of information about accommodation and support services

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[289]   See *Committee Transcripts*, 30.4.09 (ADEC), 5.11.08, p.13 (NDS), 6.11.08, p.11 (Murray Mallee Community Mental Health Services).

[290]   Committee Transcript, 5.11.08, p.13 (NDS).

available to them.[291] Without this knowledge, people may not know where to go to get help even if they are willing to receive treatment. For example, African communities have suggested that African families and individuals have minimal understanding of the nature of services in Australia due to the frequent absence of health and community services in their home countries.[292]

ADEC's advocacy manager told the Committee that many ageing carers from non-English speaking backgrounds do not know about the system as they have never sought support.[293] People are often unable to express their views or needs when they do not know about the current service provisions available.

> We sometimes find carers who have been caring for their children for 20 to 30 years and not being even aware of simple benefits like the carers allowance. You can appreciate the inability to tap into the system … [if a person does] not know about the system. The navigation of the processes is also quite a big problem for someone who does not know the welfare field.[294]

This was also supported by evidence provided to the Committee by Carers Victoria. It stated concern about people 'from diverse ethnic backgrounds who may not know about other options or their values may provide barriers to accessing other services'.[295] NDS suggested that the solution is:

> making information accessible, adapting information to whichever cultural group we are talking about, working with different cultural groups within their different culture and supporting workers from within a culture to understand what the service system is about to increase people's awareness and access.[296]

In 2004, DHS acknowledged the need for improved responses to people from culturally diverse backgrounds when it released its *Cultural and linguistic diversity strategy: Planning and delivering culturally appropriate supports for people with a disability, their families and carers.*[297] The aim of the strategy was to assist disability support providers to plan and deliver culturally appropriate disability supports. The

[291] Carlson, G. & van Kooten Prasad, M. (2001) 'Services for People with Intellectual Disability of Culturally and Linguistically Diverse Backgrounds'. *International Journal of Practical Approaches to Disability,* Vol. 25(1), p.4; Ramanathan, R. & Hickman, C. (2007) *Empowering Ethnic Communities: Fostering Inclusive Service Provision through Relationship Building.* Transcultural Mental Health Access Program Action on Disability within Ethnic Communities, July, p.6. Accessed from <http://www.adec.org.au/documents/ADECPaperFECCA2007.pdf> on 30 August 2009.

[292] Eastern and Central Africa Communities of Victoria Inc. (2005) *Submission to Senate Select Committee on Mental Health*, 24 May. Accessed from <http://www.aph.gov.au/Senate/Committee mentalhealth_ctte/submissions/sub394.pdf> on 25 May 2009.

[293] *Committee Transcript*, 30.4.09, p.4 (ADEC).

[294] *Committee Transcript*, 30.4.09, p.4 (ADEC).

[295] *Committee Transcript*, 22.10.08, p.12 (Carers Victoria).

[296] *Committee Transcript*, 5.11.08, p.13 (NDS).

[297] Disability Services Division. (2004) *Cultural and linguistic diversity strategy: Planning and delivering culturally appropriate supports for people with a disability, their families and carers* Department of Human Services, Melbourne, December. Accessed from <http://www.dhs.gov.au/disability> on 31 May 2009.

strategy outlined seven goals directed towards improving cultural responsiveness and effecting cultural change:

- Understanding people and their needs
- Encouraging participation in decision-making
- Providing culturally relevant and accessible information
- A culturally diverse workforce
- Using language services to best effect
- Meeting the specific needs of different communities
- Promoting the benefits of a culturally diverse Victoria.

This plan appears promising and comprises the key ingredients to work towards a service system that provides culturally appropriate responses to people with a disability from CALD backgrounds. The strategy, however, contains no mechanism to measure progress or to evaluate the success of its implementation.

While supportive of the efforts made by DHS relating to this strategy in the past, ADEC expressed concerns regarding the ongoing commitment of the Department to its objectives to achieve more culturally appropriate service provision. ADEC made the following observation in its evidence to the Committee:

> There is also a question about the seriousness that DHS takes in making all organisations multiculturally and culturally appropriate. The department has, for many years, had a policy of making all disability support providers, whether they be residential or support services, culturally appropriate. From our perspective, it has kind of died; the implementation of the policy has died a very slow and painful death and not much is really happening.[298]

ADEC made a clear statement that DHS needs to be providing leadership for the cultural change required in the sector.

In stating that DHS has responsibility for providing leadership on cultural change, ADEC made the qualification that service providers are not directly at fault for the lack of diversity in approaches within the sector. The organisation acknowledged the significant pressures faced by many services. ADEC stated that to increase the range of suitable options, the Victorian Government needs to provide the leadership to enable mainstream organisations to focus more specifically on their cultural approach:

> Service providers really need to be embracing working with ethnic communities as a matter of normal course of business, rather than something you add on when you might have someone as a client from a different ethnic background coming to your service.[299]

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298 *Committee Transcript*, 30.4.09, p.3 (ADEC).
299 *Committee Transcript*, 30.4.09, p.2 (ADEC).

The Committee heard that services need to be aware of and respond appropriately to a range of cultural factors and religious beliefs in their interaction with a person with a disability from a CALD background. For example, the type of food, the preparation of food, and how and where it is eaten can be influenced by a person's cultural and religious background. Furthermore, issues relating to the gender of staff in facilities can be significant in the provision of culturally appropriate support and accommodation. [300]

Some organisations indicated the importance of services using initiative at a local level to address issues, particularly in view of the perceived lack of leadership by the DHS. RIAC provided an overview of its broad approach in working with people from CALD backgrounds:

> How we go about talking, how we go about presenting, how we try and tap into them is totally different depending on the cultures. It is simply things like eye contact, how we dress, all of those sorts of things need to be considered about how we go. The structure of the families, who is going to be in the house, what is expected, where the respect is…[301]

RIAC informed the Committee that one of its workers had developed a cultural dictionary that contains cultural information about 64 ethnic communities; including some key words in the language and some basic information about customs (eye contact, shoes in homes, dress etiquette, etc).

Other service providers agreed with the need to be improving responses to people from culturally diverse communities. For example, Yooralla commented on the importance of developing genuine partnerships with specialist agencies that understand cultural nuances and working together to ensure that people with a disability from ethnically diverse backgrounds receive the response they require.[302]

Recommendations

7.26   That the Victorian Government develops an implementation plan with clear timelines and accountabilities for achieving the goals set out in the *Cultural and Linguistic Diversity Strategy* for people with a disability and their families

7.27   That the Victorian Government introduces ongoing state-wide professional development on cultural awareness for workers in the disability support sector.

7.28   That the Victorian Government measures the service needs of people with a disability from ethnically diverse communities.

7.29   That the Victorian Government introduces a 'cultural dictionary' for specialist disability services for state-wide circulation based on the Regional Information and Advocacy Council model.

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[300]   *Committee Transcript*, 18.11.08, p.3 (Goulburn Valley Area Mental Health Service).
[301]   *Committee Transcript*, 18.11.08, p.9 (RIAC).
[302]   *Committee Transcript*, 22.10.08, p.4 (Yooralla).

7.7   Supported accommodation in rural and regional areas

The Committee heard evidence regarding the situation and challenges faced by Victorians with a disability and/or mental illness when seeking access to supported accommodation facilities in regional and rural Victoria. Specific issues presented to the Committee related to the reduced accessibility of services due to distance and location and the dispersal of services across regional areas, resulting in some areas being un-serviced. Participants told the Committee that Victorians with a disability living in regional and rural areas experience a double disadvantage in accessing the services they require, due to the combination of living with a disability and living in regional areas with fewer services to access.

Distance was highlighted as a barrier to obtaining services, respite, and support in rural and regional communities. There are fewer transport options for people who need to reach specific accommodation or support facilities, which has impacts on people with a disability, their families and service providers. Many rural and regional towns are car-dependent due to the shortage of public transport options. Annecto told the Committee that the isolation of many rural areas makes it costly and difficult to travel to larger towns to receive services on a regular and ongoing basis.[303] They suggested that this situation reduces the option for families in caring relationships who want to continue supporting their family member.

Mallee Accommodation and Support Program informed the Committee of the impact of distance from a service provider's perspective. Long distances are travelled to participate in sector networks and reference group meetings:

> We are isolated up here and it comes at a cost, but we travel a lot and we make the commitment. Through that we establish credibility, and with a lot of work and negotiation eventually it comes through.[304]

The Committee heard of significant resilience in rural and regional communities and support networks that are unique to these communities.

In regard to supported accommodation options, the Committee heard that there are inconsistent accommodation and support options currently available to people with a disability living in rural and regional areas. Participants told the Committee that there has been an uneven distribution of SSA across the state. NDS explained that:

> There are particular challenges with rural and regional areas due to the history of accommodation provision in the past. There are some regional or rural areas with institutions and they have gone on to have clusters of CRUs, whereas in other regional and rural areas there is very little.[305]

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303   *Committee Transcript*, 6.11.08, p.6 (Annecto).

304   *Committee Transcript*, 6.11.08, p.7 (Mallee Accommodation and Support Program).

305   *Committee Transcript*, 5.11.08, p.13 (NDS).

In Nhill, for example, West Wimmera Health Service told the Committee that there is only one community residential service catering for five state clients and one supported accommodation facility providing minimal support.[306] The organisation said that the closest accommodation service to the catchment area is Horsham, but this is 75 kilometres away and has an extremely high occupancy demand. FamilyCare told the Committee that in rural areas people have very few options from which to choose services that meet their needs.[307] The following table demonstrates the dispersal of services across the state, highlighting the discrepancies.

Table 7.7–1: Residents in Shared Supported Accommodation by region, June 2008

Region	Number	
Metropolitan Areas		
Eastern Metropolitan	1,199	26.1%
North & West Metropolitan	1,227	26.8%
Southern Metropolitan	894	19.5%
Regional Areas		
Barwon South Western	263	5.7%
Gippsland	190	4.1%
Grampians	359	7.8%
Hume	260	5.7%
Loddon Mallee	198	4.3%
Total	**4590**	**100%**

Note: Excludes residents of Residential Institutions.

Source: Victorian Government (2008) Data provided to Family & Community Development Committee.

For some people unable to access supported accommodation in rural communities, the Committee heard that the option is to find support in another town. NDS stated that this is not an ideal situation since Victorians with a disability are forced to leave their family and community, which are important aspects of their social support networks.[308] Shepparton Access provided an example to the Committee of one person's experience in these circumstances.

> We have a person who has an ISP of probably $25,000 to $26,000 come to us and because we have to transport her to and from the service – she lives a distance out of town – she can attend two days. The rest of her funding is taken up with transport.[309]

The Committee also heard that there are limited respite options for families in caring relationship in rural and regional areas. Annecto told the Committee that to support the individual with a disability, it is important to support the carer.[310] Annecto argues that there are two issues identified with regard to respite in rural

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306   *Submission* 46, p.1 (West Wimmera Health Service).

307   *Committee Transcript*, 18.11.08, p.2 (FamilyCare).

308   *Committee Transcript*, 5.11.08, p.14 (NDS).

309   *Committee Transcript*, 18.11.08, p.5 (Shepparton Access).

310   *Committee Transcript*, 6.11.08, p.3 (Annecto).

and regional communities. First, some parents may be reluctant to accept respite, as they believe they should do it themselves. People who have lived in isolation often provide a one-person care arrangement with the support of family and friends. To accept new services can be a big issue for some families in caring relationships. The second issue is the lack of trained staff in rural and regional areas. Issues relating to families in caring relationships and workforce are discussed further in Chapter Ten.

Rural and regional services also spoke about the importance of partnerships in the provision of disability support.[311] Annecto and Shepparton Access told the Committee that to overcome distance and to provide the scale of services needed; partnerships between organisations are a key approach to service delivery. The Committee heard that partnerships with various organisations have engendered sustainable pathways that can provide varying levels of support for people with a disability in local communities.[312] These collaborative practices have enabled organisations to deliver services in more remote and rural communities to provide support that would not have been possible.

> If I have not got support workers in Kinley in Swan Hill, which is almost on the New South Wales border, there is another service there run through the local council and we can broker a service through them. Without having that opportunity I think we would be in all sorts of trouble in terms of trying to deliver everything ourselves.[313]

Additional rural and regional issues have been discussed throughout this chapter.

Recommendation

7.30   That the Victorian Government reviews the distribution and demand for SSA across the State and funds additional SSA in regions in which there are proportionally less beds relative to need.

7.31   That the Victorian Government increases respite options to people with a disability in rural and regional communities to ensure that families have the support they require, with minimal travel, to sustain their caring role.

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[311]   *Committee Transcript*, 6.11.08, p.5 (Annecto); *Committee Transcript*, 18.11.08, p.9 (Shepparton Access).

[312]   *Committee Transcript*, 6.11.08, p.8 (Annecto).

[313]   *Committee Transcript*, 6.11.08, p.8 (Annecto).

Chapter Eight:
Experiences of supported accommodation – mental health

Committee findings

- That there is under-servicing of people with an enduring mental illness (and associated disability) who require stable, long-term accommodation. **(Section 8.2)**

- That the Victorian Government has acknowledged the need to increase attention to the link between support and accommodation for people with a mental illness. **(Section 8.2)**

- That there are system blockages in clinical based treatment services, which are exacerbated by the shortage of stable, long-term accommodation options. **(Section 8.2.1)**

- That there are long-stay consumers in Secure Extended Care Units (SECU) with multiple and complex needs. **(Section 8.2.1)**

- That the Victorian Government has introduced initiatives to address SECU blockages, but these are not directly linked to increased long-term, stable accommodation options for those ready to move to the community. **(Section 8.2.1)**

- That there is broad support for the Community Care Unit (CCU) model. **(Section 8.2.1)**

- That there is a shortage of accommodation pathways to enable consumers to transition from CCU facilities to the community. **(Section 8.2.1)**

- That there is broad support for the PARC model. **(Section 8.2.1)**

- That there is no stable, long-term accommodation attached to PDRSS programs. **(Section 8.2.2)**

- That the hours of home based outreach support are frequently inadequate in meeting the needs of people seeking support to live independently in the community. **(Section 8.2.2)**

- That there is a gap between the intensive support provided in residential clinical services and the low-level support provided in Psychiatric Disability Rehabilitation and Support (PDRS) services. **(Section 8.3)**

- That people with a mental illness requiring long-term residential treatment can be at risk of losing their accommodation and can find themselves at risk of homelessness. **(Section 8.3.1)**

- That there is a need for long-term accommodation options for people with a severe and enduring mental illness with an associated disability. **(Section 8.3.2)**

- That people with a mental illness from indigenous backgrounds have specific cultural needs that are often unmet in the current mental health system. **(Section 8.4)**

- That there is a need to make mental health services more accessible to indigenous Victorians. **(Section 8.4)**

- That the needs of people from ethnically diverse communities are not well understood in Victoria. **(Section 8.5)**

- That mental health services are unequally distributed across the state. **(Section 8.6)**

T his chapter explores and reports on the findings of evidence provided to the Committee regarding the adequacy and range of support and accommodation options available to people with a mental illness. It discusses the evidence with a view to determining how individuals and organisations that engaged with the Inquiry believe these needs and aspirations are being met.

The Committee found broad support amongst participants for service models in the mental health system, particularly Community Care Units (CCUs) and Prevention and Recovery Care (PARC) facilities. It also heard, however, that there are system blockages for people with a mental illness needing access to services. Furthermore, for consumers seeking discharge into the community, the Committee found that the shortage of accommodation options may limit opportunities.

8.1 Mental health service directions

In 2006, the Boston Consulting Group reported that the mental health sector in Victoria is a complex and, at times, fragmented service system.[314] As outlined in Chapter Four, the components of the mental health system that the Inquiry is focused on relate to two areas of care – namely clinical-based treatment provided by specialist mental health services and non-clinical based support provided by the psychiatric disability rehabilitation and support services (PDRSS) sector. Linked to the health system, these services are episodic in nature. While traditionally very medical in its approach, the mental health service system is increasingly recognising the value of a more holistic approach to mental health, including the social consequences of a mental illness. This is recognised in the new mental health strategy, *Because Mental Health Matters*, released early in 2009.

Residential specialist mental health services provide 24 hour treatment and support in Secure Extended Care Units (SECUs), CCUs and (PARC). SECUs provide the highest level of care on the continuum of mental health services. They are considered an inpatient service and are typically located on hospital sites with acute mental health units. CCUs provide medium to long-term accommodation, clinical care and rehabilitation services for people with a serious mental illness. PARC is a step-down, step-up supported residential service (SRS) for people experiencing a significant mental health problem who do not need or no longer require hospital admission. Not all regions have access to all services provided in the clinical mental health service system.

Residential options provided by non-clinical support services in the PDRSS sector include residential rehabilitation and home based outreach support (HBOS). These services are provided within a recovery and empowerment model to maximise people's opportunities to live successfully in the community.

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314   The Boston Consulting Group (BCG) (2006) *Improving Mental Health Outcomes in Victoria: The Next Wave of Reform.* Department of Premier and Cabinet, Melbourne, July, pp.16, 24.

Residential rehabilitation provides either 24 hour or non-24 hour intensive psychosocial rehabilitation and support to people in group accommodation to prepare them for independent living.

Day programs and HBOS provide support to people with a mental illness living in their own home. Based on information received by the Committee, home based outreach services can generally only provide limited support. That is, approximately three to four hours per week for each consumer.[315] In providing outreach support, the worker will generally spend the time with residents in their own homes, providing support to improve budgeting skills, social skills and housekeeping. In addition, the worker will assist with clinical care coordination and provide support in pursuing activities to achieve closer integration of the resident into his/her community.

8.2 Level of service availability

To facilitate adequate accommodation and support for people with a mental illness the Committee heard that accessing mental health services at two levels is significant. Firstly, the importance of timely access to clinical and non-clinical residential treatment and support was highlighted, and secondly, participants stressed that access to adequate accommodation in the community with appropriate support is essential to recovery.

The Committee received evidence that initial timely access to mental health services for treatment could facilitate opportunities for people with a severe mental illness to live independently in the community. It was also told of the need for these services to respond to the person with a mental illness as a whole person, rather than in fragments. Timely access to treatment and support to sustain accommodation were raised as the keys to recovery.

Over the past seven years, reports and reviews of the Victorian mental health sector have identified challenges regarding timely access to services in the sector. In 2002, the Victorian Auditor-General reviewed mental health services in Victoria and concluded that timely access was an issue and that demand for services was expected to increase in the five years ahead.[316] In 2003 and 2005, the Mental Health Council of Australia released reports calling for an increase in financial resources to meet growing unmet demand.[317]

In 2006, the Victorian Government commissioned the Boston Consulting Group to review aspects of mental health services in Victoria to inform potential future directions. The findings of the report were that 44 per cent of people with a serious mental illness (such as schizophrenia or bipolar disorders)

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315 *Submission* 98, p.12 (Mental Illness Fellowship Victoria).

316 Victorian Auditor-General's Office (2002) *Mental health services for people in crisis*. Government Printer for the State of Victoria, Melbourne, p.3.

317 Mental Health Council of Australia (2003) *Out of hospital, out of mind*. MHCA, Canberra; Mental Health Council of Australia (2005) *Not for service*. MHCA, Canberra.

were not receiving mental health treatment or support. The report concluded that a prerequisite for reform in the mental health sector was ongoing increases in funding.[318]

Another finding by the Boston Consulting Group related to the under-servicing of some consumers of the mental health sector due to 'underinvestment where responsibilities [between areas and levels of Government] are blurred or there is some ambiguity about funding responsibility'.[319] In particular, it highlighted the under-servicing of people 'with a chronic mental illness who require stable long-term housing – people in this group typically have a wide range of support needs that may vary in intensity over time, so a wider range of housing and assistance options is required to meet their needs'.[320] The report identified a need for 'additional investment … in stable, long-term accommodation for people with a mental illness'.[321]

In its 2009 mental health strategy, the Victorian Government has acknowledged the challenges it faces in regard to increasing demand for mental health services. It recognises that on the basis of population growth alone, over the next 10 years the numbers of people with a mental illness requiring access to services will increase. In the strategy the Victorian Government has stated its commitment to developing a plan to estimate future demand for mental health services. [322]

The Victorian Government has acknowledged the need to focus on increasing accommodation and support options, issues identified by the Boston Consulting Group. The mental health strategy takes an initial focus on people with a mental illness who are homeless or at risk of homelessness, stating that it will:

> Give people with enduring psychiatric disability who are homeless or at risk of homelessness greater access to individually tailored packages of psychosocial outreach support linked to a range of secure and affordable long-term housing options.[323]

It also commits to exploring opportunities to increase accommodation options through 'new and existing social housing, including that provided by Housing Associations, and new housing and support models'.[324]

The Victorian Government's new measures in regard to homelessness and mental illness are a starting point, but are specific to a small population of people with a mental illness and less focused on preventing homelessness. The Boston Consulting Group suggested that to prevent homelessness among

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[318] BCG, *Improving Mental Health Outcomes in Victoria*, p.40 [see Footnote 314].

[319] BCG, *Improving Mental Health Outcomes in Victoria*, p.42 [see Footnote 314].

[320] BCG, *Improving Mental Health Outcomes in Victoria*, p.42 [see Footnote 314].

[321] BCG, *Improving Mental Health Outcomes in Victoria*, p.72 [see Footnote 314].

[322] Department of Human Services (DHS) (2009) *Because mental health matters: Victorian mental health strategy, 2009-19*. Mental Health and Drugs Division, DHS, Melbourne, p.29.

[323] DHS, *Because mental health matters*, p.15 [see Footnote 322].

[324] DHS, *Because mental health matters,* p.15 [see Footnote 322].

people with mental illness, there is a need to make available a wider range of options. The Mental Health Council of Australia also emphasises that 'appropriate housing is required to complement treatments that have replaced institutionalised care, or such procedures will be ineffective'.[325]

Recommendations

8.1 That the Victorian Government develops a housing strategy for all people with a mental illness highlighting the links between accommodation, support, treatment and recovery and communicates its plan to implement the accommodation outcomes and opportunities for people with a mental illness.

8.2 That the Victorian Government invests in new stable, long-term accommodation for people with a mental illness linked to existing coordination and support packages.

8.2.1 Clinical residential services

For some people with a mental illness, access to residential clinical based treatment services is essential due to the nature and extent of their illness. Such treatment can be for extended periods, in which case consumers are being accommodated in treatment facilities. These treatment services can be provided on a voluntary or involuntary basis. Involuntary treatment is sanctioned under the *Mental Health Act 1986*. This legislation is currently under review to align the Act with developments in human rights in Victoria.

As outlined above, the types of clinical residential treatment facilities include SECUs, CCUs and PARC services. While these are not forms of ongoing or permanent accommodation, for many people with a mental illness, stays in these facilities can be for extended periods. The Committee heard that when suitable alternative accommodation options are not available, preventing discharge from facilities, this can impact on people's quality of life, their potential to work towards a recovery goal and their ability to sustain tenancies in the community.

Evidence received by the Committee indicated that the level of timely access to these services is affected by 'system blockages' in the mental health service system. The Victorian Government has acknowledged these blockages and the subsequent pressures on the system.[326]

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[325] Mental Health Council of Australia (2009) *Home Truths – Mental Health, Housing and Homelessness in Australia.*, Mental Health Council of Australia, Canberra, p.23.

[326] Department of Human Services (DHS) (2007) *An analysis of the Victorian rehabilitation and recovery care service system for people with severe mental illness and associated disability: Project report.* DHS, Victorian Government, Melbourne.

Secure Extended Care Units

The Committee heard from numerous individuals and organisations that there is a critical shortage of placements in SECU. Secure extended care beds are designed to provide intensive treatment and support for consumers with severe and unremitting symptomatology together with associated significant disturbance in behaviour that inhibits their capacity to live in the community. SECU provide a secure, structured environment, generally located on hospital sites with acute mental health units. They represent the highest level of care on the continuum of mental health services and provide extended clinical treatment, supervision and support. In June 2008, the Victorian Government funded 103 beds, which was unchanged from 2003-04. According to DHS information provided to the Committee, the state-wide average length of stay in SECUs is 232 days, with the regional averages ranging from 27 days to 563. In December 2008, these beds were funded at $425 to $435 per day.

In 2007, the Victorian Government identified two groups of consumers in regard to the length of stay. The first comprises consumers who generally stay for periods longer than two years. It was also recognised that 'SECU had the highest proportion of consumers staying for four years or more, which was associated with high levels of behavioural disturbance and symptomatology'.[327] The second group tended to stay for up to 12 months, to be younger, prone to aggression and to have issues with substances.

The report identified that 'bed blockage' is 'clearly evident in SECUs'. Furthermore, it concluded that, on average, at any given time there are up to eight consumers waiting for a vacancy in each SECU.[328] There are currently eight SECUs across Victoria. Based on the Victorian Government's figures provided to the Committee approximately 64 high-risk consumers require placement in a SECU facility.

In addition, the Office of the Public Advocate (OPA) released a report initiated by Community Visitors in April 2009 that further endorsed the findings of the Victorian Government's report. Over a 12-month period from May 2007 to June 2008, the Community Visitors collected information about long-stay consumers in their regular monthly visits. The findings were that 34 consumers were assessed as 'long-stay' – that is, more than six months. Of the 34 consumers, 18 had been in a SECU facility for between 6 and 20 years. The reasons provided for the 34 long-stay consumers included: not ready for discharge (9), waiting on a vacancy (10) and unable to find appropriate accommodation (15). Of the 15 consumers who were unable to find appropriate accommodation, six were people with a co-existing intellectual disability (two with autism). They were aged between 46 and 52 years and in

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[327] DHS, *An analysis of the Victorian rehabilitation and recovery care service system for people with severe mental illness and associated disability*, p.22 [see Footnote 326].

[328] DHS, *An analysis of the Victorian rehabilitation and recovery care service system for people with severe mental illness and associated disability*, p.22 [see Footnote 326].

most cases their primary diagnosis is an intellectual disability.[329] These six individuals were waiting on a placement in shared supported accommodation (SSA) in Disability Services. This demonstrates the inter-connections across the disability and mental health systems. In addition, it highlights that the mental health sector faces similar challenges to the disability sector regarding the need for strengthening responses to people with complex and multiple needs.

Individuals and organisations that provided evidence to the Committee explained their experiences of the inability to access SECUs. This included organisations that expressed challenges in gaining access to SECUs for consumers of their services or struggled to get the 'throughput' in their own services.[330] SECU managers recognised that approximately 25 per cent of individuals could receive the necessary levels of support in a less restrictive setting but are unable to relocate to a more suitable environment due to the lack of appropriate accommodation and support options.[331] Subsequently, consumers can be inappropriately placed in acute units while waiting for these beds. One manager, Ms Tamara Irish, Ballarat Adult Community Psychiatric Services, expressed a view that there are two alternative options to SECU: more home-based outreach or a step-down SECU because 'the movement from what is, in fact, … a very contained, very restrictive environment is quite difficult for people'.[332]

One family carer described the experience for her and her son when a placement in a SECU facility was unavailable:

> **One family carer's experience**
>
> My son has had his illness for 25yrs and has over the years steadily got worse; because of the lack of intervention or dare I say lack of hospital beds. I so admire my son, it takes great guts to live with his illness…
>
> Not taking care of himself is one of the signs he is becoming more unwell because he normally is so fastidious about his home and person…
>
> My son was admitted to hospital boxing day 06 by his case manager because he was so unwell. We had been *promised* a bed in the secure extended care unit early September 06 for a change of medication that required constant monitoring and still requires monitoring. It was his psychiatrist who wanted him admitted but still we had to wait, once

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[329] Office of the Public Advocate (OPA) (2009) *Long-stay patient project: Full report*. Office of the Public Advocate, Melbourne.

[330] For example, see *Committee Transcript*, 20.11.08, p.7 (Ballarat Health Services); *Committee Transcript*, 22.10.08, p.9 (Carers Victoria); *Submission* 100, (Office of the Public Advocate).

[331] Department of Human Services (2008) *Because Mental Health Matters: A New Focus on Mental Health and Wellbeing in Victoria*. DHS Consultation Paper, Victorian Government Publishing Service, p.93.

[332] *Committee Transcript*, 20.11.08, p.15 (Ballarat Health Services).

> again no hospital beds available, while my son suffered the effects of his illness in the community…
>
> It is known that the sooner an episode is treated, with change of medication and a safe environment for this to take place the better the outcome and that unless this happens the more engrained the paranoia becomes which is what has happened in my son's case.
>
> The fact that we have only 25 acute care hospital beds 6 SECU beds and 2 adolescent beds a total of 33 beds in the whole of greater Gippsland dictates to the conditions they live in when they are unwell and unable to take care of themselves and I mean unable to care for themselves in an appropriate manner in the community with or without support … this is why they need a safe place…[333]

Participants in the Inquiry told the Committee that the shortage of stable, long-term accommodation options can prevent consumers leaving SECU facilities. Ms Leesa Cornthwaite, former medical officer at a SECU facility, explained that:

> To discharge complex patients with high needs to some of the available SRS options would result in an unsuitable level of supervision or support for the person involved and/or concerns that the patient may potentially regress or revert to their pre-rehabilitation mental health status and level of function.[334]

The Committee heard that the consequence for people with a mental illness who no longer require the level of support and treatment provided by SECU, but have no other accommodation option, is that their freedom and movement is restricted and they are unable to participate in the community, contributing to further marginalisation. In addition, such environments can be 'un-therapeutic' for individuals no longer requiring this level of treatment and support.[335]

The Committee also heard from the Victorian Institute of Forensic Mental Health (Forensicare) regarding access to SECU facilities. Forensicare is responsible for the provision of adult forensic mental health services in Victoria. In its submission Forensicare stated that since opening in 2000, the Thomas Embling Hospital has struggled to meet the demand for inpatient care and treatment from prisons, courts and the mental health sector. The demand for this service has 'increased steadily, and prisoners requiring admission are now frequently required to wait in prison for up to a month, as are people ordered by courts to be detained in the hospital'.[336] It suggests that a key factor leading to these pressures relates to the use of the program by consumers who are eligible for SECU, but cannot gain access. Forensicare suggests that:

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[333]   *Submission* 135, pp.2-5 (L. Douglas).

[334]   *Submission* 7, p.2 (L. Cornthwaite).

[335]   *Submission* 7, p.1 (L. Cornthwaite).

[336]   *Submission* 122, p.5 (Forensicare).

> The development of additional secure beds for high risk, long stay acute patients who are not safe to return to the community will free up capacity in existing forensic and adult acute inpatient facilities.[337]

One program piloted to respond to long-stay consumers in SECU is the Integrated Rehabilitation and Recovery Care (IRRC) program. This was established in 2006 as a pilot to three metropolitan SECU sites to support the transition of long-stay consumers into the community. The program aims to support the successful transition of long-stay consumers from bed-based extended care clinical facilities to the community by providing a dedicated, intensive, sustained and integrated clinical and psychosocial support response. The program is a collaborative initiative between the PDRSS and clinical mental health service sectors and targets consumers with severe mental health issues and enduring psychiatric disability.[338] In December 2008, the program had supported 14 long-stay consumers into the community. An evaluation was underway, with a state-wide rollout planned.

Participants in the Inquiry supported the IRRC program. For example, the OPA stated that acquiring secure and affordable accommodation is critical if people with a mental illness are to maintain a level of stability. The OPA acknowledged the program, which they said 'targets people who have remained in CCU and SECU for extended periods, but whose discharge requires an intensive period of case management support'.[339]

The IRRC program has since been extended as the Building Intensive Psychiatric Disability and Rehabilitation Support Service package. It aims to build on the outcomes of the IRRC program, providing intensive clinical and psychosocial support to individuals with high support requirements. The Victorian Government has allocated $3.75 million in recurrent funding to deliver a total of 50 packages of intensive psychosocial rehabilitation outreach support. The service model will be evaluated in three years to determine its success in achieving the stated outcomes and the efficacy of local arrangements and targeting.

A second strategy recently instigated in response to the issue of blockages in SECU facilities is a new SECU diversion and substitution initiative. In 2009 the Victorian Government committed $3.6 million in recurrent funding for 30 intensive clinically focused treatment and support packages targeted to the highest need consumers on the SECU waiting list. According to the Victorian Government, the initiative:

> aims to enable the consumer to be adequately and safely supported in the community by the MST [mobile support team] team while they wait for admission to a SECU. The service model will also provide a community based

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[337]   *Submission* 122, p.5 (Forensicare).

[338]   DHS, *An analysis of the Victorian rehabilitation and recovery care service system for people with severe mental illness and associated disability*, p.4 [see Footnote 326].

[339]   *Submission* 100, p.24 (OPA).

alternative to SECU admission for high need consumers currently being supported in inpatient settings (acute and forensic) who fit the SECU eligibility criteria.[340]

The Committee acknowledges that these recent initiatives are positive steps towards addressing system blockages in SECU. With any new initiative, there is value in embedding mechanisms for future measurement of their success. The Committee remains concerned, however, that while the Victorian Government has increased support and coordination for people with a mental illness who have been falling between the gaps, there has been no equivalent investment in accommodation options.

Recommendation

8.3   That the Victorian Government increases the level of availability of SECU beds on the basis of population based planning and the knowledge that numbers of people with a mental illness requiring services are likely to increase.

Community Care Units

The Committee heard that CCUs provide a type of residential treatment and support that is well suited to many people with a serious mental illness requiring 24 hour clinical support in the community. CCUs have been operating since 1996 and provide medium to long-term accommodation, clinical care and rehabilitation services. Unlike SECUs, they are not locked facilities. They are located in residential areas and provide a 'home-like' environment where people can learn or re-learn everyday skills necessary for successful transition to community living.

All 21 area mental health services (AMHS) have access to CCU beds. At June 2008, there were 336 beds in Victoria. This represents an increase of 24 beds in CCUs since the July 2003 financial year. The Department of Health acknowledges that while it 'is envisaged that people will move through the units to other community residential options, some consumers will require this level of support and supervision for a number of years'.[341] According to DHS information provided to the Committee, the state-wide average length of stay in CCUs is 193 days, with the regional averages ranging from 53 days to 404. In December 2008, these beds were funded at $297 to $300 per day.

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340   Department of Health (2009) *Request for proposal: Secure and Extended Care Unit (SECU) Diversion and Substitution initiative.* Mental Health and Drugs Division, Victorian Department of Health, Melbourne, p.3.

341   Department of Human Services (2007) *Community care (CCU) and secure extended care (SECU) units: Program management circular.* Mental Health and Drugs Division, DHS, Victorian Government, Melbourne, p.2.

There was significant support for the community care model in evidence given to the Committee. The Director of Mental Health Services at Peninsula Health, Associate Professor Richard Newton, told the Committee that:

> People who have got well-established schizophrenia actually do quite well within a supported accommodation service like the community care unit. In fact, compared to the previous accommodation, the community care unit style of accommodation increases their quality of life and increases their social networks. Their number of friends increases, and they feel comfortable making friendships within that group.[342]

Families that were carers validated this view, with many expressing a desire to see their family member placed in a CCU. For example, one family carer explained that her son:

> has just spent 12 months in the new CRCU units, where, I must say, the care was excellent. And with assistance on a day to day basis, it was 24/7 care, that they were there, available in the office.
>
> They had their own units, their own TV, own cooking – they pay rent which covers their electricity, and their rent. They go and buy their own food. But because they lose all their social skills it can even include sitting down and making a recipe – thinking what we're going to have for a meal, making shopping lists, budgets, how to wash a fridge out. Even though I know that I have taught my son all these things, they lose their skills when they're unwell and untreated.[343]

Despite this support for the model, individuals and organisations told the Committee that there are high levels of unmet demand for CCU beds. As with SECU facilities, the Victorian Government project that analysed the rehabilitation and recovery service system identified demand pressure on CCUs. It noted that limited pathways beyond CCUs were a key issue impacting on unmet demand.[344]

The OPA reported similar results. It noted that there were 39 consumers who had resided in a CCU facility for longer than two years. Of these, nearly half were unable to move on due to 'no suitable accommodation available'.[345] The Health And Community Services Union (HACSU) told the Committee that there are specific pressure points with regard to CCU bed distribution across the state.[346] Evidence given to the Committee confirmed the view that there is a shortage of accommodation pathways with adequate support to enable consumers to leave CCU facilities.

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[342]   *Committee Transcript*, 5.11.08, pp.6-7 (Peninsula Health and Peninsula Carer Council).
[343]   *Committee Transcript*, 21.10.08, p.4 (L. Douglas).
[344]   DHS, *An analysis of the Victorian rehabilitation and recovery care service system for people with severe mental illness and associated disability*, p.24 [see Footnote 326].
[345]   OPA, *Long-stay patient project*, p.19 [see Footnote 329].
[346]   *Submission* 121A, p.10 (HACSU).

An additional issue was raised regarding the blurring of boundaries between CCUs, PARC and residential rehabilitation. HACSU provided the following information:

> Currently the Shepparton/Goulburn Valley area has been denied a CCU, making this community one of only three in Victoria that does not have access to its own CCU. Promised by the State Government, in the 2006 State Budget the new 'CCU' has in fact now turned out to be an existing RRS [residential rehabilitation service] that was merely moved into a new building. Although it is described as a 'unique' and 'new partnership', it is actually the same as all RRSs, that is, a service managed by a PDRSS with clinical input provided by the local mental health service.[347]

Goulburn Valley Mental Health provided a description of the service that it provides, noting that there are no clinical staff in the facility, which is a critical component of the CCU model.[348] HACSU expressed its concern that this 'loosening of boundaries' minimises the opportunities for people whose clinical needs mean that they cannot be safely located in a PDRS service. It advised the Committee that 'there is a need to clarify and reaffirm the role and function of CCUs, rather than blurring their distinctive role with that of a RRS. HACSU considers the Goulburn Valley has a need for a CCU and that a CCU should be provided as promised in 2006'.[349]

The Committee acknowledges that there is an emerging potential for service model boundaries to be blurred.

Prevention and Recovery Care

DHS explains that Prevention and Recovery Care (PARC) services 'are a new supported residential service for people experiencing a significant mental health problem but who do not need or no longer require a hospital admission'.[350] The core aims of PARCs are to improve the health outcomes of people with a serious mental illness who become acutely unwell and to prevent avoidable admissions to acute units and avoidable re-admissions following an acute episode. PARC services usually provide services through a partnership between a clinical service and a PDRSS provider.

At June 2008, there were 78 PARC beds across Victoria. While additional PARCs are still being developed, facilities are currently not available in all AMHS. The state-wide average length of stay in PARCs was 20 days in June 2008. In December 2008, these beds were funded at $351 per day.

The Committee heard that this new 'step-up, step-down' facility is proving to be a successful model. Many individuals and organisations supported the principle

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347   *Submission* 121A, p.11 (HACSU).
348   *Committee Transcript*, 18.11.08, p.10 (Goulburn Valley Mental Health).
349   *Submission* 121A, p.11 (HACSU).
350   Department of Human Services (2005) *Specialist mental health service components.* Mental Health and Drugs Division, DHS, Victorian Government, Melbourne, p.3.

behind PARCs and felt they add value to the service system. For example, the Clinical Manager at Goulburn Valley Area Mental Health Service commented that:

> Basically I see PARC services as an extremely valuable point to discharge out of the ward, speed it up, get the person back into independent living scenario so we can assess that but it also gives us, as a service, some breathing space to look at some bigger picture stuff. Do they function well in independent living? What's their social circumstances? Do they have support structures? So it gives us just a breath to go, right, what do we need to actually get them back into the community that's going to be sustainable.[351]

The level of support for PARCs from service providers and carers was confirmed in the 2008 report of a Victorian Government commissioned external evaluation of the facilities. Furthermore, findings were reported that 'PARC services are highly regarded by ex-clients and seen as providing appropriate and useful care and support in a secure and normalised environment'.[352] In view of their perceived success in preventing hospitalisation, many individuals and organisations recommended greater investment in PARC facilities.[353] In particular, a case was argued by NorthWestern Mental Health to work towards one PARC in every AMHS.[354]

The PARC model was rolled out by the Victorian Government in 2003, following an earlier demonstration project to pilot the model. In December 2008, an external evaluation of the PARC model was undertaken that recommended the model should continue.

The current spread of PARCs across AMHS is outlined in the Table 8.2.1-1. Of the total 88 PARC places operational across the state, the Victorian Government has a further 68 beds planned. In metropolitan Victoria, there are 68 existing beds and 50 planned and in various phases of development. In rural and regional Victoria, there are 40 beds in operation, with 8 beds planned for the Bendigo Youth PARC. An additional 30 beds are planned in the Dandenong Area Mental Health Service, with the Victorian Government yet to determine the breakdown between Residential Rehabilitation Service beds and PARC beds.

The Committee supports the continued expansion of PARCs at the current rate of development and considers that all AMHS should be serviced by a PARC facility.

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[351]   *Committee Transcript*, 18.11.08, pp.9-10 (Goulburn Valley Mental Health).

[352]   Dench McClean Carlson (2008) *Final report for Evaluation of the Prevention and Recovery Care (PARC) Services Project*. Dench McClean Carlson Corporate Advisory, Melbourne, p.v.

[353]   *Submission* 100, p.29 (OPA); *Submission* 121A, p.12 (HACSU); *Submission* 119, p.13, (NorthWestern Mental Health); *Submission* 126, p.4 (Mind).

[354]   *Submission* 119, p.1 (NorthWestern Mental Health).

Table 8.2.1-1: PARCs across AMHS in Victoria, 2009

Area mental health service	PARC	PARC Open	PARC Planned	Beds
Metropolitan Service Areas				
Central East	Linwood, Box Hill	10		10
Dandenong	Springvale PARC	10		10
Inner South East	Alfred PARC	10		10
Inner Urban East				0
Inner West	Arion PARC, Flemington	8	2	10
Mid West	Burnside PARC*	10		10
Middle South	Monash PARC	10		10
North East				0
North West	Broadmeadows PARC		10	10
Northern	Preston PARC		10	10
Outer East	Ringwood PARC		10	10
Peninsula	Peninsula PARC		10	10
	Frankston Youth PARC		8	8
South West	Burnside PARC*	10		10
Rural Service Areas				
Barwon	Barwon PARC	10		10
Gippsland	Gippsland PARC	10		10
Glenelg (South Western)				0
Goulburn & Southern	Shepparton, Ambermere PARC	10		10
Grampians				0
Loddon Campaspe / Southern Mallee	Bendigo PARC (Golden Oaks)	10		10
	Bendigo Youth PARC		8	8
Northern Mallee				0
North Eastern Hume				0
TOTAL		**98**	**68**	**166**

* Collectively Mid West and South West AMHS have 20 beds from the refurbishment of Burnside.

Nb: The additional 30 beds in the Dandenong AMHS are not included in this table.

Source: Victorian Government (2008, 2009) Data provided to Family & Community Development Committee; Department of Human Services website, Adult Mental Health Services. Accessed on 26 November 2009 from http://www.health.vic.gov.au/mentalhealth/services/adult/.

Recommendation

8.4   That the Victorian Government continues the current rate of expanding PARC services and extends the model to all 21 area mental health services in Victoria.

8.2.2   Non-clinical residential support services

For people with a severe mental illness that requires ongoing support to live independently outside the clinical treatment system, the PDRSS sectors provide a number of support options. The non-government PDRSS sector is a critical component of the mental health sector and sits within the health system, but is

distinct in that it does not provide clinical treatment. It provides a psychosocial model of recovery in transitional residential settings and in home-based support.

The previously named Housing and Support Program was operated by the PDRSS sector. The Committee heard that the PDRSS sector struggles to provide the level of service required by consumers; that is, in the number of hours and in the intensity of support required. One family carer stated that:

> PDRSS services provide extra support by having activities when the client is well enough to go and feels they can cope. The client has to choose to go to these activities and sometimes they are not well enough to make that choice.
>
> His caseworker is wonderful and has fought alongside me to get treatment for my son, but their work load is great and they themselves are constrained by the system and they are so frustrated when they know their client needs extra help, maybe a stay in hospital to stabilise them but there are no beds.[355]

PDRSS provide residential rehabilitation services, home-based outreach support and specialist supported accommodation, which is discussed below.

PDRSS residential rehabilitation services

Residential Rehabilitation Services (RRS) are non-clinical facilities that are operated by the non-government PDRSS sector. They provide intensive psychosocial rehabilitation and support in group accommodation to prepare residents to live independently in the community. According to DHS, the 'residential rehabilitation model requires a commitment by clients of typically one to two years of active engagement to enable a process of individual growth and change leading to independent living'.[356] At June 2008 there were 101 beds in adult RRS, and 163 beds in youth RRS. There was a small reduction of 4 beds in adult RRS from July 2003 to June 2008, with an equivalent increase in youth RRS of 4 beds.

DHS has recognised demand pressures on residential rehabilitation services. It estimated that for each adult RRS vacancy in 2007, there was an average of four people seeking a placement, and an average of five people for each youth RRS vacancy. These support services are limited as the sector is under-funded in contrast to the service value provided in prevention and recovery.

Some participants in the Inquiry believe there is a need to increase the bed capacity of RRS, particularly in rural and regional areas.[357] This was linked to

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[355] *Submission* 135, p.3 (Ms L Douglas).

[356] Victorian Government (2008) Data provided to Family & Community Development Committee.

[357] *Submission* 119, p.1 (NorthWestern Mental Health); *Committee Transcript*, 19.11.08 , p.3 (Bendigo Health Care).

views expressed that people with a mental illness need improved access to early intervention support and assistance in the community.[358]

The Committee heard that residential rehabilitation programs have a key role in providing time-limited rehabilitation and support to assist the consumer to recover sufficiently to live 'more independently' in the community. They provide assistance in developing or regaining skills to enable each resident to deal with daily living activities, developing confidence to commence or continue schooling, training or employment, as well as supporting positive contact with their family and friends. RRS are transitional, and therefore do not offer permanent accommodation. Residents are supported to move into more independent accommodation after a period of approximately two to three years of the program.[359]

Neami comments that in the context of accommodation models, it 'does not think that residential rehabilitation is an especially useful model, as it is transitional. The consumer's tenure at the accommodation is based upon time, as well as their ability or desire to engage with the service in ways prescribed by the service. These limits require the consumer to change in order to fit in with the service'.[360] The Mental Illness (MI) Fellowship similarly argue that:

> In our considerable experience as a provider of residential rehabilitation, we have explored congregate care in some depth. Our conclusion is that the only group that consistently derives therapeutic benefit from congregate care is young people aged 16-25.[361]

The Committee heard, therefore, that the model of residential rehabilitation services is more suited to a younger population cohort than older people with a mental illness. As noted above, the Committee heard that people with a mental illness generally seek to live independently in the community with adequate levels of support rather than in congregate models of supported accommodation.

The Committee found, therefore, that there are mixed views relating to RRS and the capacity of the model to meet the needs of people with a mental illness.

Recommendation

8.5   That the Victorian Government evaluates the model of Residential Rehabilitation Services with a view to determining its effectiveness in meeting its stated objectives.

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[358]   *Submission* 100, p.23 (Office of the Public Advocate); *Committee Transcript*, 20.11.08, p.69 (Ballarat Adult Community Psychiatry Service).

[359]   *Submission* 126, p.10 (Mind).

[360]   *Submission* 75, p.2 (Neami).

[361]   *Submission* 98, p.14 (Mental Illness Fellowship Victoria).

PDRSS supported accommodation

Supported accommodation is a PDRSS service-model that provides long-term support and accommodation to people with a severe and enduring mental illness and an associated disability resulting in the need for long-term support to maintain their accommodation and inclusion in the community. It is a slow-stream model and may continue for a long period, or even for life. There are two models – 24 hour onsite (generally provided in shared congregate accommodation environment) and a mix of onsite support and after-hours on-call (generally in the person's own accommodation). Government organisations and a number of Community Health Services provide PDRSS. DHS enters into Funding and Service Agreements with participating organisations to deliver a suite of community-based supports.

Currently there are 104 beds provided in seven sites.

PDRSS home based outreach support

A key component of the PDRSS sector is HBOS. While this does not involve the specific provision of residential support, participants indicated that HBOS is relevant to this Inquiry in view of its focus on providing support to people with a mental illness to live as independently as possible in the community. HBOS provides support to consumers living in their own homes, or other community residential settings. The services provide training in social and living skills in the resident's home, and focus on the activities and interactions of everyday life.

Outreach models can accommodate a variety of support needs required by individuals. The Committee heard that HBOS offers individualised and cost-effective support to people living in independent accommodation and is a successful mechanism with which to extend and increase the support options for people with a mental illness. It has a number of sub-programs, including standard HBOS (provided by 39 PDRSS) and intensive HBOS (provided by 28 PDRSS). Intensive HBOS was established in 2002 as an initiative of the Victorian Homelessness Strategy, with the intention of providing an improved service response to people who are homeless or at risk of homelessness and have an enduring and severe mental illness and associated disability. Frequently these individuals are transient, difficult to engage and often not connected to mental health services. The key distinction in the level of intensity is in the worker ratio. That is, standard HBOS has a worker to consumer ratio of 1:10 whereas intensive HBOS has a ratio of 1:5.

Several individuals and organisations stressed the need for additional resources to be allocated to HBOS.[362] In 2007, the Victorian Government acknowledged

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[362] *Committee Transcript*, 21.10.08, p.5 (SNAP Gippsland); *Committee Transcript*, 21.10.08, p.5 (Barrier Breakers); *Committee Transcript*, 6.12.08, p.12 (Murray Mallee Community Health Service); *Submission* 96, p.9 (VCOSS); *Submission* 98, p.12 (Mental Illness Fellowship Victoria); *Submission* 126, p.4 (Mind).

it is a service in demand.[363] The hours vary slightly depending on the service provider. According to participants in the Inquiry, the ratio outlined above translates to approximately four hours per week per consumer for standard HBOS. If a consumer is eligible for intensive outreach, they can receive up to eight hours per week.[364]

As noted in earlier sections, the Victorian Government has recently released recurrent funding of $15 million over four years to provide intensive integrated clinical and psychosocial rehabilitation support packages to people on waiting lists for SECU beds.[365]

MI Fellowship Victoria provided an overview of a model they refer to as 'recovery in place' that would involve expanding the current HBOS approach. Recovery in place is a model where the consumer stays in the home and the three key pillars of treatment and support are wrapped around the individual. These pillars are the specialist services of clinical treatment, tenancy support and psychosocial rehabilitation. The model requires one service to be responsible for the coordination of the three services. MI Fellowship suggests that this model would offer people with a mental illness the most suitable conditions in which to recover. It advocates for greater investment in social housing and HBOS to achieve effective recovery in place. MI Fellowship argued that this will reduce some of the capital and recurrent costs associated with residential treatment settings.[366]

> Home-based psychosocial rehabilitation support is the vital ingredient that can make the difference between long-term, quality, independent living, and unstable, poor quality, cyclical stays in inpatient care and various forms of transitional accommodation. The allocations of individual HBOS support per household should be increased to take more account of variable needs.[367]

This model is similar to the Housing and Support Initiative that has been rolled out in New South Wales. The initiative was discussed further in Chapter Six.

MI Fellowship also explains that current funding levels of HBOS permit them to provide approximately three hours per week to be spent with residents in their own homes to assist with budgeting, relationships, housekeeping, clinical care coordination issues and activities to assist the consumer to integrate into the community. MI Fellowship state that:

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[363]   DHS, *An analysis of the Victorian rehabilitation and recovery care service system for people with severe mental illness and associated disability*, p.30 [see Footnote 326].

[364]   For example, *Committee Transcript*, 6.12.08, p.4 (Murray Mallee Community Health Service); *Submission* 98, p.12 (Mental Illness Fellowship Victoria).

[365]   Victorian Government (2009) *Victorian State Budget 2009–10: $150.6 million boost to mental health reform*. Accessed from <http://www.budget.vic.gov.au/domino/Web_Notes/budgets/budget09.nsf/d6e571e551b ef80eca2572bb002bcea7/692ba59394974a52ca2575ac004147c9!OpenDocument> on 16 October 2009.

[366]   *Submission* 98, p.11–12 (Mental Illness Fellowship Victoria); See also, *Submission* 121A, p.13 (HACSU).

[367]   *Submission* 98, p.12 (Mental Illness Fellowship Victoria).

> This works for many, but we need additional hours. There has not been sufficient growth in the HBOS program in recent years to support the demands now felt in the community for this form of individualized, in-reached service.[368]

MI Fellowship refer positively to the Victorian Government's promise to deliver graduated packages of HBOS for households in varying levels of need, outlined in the mental health reform strategy, *Because Mental Health Matters*.

HBOS providers have nomination rights to more than 140 transitional housing properties. In a partnership with transitional housing providers, HBOS services can allocate a consumer with a severe mental illness into transitional housing properties while they wait for more stable, long-term accommodation (usually through the Office of Housing). HBOS provide outreach support to achieve this goal.

This program is a variation on the former Housing and Support Program (HASP). The HASP provided access to long-term Office of Housing properties, whereas the current program provides access to transitional houses, which is less secure. SNAP Gippsland commented that the 'Victorian Housing and Support Program of the early to mid nineties is proof of the benefits of secure, appropriate, affordable housing'.[369] It went on to explain that:

> This end destination housing, spot-purchased, close to services and amenities, with tenancy management by the Office of Housing, and support to the residents provided by PDRS services, change the lives of people with mental health problems. Many PDRS services still have nomination rights to the remnants of this program.[370]

Carers Victoria, however, suggested that the program

> was highly successful and almost a victim of its own success, because when people with long-term psychiatric disabilities were in secure housing of their own with support, they actually got better and then needed less support. The problem then was that there was no turnover to provide housing support for other people, because there was not enough supply of housing to provide replacement stock. That program has not grown.[371]

VICSERV also commented on the

> housing and support program which … through the early 1990s funded about 1200 properties and support placements. It was based on an assumption that people would either move through the properties or that other properties would be provided, and it was a roaring success. People were able to establish a home finally, and are still not moving; it is permanent housing. The housing

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368 *Submission* 98, p.12 (Mental Illness Fellowship Victoria).
369 *Committee Transcript*, 21.10.08, p.4 (SNAP Gippsland).
370 *Committee Transcript*, 21.10.08, p.4 (SNAP Gippsland).
371 *Committee Transcript*, 22.10.08, p.10 (Carers Victoria).

was never replaced for that service to gain access to. So in a way we have got a sort of a mismatch with in some cases support resources that are diminishing as people become stabilised, but the housing is not replaced for others to access. [372]

SNAP Gippsland recommended that 'this effective program could still be revitalised by the Department of Human Services now, by the investment in replacement properties when residents no longer require the support of the PDRS service'.[373]

Recommendations

8.6   That the Victorian Government re-establishes an evaluated model of the Victorian Housing and Support Program to increase accommodation options for people with a mental illness.

8.7   That the Victorian Government funds additional hours for the provision of standard and intensive home based outreach services across all psychiatric disability rehabilitation and support services.

8.3   Accommodation, support and connectedness within the mental health system

In addition to the significant concerns about accessibility of specialist mental health services, the Committee heard about gaps in the mental health service system that have implications for people with a mental illness who need support and accommodation. In particular, individuals and organisations referred to gaps between clinical based residential treatment and the move into the community. The issue of limited pathways were identified in the previous section, particularly in regard to system blockages.

Furthermore, the evidence received by the Committee suggested that the issue of accommodation for people with a severe mental illness has not been fully resolved since the closure of institutions. The Mental Health Council of Australia (MHCA) sees this as an issue across all jurisdictions in Australia. MHCA acknowledges that the closure of institutions was (and is) an important progression in the response to mental illness, noting that such facilities have broadly been considered 'an unhealthy mix of substandard care and human rights abuses'.[374] It suggests, however, that the process of closing institutions has been incomplete, stating that in most states and territories:

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[372]   *Committee Transcript*, 30.4.09, pp.4-5 (VICSERV).

[373]   *Committee Transcript*, 21.10.08, p.4 (SNAP Gippsland).

[374]   Mental Health Council of Australia (MHCA) (2009) *Home Truths – Mental health, housing and homelessness in Australia*. Mental Health Council of Australia, Canberra, p.22.

> The closure of institutions was not balanced with the development of sufficient housing options that had adequate support for people to build community connections and focus on their psycho-social recovery.

> The problem with deinstitutionalisation was that it was not accompanied by any clear concept of people's housing needs as well as their needs for health care and protection within the community.[375]

Based on the evidence received by the Committee, this disjuncture between the health needs and accommodation needs of people with a mental illness appears to be a factor in Victoria.

Previous studies and reviews of mental health services have identified gaps in the available options in accommodation and residential support for those consumers leaving clinical based treatment services and intensive residential support provided by the PDRSS sector. In 2006, the Boston Consulting Group identified these gaps in its report to the Victorian Government. It referred to this issue as the 'lack of connectedness' in the mental health sector, noting that 'the State and Commonwealth funded clinical sectors are not sufficiently integrated, leading to poor continuity of care as individuals move between service providers'.[376] As outlined earlier in this chapter, the Boston Consulting Group reported specifically on the under-servicing of people with an enduring and severe mental illness who require stable long-term accommodation.[377]

People with a mental illness for whom accommodation is a significant issue broadly fall into two categories. Firstly, people with a severe mental illness who frequently cycle in and out of extended treatment. Secondly, people with an enduring and severe mental illness (with an associated disability) who cannot be discharged, due to the lack of adequate accommodation and support options.

8.3.1 Mental illness and sustaining accommodation

The Committee heard that the transitional nature of extended care in mental health services can be particularly difficult for consumers needing treatment and trying to sustain their current accommodation. Mind argues that 'the ceaseless "transitionalism" that is characteristic of the entire system is itself bad for people's mental health".[378] Participants in the Inquiry stated that the current shortage of appropriate rental accommodation in the general community presents particular challenges for people with a mental illness following a period of treatment or rehabilitation. For example, Mind told the Committee that consumers in RRS:

> find it difficult to access suitable accommodation at the end of their stay in the program. This results in people who have been living in our programs moving

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[375]   MHCA, *Home Truths*, p.23 [see Footnote 374].

[376]   BCG, *Improving mental health outcomes in Victoria*, p.23 [see Footnote 314].

[377]   BCG, *Improving mental health outcomes in Victoria*, p.42 [see Footnote 314].

[378]   *Submission* 126, p.7 (Mind).

to unsatisfactory accommodation where they are more likely to be at risk of a relapse in their mental health condition. It also causes bottlenecks in our residential programs while the best accommodation opportunity for each person is sought.[379]

Mind goes on to suggest that these risks at times of transition can be associated with a change in medication or a key worker, but more often relate to the move from one transitional accommodation setting to another. Mind stated that similarly to clinical based facilities, residential rehabilitation services are only likely to be successful if an individual can access the right level of support and accommodation when required.[380]

Another issue raised before the Committee relates to the implications for people at risk of losing their current accommodation. MI Fellowship Victoria advised the Committee in its submission that:

> When length of stay is long, it is not uncommon for people to forfeit their other accommodation arrangements, thus intensifying their accommodation dependence on the treatment facility. However there is no intention in treatment facilities to provide long term accommodation; the logic of residential treatment is that one stays only as long as required for illness to stabilize and improve.[381]

The Victorian Government has indicated its awareness of this issue and implemented strategies to address the need for people with a mental illness at risk of homelessness due to the need for long-term treatment. This includes the Pathways project, which provides approximately 320 episodes of support in a year and has a focus on preventing homelessness. It also includes the High Risk Tenancy Project that was launched in May 2007, a regionally based program that provides 220 episodes of support per year to clients with complex needs.

Recommendation

8.8   That the Victorian Government extends the eligibility of the Pathways and High Risk Tenancy Projects to all Victorians with a mental illness who require residential based treatment and seek support to sustain their tenancies.

8.3.2   Accommodation options for enduring and severe mental illness with an associated disability

Participants in the Inquiry also raised the issue of the gap for consumers transitioning out of 24 hour treatment and support into the community. The available options for these individuals tend to be either a supported residential service or support from the PDRSS sector. Many participants presented a view

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[379]   *Submission* 126, p.3 (Mind).
[380]   *Submission* 126, p.2 (Mind).
[381]   *Submission* 98, p.9 (Mental Illness Fellowship Victoria).

that for people with an enduring and severe mental illness and associated disability these services are inadequate.

Privately funded SRSs are considered a part of the mental health service system. For example, the Victorian Government's analysis of the rehabilitation and recovery care service system for people with severe mental illness and associated disability includes pension-level SRSs. It states that SRSs form a 'significant element of Victoria's accommodation and support infrastructure for people with mental illness and psychiatric disability'.[382] As outlined further in Chapter Eleven, the Committee heard a consistent message that SRSs are generally not an adequate form of supported accommodation for people with an enduring and severe mental illness.

In regard to the capacity of the PDRSS sector, there are limitations on the sector to provide the levels of intense support required by those consumers ready to move from long-term residential clinical treatment into more independent community living arrangements. This is supported by the findings of the Boston Consulting Group, which noted that 'some key non-clinical services cannot provide sufficient support to people with a mental illness'.[383]

Many participants in the Inquiry stressed the importance of a continuum of service provision for people accessing the mental health service system. In particular, participants advised the Committee that people with a mental illness need pathways to be created for greater continuity and planned security whilst they are moving through the treatment system.[384] A critical link to effectively stabilising accommodation and reducing the number of hospitalisations for a person with a mental illness has been shown by many studies to be the 'existence of intensive case management'.[385]

The importance of adequate accommodation and support as an integral part of the response to people with a mental illness is also emphasised by Ms Catherine Robinson in her study of homelessness and mental illness. She concludes that 'what is needed is a system of accommodation, support, and mental health care with the capacity to form ongoing relationships with clients, and to respond to the destructive experiences layered under presenting disadvantage and distress'.[386]

A prerequisite of the PDRSS sector in providing support for a person to live independently in the community relates to a person's insight into and

[382]   DHS, *An analysis of the Victorian rehabilitation and recovery care service system for people with severe mental illness and associated disability*, p.11 [see Footnote 326].

[383]   BCG, *Improving mental health outcomes in Victoria*, p.23 [see Footnote 314].

[384]   *Submission* 98, p.11 (Mental Illness Fellowship Victoria).

[385]   Reynolds, A., Inglis, S. & O'Brien, A. (2002) *Linkages between housing and support – what is important from the perspective of people living with a mental illness.* AHURI Positioning Paper No.33, Australian Housing and Urban Research Institute, Swinburne/Monash Research Centre, p.9.

[386]   Robinson, C. (2003) *Understanding iterative homelessness: the case of people with mental health disorders.* AHURI Final Report No.45, Australian Housing and Urban Research Institute, UNSW-UWS Research Centre, pp.42-43.

acknowledgement of their mental illness. In a study exploring what people with a mental illness consider are key factors in helping them to stay housed, a number of attributes were found that potentially contributed to their ability to achieve accommodation stability. In addition to having a regular income (such as a pension) and living in suitable accommodation, acknowledging their mental illness was a key characteristic. Being supported by a program, such as those provided through PDRS services, was also identified as a key factor.

The issue of a person's insight into their mental illness is a further factor contributing to the distinction between clinical and non-clinical services. Gaining access to services in the PDRSS sector frequently requires people to have awareness of their condition, which some people regard as a limiting factor of the service. One PDRSS consumer (including a key worker in the day program and outreach support), explained that in his view the negatives of the current approach is that 'a person needs insight to use the current system. If a person doesn't have insight then they can't ask to access services available'.[387] Similarly, a carer commented that her son receives PDRSS support if 'he is well enough to go and attend their activities. They say that they have to choose to go there, but it's more – always not a choice. It's if they feel they can cope with their illness at that time'.[388]

In view of the requirement within the service system for a person to have awareness of their mental illness, a question arises in regard to accommodation and support options for people who have not acknowledged their mental illness and who are resistant to treatment. The Victorian mental health service system is episodic and aims to provide clinical treatment options for people when they are unwell, and a range of less intensive supports in the community when they have reached a point of stability that enables them to work towards recovery.

Participants in the Inquiry stressed, however, that the needs of people with a mental illness are not this simple and straightforward. The Chief Psychiatrist stated in regard to options for people who are treatment resistant and who potentially do not have capacity to gain insight into their mental illness:

> Some people in secure extended care units do not need 24 hour nursing staff or very heavy psychiatric input. But they remain vulnerable because they may have a coexisting intellectual disability, they may have coexisting acquired brain injury, or they may be unreliable in terms of using illicit substances. In fact what they need is security. But we do not have many other locked options because there is a whole other human rights argument about detaining people.[389]

NorthWestern Mental Health made a similar statement, noting that:

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[387] *Submission* 87, p.47 (Murree Mallee Community Mental Health Service).

[388] *Committee Transcript*, 21.10.08, p.5 (L. Douglas).

[389] Chief Psychiatrist (2009) Permission to use extracts from briefing, email received 10 December 2009.

consumers with complex and multiple needs, enduring disability and chronic risk require specifically tailored accommodation and support services, such as a specialist dual disability community residential unit for both respite and long term accommodation. For a small but often overlooked group of consumers currently residing in SECU, the development of secure life long care in a more permanent home-like environment is needed to ensure their right to stable and safe supported housing.[390]

The Victorian Government is aware of and acknowledges limitations in the current system. Firstly, in the analysis of the rehabilitation and recovery care service system, the DHS project report identified system gaps and quality issues, particularly in the context of accommodation options. It acknowledged that

While the preferred outcome is that consumers in SECU and CCUs be discharged to the community with clinical and PDRS outreach support, some consumers, due to the enduring nature of their psychiatric disability, require long-term access to stable and affordable accommodation with on-site, 24 hour, seven-day-a-week psychosocial support. These consumers have needs in excess of what can be provided in a cost-effective manner in the community by clinical ambulatory or PDRS services. Long-term accommodation and support options are currently limited to a small number of SASs or pension-level SRSs provided by the private sector.[391]

Secondly, the DHS mental health reform strategy, *Because Mental Health Matters*, states that a key focus will be on 'meeting the needs of those who currently fall through the gaps in service provision, particularly those who are not severely ill enough to be prioritised for specialist services but who are either at an early stage of their illness or who have concurrent health and social issues that put them at risk'.[392] The outcome has been recurrent funding for packages that provide care coordination for people with a severe mental illness and multiple needs. This care coordination has a focus on people at risk of homelessness.

The intention of the Building Intensive Psychosocial Rehabilitation Outreach Support initiative is to provide 50 new packages of flexible, scaled psychosocial rehabilitation support linked to a range of housing options for adults with severe and enduring mental illness and high level of psychiatric disability, who have a history of hospitalisation and entrenched homelessness or risk of homelessness.

A key issue in relation to this approach of providing packages of care coordination is that the availability of long-term, stable accommodation is critical.

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[390]   *Submission* 119, p.2 (NorthWestern Mental Health).

[391]   DHS, *An analysis of the Victorian rehabilitation and recovery care service system for people with severe mental illness and associated disability*, p.40 [see Footnote 326].

[392]   DHS, *Because mental health matters,* p.31 [see Footnote 322].

Recommendations

8.9	That the Victorian Government provides accommodation options for people with a mental illness who are receiving care coordination packages and require stable, long-term housing.
8.10	That the Victorian Government develops and pilots a long-term accommodation and support model for people with a mental illness requiring onsite, 24 hour, seven days a week psychosocial support with clinical oversight in a least restrictive environment.

8.4   Mental illness and indigenous consumers

The Committee's Terms of Reference require that it inquires into the adequacy of options for people from an indigenous background. As already noted, the Committee received little evidence regarding the experience of indigenous people with a mental illness and their communities. In the evidence received, the Committee heard that there are service gaps for people with a mental illness from indigenous backgrounds who require support and accommodation.

The indigenous understanding of health, including mental health, is holistic. That is, health 'does not mean just the physical wellbeing of the individual but refers to the social, emotional and cultural wellbeing of the whole community'.[393] The Victorian Aboriginal Community Controlled Health Organisation (VACCHO) highlighted to the Committee the importance of indigenous understandings of health:

> The indigenous definition of health is a broad definition that includes the cycle of birth, life and death. It includes a relationship to the individual — their autonomy — and it includes relationships to community and relationships to land.[394]

VACCHO told the Committee that there are also culturally different experiences of trauma, grief, and loss.[395] This is complicated by intergenerational trauma, including the removal from family. This issue is carried by people their whole lives and is passed on when they become a parent.

Mr Tim Moore, Senior Policy Officer at VACCHO, explained the implications for service delivery in the context of responding to indigenous health issues: 'It is not surprising that the health programs that were set up by a community with that view are wide ranging and multifunctioned. It is very difficult to successfully

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[393]   Steering Committee for the Review of Government Service Provision (2009) *Overcoming indigenous disadvantage: Key indicators 2009*. Productivity Commission, Canberra, p.7.55.

[394]   *Committee Transcript*, 30.4.09, p.4 (VACCHO).

[395]   *Committee Transcript*, 30.4.09, p.4 (VACCHO).

address one element of a person's health without addressing a suite of factors'.[396]

VACCHO informed the Committee that it is widely accepted that people from indigenous backgrounds are affected disproportionately by mental health in comparison with people from non-indigenous backgrounds.[397] This has been confirmed in a range of other reports. Statistics from the Mental Health Council of Australia reveal that people from indigenous backgrounds experience much higher rates of mental illness and are 'up to twice as likely to be hospitalised for mental and behavioural disorders as other Australians'.[398]

In 2009, the Productivity Commission Steering Committee for the Review of Government Service Provision also reported that rates of hospitalisation are approximately 1.8 times higher than the non-indigenous population. The report also identified that people from indigenous backgrounds have higher rates of mental health issues (17.6 per cent) than non-indigenous populations (10.6 per cent).[399]

In regard to access to services in Victoria, the Committee heard that there are significant issues relating to the collection of data, and therefore to gaining an accurate understanding of how many people from indigenous populations use services. For example, Murray Mallee Community Health Centre told the Committee:

> The statistics that we get through the bureau of statistics indicate that there are about 1200 indigenous people living within the Mildura Rural City Council, whereas I know the Aboriginal co-op here in town has got around 5000 people registered. We all know the difficulties that we have had in trying to get accurate statistics on indigenous people, but when you look at that, about 10 per cent of the population in the area is from an indigenous background.[400]

The Victorian Government provided the Committee with its statistics on people with indigenous status using mental health services in Victoria. The following table outlines the services relevant to the Committee's Inquiry.

Table 8.4–1: Indigenous status by service type, 2007-08

Service type	Indigenous
CCU	1%
SECU	2.8%
PARC	2.1%
RRS	4.0%

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396   *Committee Transcript*, 30.4.09, p.4 (VACCHO).

397   *Committee Transcript*, 30.4.09, p.3 (VACCHO).

398   MHCA, *Home Truths*, p.17 [see Footnote 374].

399   SCRGSP (Steering Committee for the Review of Government Service Provision) (2009) *Overcoming Indigenous Disadvantage: Key Indicators 2009*, Productivity Commission, Canberra. p.7.60.

400   *Committee Transcript*, 6.11.08, p.11 (Murray Mallee Community Health Centre).

Source: Victorian Government (2008) Data provided to Family & Community Development Committee.

These figures indicate that low numbers of people from indigenous backgrounds access mental health services in Victoria, which is consistent with the findings of the Committee. Furthermore, according to VACCHO, there is a lack of statistical information regarding mental health and people from an indigenous background.

The Committee heard about many issues relating to people from indigenous backgrounds who have a mental illness and need access to services and/or accommodation. These included the lack of understanding of the needs of indigenous consumers, the reluctance of people from indigenous backgrounds to access mainstream services and the experience of discrimination common to many indigenous Victorians in the context of accommodation.

The evidence provided to the Committee identified a need for improved responses to indigenous consumers requiring mental health services. The Central Gippsland Aboriginal Cooperative told the Committee that indigenous consumers may be reluctant to access mainstream services that they believe do not understand their culture, language and customs. The Cooperative explained that:

> if you lose touch with reality, you need something to stabilise you, you know, to ground you, almost. So being with somebody who looks the same – similar to me, somebody who comes from the same culture, speaks a similar language, if not the same language, has the same customs, has been through similar issues as what I have been through, I would find that quite comforting.[401]

Ballarat Adult Community Psychiatric Service emphasised that the accommodation and support needs of indigenous communities are complex. The organisation said that it was unaware of any supported accommodation environment that was sensitive to Aboriginal issues and cultural sensitivity.[402] The Committee heard that 'the consequences of that are probably fairly obvious. People are not going to hang around and stay in programs that don't meet their needs, so are lost to the streets or simply lost'.[403]

Murray Mallee Community Mental Health Services acknowledged that many indigenous consumers are reluctant to access mainstream health services. It suggested that 'the Aboriginal community has specific needs that could only be serviced by them'.[404] At the same time, however, it explained to the Committee that it tries to make its services culturally appropriate by partnering with indigenous groups, for example they try to have good links with the Mildura

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[401]   *Committee Transcript*, 21.10.08, p.6 (Central Gippsland Aboriginal Cooperative).
[402]   *Committee Transcript*, 20.11.08, p.4 (Ballarat Adult Community Psychiatric Service).
[403]   *Committee Transcript*, 20.11.08, p.4 (Ballarat Adult Community Psychiatric Service).
[404]   *Committee Transcript*, 6.11.08, p.11 (Murray Mallee Community Mental Health Services).

Aboriginal Cooperative, and they also employ indigenous staff members in their mental health services.[405]

Murray Mallee Community Mental Health Services suggested that better alternatives to the mainstream mental health and public hospital are needed for indigenous consumers. In their efforts to improve indigenous mental health services for indigenous communities, the organisation explained that:

> We are looking at tightening up some memorandums of understandings between ourselves and the Aboriginal co-op and see how we can better service that community… A number of community consultations have said that the service that we provide has not been meeting the needs. That is aside from the accommodation aspect. We still have a lot of work to do.[406]

VACCHO told the Committee about a former residential facility that accommodated 10 patients. This facility provided support to indigenous consumers to enable them to become more independent and to work towards living in the community.[407] VACCHO explained that:

> It was culturally appropriate in the sense that the workers were Aboriginal, there was staff 24 hours a day, they had direct access to the doctors, the psychiatric nurse, the psychiatrist, as well as other support services that were needed. I guess something like that did work; it was closed down, however, some years ago now.[408]

VACCHO also suggested that traditional indigenous approaches to healing could be embedded in the delivery of mental health services for people from indigenous backgrounds, such as going back to country and being with family and elders.[409] It also noted, however, that while this form of treatment can be successful, there are challenges due to current under-resourcing of Aboriginal health services.[410]

Government policy direction

The recently released Mental Health Strategy acknowledges the gap in service provision to the indigenous community. In identifying a need for improved responses to Aboriginal communities, the Strategy outlines new objectives to achieve this with a focus on reducing inequalities. The specific goal is:

> **Goal 6.1** – Improve the social spiritual and emotional wellbeing of Aboriginal people, their families and communities through
>
> ▪ building partnerships

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405   *Committee Transcript*, 6.11.08, p.11 (Murray Mallee Community Mental Health Services).
406   *Committee Transcript*, 6.11.08, p.11 (Murray Mallee Community Mental Health Services).
407   *Committee Transcript*, 30.4.09, p.10 (VACCHO).
408   *Committee Transcript*, 30.4.09, p.10 (VACCHO).
409   *Committee Transcript*, 30.4.09, p.9 (VACCHO).
410   *Committee Transcript*, 30.4.09, p.10 (VACCHO).

- supporting health promotion efforts
- improving outcomes for children and young people and their families
- improving access to social and emotional wellbeing services
- workforce development
- developing culturally responsive mainstream services
- building the evidence base.[411]

The Victorian Government has recently invested $874,000 in a four-year initiative to improve the mental health outcomes for Aboriginal people. The metro-wide initiative will be developed in collaboration with the Victorian Aboriginal Health Service (VAHS), the Victorian Aboriginal Community Controlled Health Organisation (VACCHO), local Aboriginal organisations and mental health services. Funding has also been allocated to VACCHO to support workforce training and development to meet the needs of people from indigenous backgrounds.

The Committee welcomes the Victorian Government's initiatives to address treatment options for people from indigenous backgrounds. It recognises, however, that this is an initial step and that the amount that can be achieved with the resources provided is limited. In addition to the focus on improving the cultural awareness of workers in the mental health sector, the Committee considers that the Victorian Government should be exploring future directions that embed a more culturally aware practice in services through change agents. One potential strategy to progress these directions would be to consider increasing the numbers of Koori liaison workers linked to mental health services.

Recommendations

8.11   That the Victorian Government establishes Aboriginal liaison workers to facilitate relationships with mainstream mental health services and improve their capacity to provide culturally appropriate services to people from indigenous backgrounds.

8.12   That the Victorian Government measures the needs of people from Indigenous backgrounds for supported accommodation options.

8.13   That the Victorian Government appoints Aboriginal liaison workers in the mental health sector to facilitate increased cultural awareness in mental health service provision.

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[411]   DHS, *Because mental health matters,* pp.116–20 [see Footnote 322].

8.5   Cultural diversity and mental health

Available data suggests that individuals with a mental illness from CALD communities use public mental health services at lower rates than the general community.[412] The Victorian Transcultural Psychiatry Unit explained to the Committee that although CALD communities tend to use services at lower rates, the data used to determine this is not adequate and potentially underestimates the level of under-servicing the community.[413]

In an analysis of the rates of access to Victorian inpatient and community mental health services in 2004-05, Professor Harry Minas provided four key findings of the under-utilisation of services by individuals from CALD backgrounds. These were that:

- Immigrants have substantially lower access to public community mental health services than the Australian-born

- Rates of access vary considerably

- Access to services – inpatient and community – is substantially lower in the Asian-born groups than for other CALD communities

- Over an approximate ten-year period, the gap in access between the Australian-born and immigrants has widened. While there has been a very substantial increase in rates of access to public mental health services by the Australian-born, the increase for immigrants has been much smaller. The system reforms and increased mental health investment over a decade have differentially benefited (in terms of access to treatment and care) Australian-born and immigrant communities in Victoria.[414]

DHS provided the Committee with information relating to its statistics on people from CALD communities using mental health services in Victoria. The table below outlines the services related to the Committee's Inquiry.

Table 8.5–1: CALD status by service type, 2007-08

Service type	CALD
CCU	2.7%
SECU	1.9%
PARC	4.4%
RRS	5.1%

Source: Victorian Government (2008) Data provided to Family & Community Development Committee.

The figures in the table above indicate that a limited number of individuals from CALD backgrounds access mental health services in Victoria. This is consistent with the evidence received for the Inquiry.

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[412]   *Committee Transcript*, 30.04.09, p.3 (Victorian Transcultural Psychiatry Unit).

[413]   *Committee Transcript*, 30.04.09, p.3 (Victorian Transcultural Psychiatry Unit).

[414]   Minas, H. (2009) 'Proposal for a Victorian Mental Health and Cultural Diversity Taskforce'. *Newparadigm*, Vicserv, Summer, p.40.

Despite the shortage of data regarding the needs of CALD communities in accessing mental health services, it is important to remember that people do not have to provide information about their background in order to receive a service. The respect for privacy and dignity is highlighted in the *Mental Health Act 1986*, which provides a legislative framework for care and treatment of individuals with a mental illness.

The Victorian Transcultural Psychiatry Unit told the Committee it believes the policy focus on CALD issues has waned.[415] It explained that:

> There does not seem to be the same emphasis on CALD issues now as there was perhaps 10 years or so ago, and that one of the problems that we have in that regard is that these competencies are not mandatory across the services.[416]

Professor Harry Minas suggested that there are impediments to improving the performance of Victoria's mental health system.[417] These impediments relate to the lack of policy implementation and scaled up approaches that have proven to be successful. Professor Minas expressed the view that:

> The cultural and linguistic diversity of the Victorian population has not influenced mental health policy making, service design or clinical practice in a sustained and continuing fashion. Immigrant and refugee communities continue to be characterized as 'special needs groups'. Understanding that diversity is a fundamental feature of the Victorian population, requires a basic re-thinking of the policy response.[418]

To meet the support needs of individuals from CALD backgrounds with a mental illness, the mental health workforce needs the flexibility to respond to diverse needs. The Victorian Transcultural Psychiatry Unit maintained that part of this issue is systemic, as not all services are able to provide that level of flexibility, and suggested that this relates to the learning priorities at an undergraduate level. It told the Committee that 'the emphasis is not there in the undergraduate courses so by the time people become professionals in the field, the idea is not there that developing cultural competence is an issue required in the workplace'.[419]

In his article, Professor Minas proposes that the establishment of a Victorian Mental Health and Cultural Diversity Taskforce would assist the Victorian Government to develop mental health legislation, policies and services that are relevant to, and that benefit, all Victorians.[420]

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[415] *Committee Transcript*, 30.4.09, p.4 (Victorian Transcultural Psychiatry Unit).

[416] *Committee Transcript*, 30.4.09, p.4 (Victorian Transcultural Psychiatry Unit).

[417] Minas, 'Proposal for a Victorian Mental Health and Cultural Diversity Taskforce', p.40 [see Footnote 414].

[418] Minas, 'Proposal for a Victorian Mental Health and Cultural Diversity Taskforce', p.40 [see Footnote 414].

[419] *Committee Transcript*, 30.4.09, p.4 (Victorian Transcultural Psychiatry Unit).

[420] Minas, 'Proposal for a Victorian Mental Health and Cultural Diversity Taskforce', p.41 [see Footnote 414].

The purposes of such a task force would be to remedy some of the deficiencies that are identified in what we know about CALD communities, and to provide better quality information for us to be able to think about policy development more clearly, to plan implementation in a more intelligent way and to evaluate the quality of what we do for all Victorians who have a right to the public services that we provide.[421]

The Committee recognises that there would be value in further exploring mental health issues in CALD communities and developing strategies to improve responses in the mental health sector.

Recommendation

8.14   That the Victorian Government establishes a CALD Taskforce as proposed by the Victorian Transcultural Psychiatry Unit.

8.6   Mental Health and rural and regional contexts

The Committee heard from participants about challenges faced by Victorians with a mental illness in regional and rural Victoria. These challenges relate to shortages of available services and reduced accessibility of services due to distance and location.

The evidence suggests that the situations of many individuals and their carers are complicated by the distance or location of mental health services in rural and regional areas and a lack of transport options for people to reach specific accommodation or support facilities. The Goulburn Valley Area Mental Health Service stated that 'we've extremely limited public transport. It does exist but it's not ideal'.[422] The evidence suggests that this impacts on people with a mental illness, their families, other carers and service providers. Research also suggests that transport and accommodation problems are linked, due to location and accessibility.[423]

The inability to access supported accommodation in rural communities may force people to find support in another town. The Committee heard that this is not an ideal situation since individuals with a mental illness are forced to leave their family and community, which are important aspects of their social support networks. Goulburn Valley Area Mental Health Service maintained that the relocation of people affects both the family and the individual in the long

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421   *Committee Transcript*, 30.4 09, p.3 (Victorian Transcultural Psychiatry Unit).

422   *Committee Transcript*, 18.11.08, p.3 (GV Area Mental Health Service).

423   Turpin, M., Bartlett, H., Kavanagh, D. & Gallios, C. (2007) 'Mental health issues and resources in rural and regional communities: An exploration of perceptions of service providers. *Australian Journal of Rural Health*. Vol. 15, p.134.

term.[424]   The organisation said that they were often forced to refer people to out-of-area-services due to the lack of suitable supported accommodation.

HACSU advised that some rural and regional areas have inadequate access to CCUs.   Murray Mallee Community Mental Health Service outlined the challenges that it faces in accessing CCU facilities for consumers in Mildura. Mildura does not have a CCU, and the nearest facility is in Bendigo, about 450 kilometres away.   The Director of Clinical Mental Health at Mildura Base Hospital explained that:

> If we have somebody who requires a longer-term accommodation and rehabilitation option which is staffed 24/7, they are currently required to go to Bendigo. I have been in Mildura six and a-half-years and we have successfully been able to admit one person to the CCU in Bendigo, and I believe in the last 10 years we have been able to admit two people to the Bendigo CCU. It is not so much through a lack of trying but simply through a lack of availability of their beds. They have got their own inpatient unit sitting there with its patients.[425]

HACSU recommended to the Committee that 'a review should be undertaken as a matter of priority, to ascertain access and ensure adequate provision for AMHS of CCU beds in significant growth corridors in both rural and metropolitan areas'.[426]

Furthermore, the Committee heard that the Northern Mallee AMHS is particularly under-serviced by residential clinical treatment services for people with a mental illness.   As noted above, Mildura does not have access to a CCU. Northern Mallee is the only AMHS that does not have a CCU.   Murray Mallee Community Mental Health Service explained that

> We do not have a PARC, a MIND or a CCU. To paraphrase that: we do not have a step-up, step-down from a hospital facility; we do not have an adolescent psychiatric accommodation facility; and we do not have community care units specifically designed for those who have a psychiatric disability. The only model employed here for these people, and in the electorate of Swan Hill, is one of sourcing accommodation independently and then inserting home-based supports into this situation.[427]

Given the significant distances for people with a mental illness in the Northern Mallee AMHS, the Committee considers that the Victorian Government needs to give specific consideration to the adequate servicing of the AMHS.

Rural and regional organisations told the Committee of the importance of developing partnerships in regional communities.   Mind explained that a range

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[424]   *Committee Transcript*, 18.11.08, p.6 (GV Area Mental Health Service).

[425]   *Committee Transcript*, 6.11.08, p.6 (Murray Mallee Community Mental Health Service).

[426]   *Submission* 121A, p.10 (HACSU).

[427]   *Committee Transcript*, 6.11.08, p.3 (Murray Mallee Community Mental Health Service).

of organisations and services have established an alliance group in Bendigo, stating that:

> This is to coordinate how we work and get really good working relationships together. That has been a really useful thing for us. We also do a lot of what is called collaborative practice, so our actual program here in Bendigo has been the pilot with the YMCA in Melbourne for the last year and a half in developing a specific recreational camp focused on people with mental illness.[428]

The Committee heard that working partnerships with various organisations have engendered sustainable pathways, which can provide varying support needs for individuals at different times in local communities. These collaborative practices have enabled organisations to deliver services in more remote and rural communities, providing support that would otherwise not have been available.

In addition to the issues raised in this section for rural and regional communities in Victoria, additional recommendations have been made throughout the report that relate specifically to rural and regional communities.

Recommendations

8.15   That the Victorian Government provides a community care unit in the Northern Mallee area mental health service (AMHS) and reviews the level of residential clinical treatment service availability in the Northern Mallee AMHS.

8.16   That the Victorian Government undertakes a review of the current dispersal of community care units across the state and their capacity to meet expressed demand, particularly in rural and regional areas.

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[428]   *Committee Transcript*, 19.11.08, p.4 (Mind).

Chapter Nine: Quality systems & workforce capacity

Committee findings

- That the Victorian Government has established a range of frameworks that identify service standards and monitor quality of services for people with a disability and/or mental illness. **(Sections 9.1 & 9.2)**

- That there is support for the new quality framework in the disability sector. **(Section 9.1.1)**

- That expectations of quality and standards have increased with the new framework. **(Section 9.1.1)**

- That the *Disability Act 2006* has established new mechanisms for monitoring restrictive interventions. **(Section 9.1.2)**

- That the *Disability Act 2006* has established new mechanisms of complaints monitoring with the introduction of the Disability Services Commissioner. **(Section 9.1.3)**

- That the mental health sector has well established standards in the provision of service. **(Section 9.2)**

- That the mental health sector has adopted a program to reduce the use of restraint and seclusion in secure extended care units. **(Section 9.2.2)**

- That complaints about mental health services can be lodged with the Chief Psychiatrist and the Health Commissioner, but these mechanisms do not have the same legislative authority as the Disability Services Commissioner. **(Section 9.2.3)**

- That Community Visitors play a key role as an independent 'watchdog' in the mental health and disability sectors. **(Section 9.3)**

- That the role of Community Visitors has limitations, particularly in the context of significantly changing service systems. **(Section 9.3)**

- That workforce capacity underpins quality of service provision in supported accommodation to people with a disability and/or mental illness. **(Section 9.4)**

- That in 2009 the Victorian Government introduced both the mental health and disability workforce strategies that will potentially address a number of issues relating to these workforces. **(Section 9.4)**

- That the disability workforce is based on a flat structure with few career pathways and low remuneration **(Section 9.4.1)**

- That consistency in staffing is important in the quality of life of people with a disability. **(Section 9.4.1)**

- That the mental health workforce has a range of roles with different skills levels and qualifications. **(Section 9.4.2)**

C hapters Seven and Eight explored experiences heard by the Committee relating to the adequacy and range of support and accommodation in disability and mental health services. This chapter turns to the adequacy of systems of standards, accreditation and quality monitoring in the provision of support and accommodation for people with a disability and/or mental illness. The Committee found that the quality of service provision and a commitment to continuous improvement is critical in ensuring people with a disability and/or mental illness have the opportunity to live a quality life and/or to pursue a recovery path.

Key elements of a service system with the capacity to provide adequate accommodation and support include mechanisms for accreditation, standards and quality monitoring in addition to a workforce with the capacity to provide quality service. Equally critical are the systems of accountability that surround mechanisms and frameworks that seek to achieve quality services and systems.

Participants that provided evidence to the Committee raised issues relating to quality systems and workforce capacity. Community expectations of the quality of supported accommodation cover multiple dimensions of service delivery. These include quality systems, complaints mechanisms, and the use of restrictive practices such as restraint and seclusion.

The Committee found that the Victorian Government has a range of frameworks and strategies in place that aim to achieve quality services and systems to address issues relating to workforce capacity. In disability services, for example, recent changes in legislation and policy direction have led to the introduction and roll-out of a comprehensive quality framework. The Committee also found that individuals and organisations were frequently unaware of these new initiatives and directions.

The Committee heard that those involved with the mental health and disability services systems placed considerable emphasis on the importance of external monitors in overseeing the quality of service provision. In both the mental health and disability sectors there is a range of mechanisms to oversee the quality of service components. These include the Chief Psychiatrist, the Disability Services Commissioner, the Senior Practitioner and Community Visitors.

This chapter provides an overview of the perspectives and expectations of individuals and organisations that provided evidence to the Committee concerning quality systems and workforce capacity. It also outlines the systems and mechanisms in place to monitor quality, to respond to complaints and to build workforce capacity.

As with other aspects of supported accommodation, the systems that determine quality and standards, monitoring and establish complaint mechanisms are different across disability services and mental health services. Similarly, strategies for building workforce capacity differ across the two sectors. Chapter

Three outlined the different legislative and policy frameworks that inform the two service systems. While there are some overlaps and similarities in the issues and approaches, this chapter addresses the mental health and disability sectors and their quality mechanisms separately.

9.1   Disability quality services and systems

Over the past 10 years, the Victorian Government has steadily established a broad range of standards and quality systems. The history of the existing standards in disability services dates back to 1997, when a set of industry standards for disability service providers was established. The Department of Human Services (DHS) issued nine Victorian Standards for Disability Services that set minimum industry standards for DHS and CSO service providers. These were:

Service access	Individual needs
Decision-making and choice	Privacy, dignity and confidentiality
Participation and integration	Valued status
Complaints and disputes	Service management
Freedom from abuse and neglect	

By 2003, all service providers were expected to fully comply with these standards. The *Disability Act 2006* established a number of new requirements for service quality. These included a provision for closer monitoring of services against standards. As a result, DHS developed a further five disability outcome standards to align with the goals of the State Disability Plan. These were:

Individuality	Capacity
Participation	Citizenship
Leadership	

In 2007, DHS incorporated the nine industry standards and five outcome standards into its *Quality Framework for Disability Services in Victoria*. In assessing services against the standards, a set of indicators is used to demonstrate compliance. Disability Services Division is currently establishing processes that will enable independent auditors to monitor providers against existing standards in the context of the quality framework.

DHS has also revised its previous system of self-monitoring against the standards. In 2008 it advised that the previous Disability Self-Assessment System was no longer recognised as a monitoring mechanism. State-wide implementation of the Department's independent monitoring of disability services took effect from July 2009. The new system requires that all disability service providers, including Department-managed services, are subject to independent monitoring and are expected to achieve certification by 2012.

Certification against the quality standards is expected to be an important factor in determining registration of CSO providers and the ongoing funding of both DHS and CSO providers. Notably, it is not yet clear how this will be managed.

9.1.1   Experiences and perspectives

The Committee heard a range of views in relation to the quality of services in the disability sector. These included support for new directions that aim to enhance the quality of life of people with a disability. In addition, concerns were expressed regarding the systems in place to achieve the desired quality outcomes that the Victorian Government is aiming for.

Interchange Loddon Mallee highlighted the raised expectations in regard to service quality and accountability that has emerged with the increased focus on rights:

> The rights of people with a disability are increasing and are much more out in the community. And people watch more, therefore more accountability … is being created, and that is a good thing.[429]

With these heightened expectations, the Committee heard evidence relating to the quality systems and monitoring mechanisms in place in the disability services sector. Those involved with the disability services system stressed the importance of adequate mechanisms for setting standards, accreditation and ensuring compliance.

The Committee heard from families in caring relationships who were aware of the Department's broad policy directions regarding quality and monitoring. Some viewed the intentions underlying the standards and quality framework as being excellent, for example:

> The Department of Human Services, Head Office, produces and promotes an extensive range of excellent care policies, standards and values to direct and guide the department's direct service provision, and that of the non-government sector – NGO, not-for-profit services.[430]

The Committee heard that these improved policy and practice directions have led to increased expectations regarding standards and quality. Some participants, however, indicated that the Victorian Government has yet to achieve the levels of quality provision it is striving for. For example, a family carer told the Committee that: 'We consider the DHS policies, which are extensive, are in fact very good. They just need to be implemented as defined and intended, and with the spirit of these policies — at the service point to give the quality of care'.[431]

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[429]   *Committee Transcript*, 19.11.08, p.5 (Interchange Loddon Mallee).
[430]   *Submission* 53, p.2 (H. & T. Tregale).
[431]   *Committee Transcript*, 22.10.08, p.2 (H. & T. Tregale).

This view regarding a disconnect between the policies and frameworks that aim to achieve quality service provision and the actual implementation of standards in service provision was also raised by the Auditor-General in his report into disability accommodation services in 2008. He made the following statement in his Foreword to the report:

> I consider the service model to be conceptually sound...
>
> Based on the results of the audit, I have doubts that the service model will be successfully applied by service providers. There is a large disconnect between what is currently happening in the accommodation houses we examined and what the service model aspires to achieve. It was particularly concerning that three core aspects of service delivery raised in VAGO's 2000 disability audit have yet to be resolved.[432]

This is also acknowledged in the findings of the recent pricing review by PricewaterhouseCoopers (PwC). The key point made by PwC is that to successfully implement and achieve the new person-centred approach to service provision, the allocation of resources to build sector capability is critical. Inadequate resource provision could result in a failure to implement the changes and a failure to achieve the quality outcomes the new quality framework is striving for.[433]

The Committee heard that providing consistent services that meet an agreed standard of delivery is a key component of quality systems. That is, a person with a disability should receive the same level of care and quality support regardless of the service providing that support. However, information given to the Committee suggested a lack of consistency in service provision in the disability service system. For example, Kew Cottages Parents Association stated that:

> We have found that there has been an inconsistency in quality of care and support being received by individuals in Kew CRUs…
>
> This lack of consistency is demonstrated in a range of ways, including interpretation and implementation of policy, quality and skills of staff, and allocation of funding.[434]

These concerns regarding consistency of quality in service provision were raised by the Victorian Auditor-General in his 2008 report. The report noted the need for service provider requirements to be spelled out clearly in order to ensure the adequate levels of consistency:

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[432] Victorian Auditor-General (2008) *Accommodation for people with a disability*. Victorian Auditor-General's Office, Victorian Government Printer, p.v.

[433] PricewaterhouseCoopers (2009) *Department of Human Services: Price Review Out of Home Disabiltiy Services Final Report*, p.8. Accessed from <http://www.dhs.vic.gov.au/disability/improving_supports/industryplan/pwc> on 20 October 2009.

[434] *Committee Transcript*, 22.10.08, p.3 (Kew Cottages Parents Association).

> DHS has not clearly specified the detailed contents of residents' support plans, and the form they will take, beyond the key elements. As such, there is a risk these support plans will not be prepared on a consistent basis or to a quality consistent with providing individualised service responses.[435]

The Victorian Auditor-General's Office (VAGO) found that the plans did 'vary considerably in consistency and quality'.[436] Furthermore, this is not a new issue: VAGO highlighted this issue in its 2000 audit into disability accommodation services.[437] This has also been noted by Community Visitors in their 2009 Annual Report.[438]

As discussed later in this chapter, in order to achieve the level of standards and consistency in quality required, extensive staff training across all service providers is essential as a component of the implementation of the new quality framework. In addition, the Committee heard that communication by DHS – both internally and externally – is a critical factor in ensuring the exact requirements relating to quality are understood across all service providers.

A number of individuals and organisations told the Committee that in order to improve the quality and standard of services in the disability sector there is a need to strengthen the levels of accountability of disability service providers, including government-run services. For example, Gippsland Carers Association stated that stronger sanctions are needed for those service providers that do not comply with standards.[439]

Recommendation

9.1   That the Victorian Government improves enforcement of penalties for service providers that do not comply with relevant standards and regulations in the *Disability Act 2006*.

9.1.2   Restrictive interventions

In the context of quality service provision in shared supported accommodation (SSA), participants drew the Committee's attention to concerns relating to the use of restrictive practices.[440] Restrictive interventions are sometimes used in response to people with a disability exhibiting behaviours of concern. These behaviours can include aggression, property destruction, self-injurious behaviour, socially inappropriate behaviour, and/or withdrawn behaviour.

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[435]   Victorian Auditor-General, *Accommodation for people with a disability*, p.3 [see Footnote 432].

[436]   Victorian Auditor-General, *Accommodation for people with a disability*, p.18 [see Footnote 432].

[437]   Victorian Auditor-General, *Accommodation for people with a disability*, pp.18-19 [see Footnote 432].

[438]   Community Visitors (2009) *Annual Report 2008-09*. Office of the Public Advocate, Victorian Government Printer, p.25.

[439]   *Submission* 52, p.25 (Gippsland Carers Association).

[440]   *Submission* 100, pp.39, 45 (OPA).

Restrictive interventions are defined in the *Disability Act 2006* as any intervention that is used to restrict the rights or freedom of movement of a person with a disability, including (involving the use of, but not restricted to) chemical restraint, mechanical restraint or seclusion. Restraint and seclusion can only be used to prevent a person from causing physical harm to themselves or others, or destroying property in a manner that may cause harm to themselves or others. Other criteria for the use of restrictive interventions require that restraint and seclusion is the least restrictive option. Restraint and seclusion is expected to be included in the person's behaviour management plan, and any use of restraint or seclusion needs to be in accordance with that plan.

Dr Jane Tracy works in the sector and has a son with multiple disabilities. She expressed the view that some people with a disability experience greater trauma when change and transition occurs in their life, which can contribute to behaviours of concern. She suggested that restrictive interventions are not the most appropriate response to behaviours of concern arising from such traumatic experiences:

> Understandably these grieving, lonely, frightened people, many with limited communication ability, may express their distress through their behaviour (self injury, property damage, assault). They may then be taken then to doctors for medication (to 'settle them down') when the answer is clearly not medical.[441]

The Committee heard evidence about people with a disability being subject to restrictive interventions. One family spoke of the experience of their son who has autism and recently underwent a change of management and also a change in his long-term carer who left. The result was that their son's behaviour and health deteriorated and he is now frequently subject to seclusion. That is, he is often locked up in the SSA facility on his own in response to behaviours of concern that he presents with.[442] The following case study provides an example of another family's experience with the use of restrictive intervention in the form of seclusion. Their son Luke has autism and is 19 years old.

Luke's story

There are currently four people living [in the house]. Luke and three older people. The house is usually staffed at a ration of 1:1. That is, there is usually four staff on duty at any time. The team consists of about 17 full time permanent employees of DAS[443] and about 15 casuals that are called in as needed. There is no facility for sleep overs. Every night is an active night with a minimum of two staff on duty at all times.

All exterior doors remain locked most of the time. Most of the internal doors are self locking.

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[441] *Submission* 114, p.1 (Dr J. Tracy).

[442] *Submission* 86, p.1 (S. & S. Waters).

[443] Disability Accommodation Services.

> Luke currently spends most of his time locked in what they call 'Luke's Area'. The only time he gets to go into the rest of the house, or the backyard, is if two of the other residents are not in the house.
>
> Luke has no contact with the other residents…
>
> "Luke's area" comprises –
>
> - Bedroom
>
> - Bathroom with Toilet
>
> - Living Area – a corridor wide enough to house a TV, couch and table.[444]

The Senior Practitioner is a new statutory role appointed under the *Disability Act 2006* and is responsible for ensuring that the rights of people who are subject to restrictive interventions and compulsory treatment are protected, and that appropriate standards are complied with in relation to restrictive interventions and compulsory treatment. The Senior Practitioner has powers to set standards and guidelines, and to monitor disability service providers in relation to the use of restrictive interventions and compulsory treatment. As the role is new, reporting processes on the use of restrictive interventions by service providers are currently being rolled out and providers are continuing to adjust to new compliance requirements. It is too early, therefore, to determine the impact of these new reporting and monitoring mechanisms.

The Committee sought to hear from the Senior Practitioner, but was advised by the Minister for Community Services that it was not appropriate in view of his statutory responsibilities. Recent publications prepared by the Office of the Senior Practitioner, however, provide some insight into the extent of use of restrictive interventions and issues relating to this use.

Between July and December 2008, 1,836 people were reported to the Senior Practitioner as being subject to restrictive interventions in SSA. This figure included 249 cases of restrictive intervention use reported for the first time. The majority of restrictive interventions during this period involved the use of chemical restraints (96 per cent), followed by mechanical restraint (6 per cent) and seclusion (5 per cent). In some instances, combinations of restraint and seclusion were used. Importantly, during this reporting period, the Senior Practitioner identified a decline in the use of restrictive interventions.

In the previous reporting period, the Senior Practitioner had identified that people with autism in SSA settings were particularly vulnerable to the use of restrictive interventions. The Senior Practitioner had reported in July 2008 that during the period 1 July 2007 to 30 December 2007:

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[444]   *Submission* 90, pp.14-15, 36 (L. & M. Modra).

It appears that younger people, especially those with autism or multiple disabilities, are more likely to be subjected to restraint and seclusion... People with autism and those with multiple disabilities are more likely to be restrained and secluded than other people, they also have the highest rates of PRN and emergency restraint and seclusion.[445]

The Senior Practitioner concluded that 'this finding suggests services need to find better ways to support young people with a disability who show behaviours of concern, especially young people with autism and multiple disabilities'.[446] Notably, of the 249 people being reported for the first time in the July to December 2008 reporting period, according to the Senior Practitioner, 'approximately a third ... were reported to have autism and 85% of those with autism were males'.[447]

This finding concurs with the evidence heard by the Committee. Most families and other carers who expressed concern regarding the use of restrictive interventions referred to a person with either autism or multiple disabilities. It is worth noting that SSA facilities do not accommodate many people with autism or multiple disabilities. In June 2008, of a total of 4,590 people in SSA there were 33 people with autism and 19 people with multiple disabilities. Furthermore, in view of the low numbers of people with autism and multiple disabilities in SSA, these figures relating to the use of restrictive interventions reinforce the findings raised later in this chapter. That is, many disability service providers have not yet developed the expertise and skill base needed to respond effectively to people with disabilities, other than intellectual disability, who present with complex and changing needs.

The Committee heard that the use of restrictive interventions needs to be monitored and minimised. For example, the Office of the Public Advocate (OPA) stated:

Strategies for minimising the use of restrictive interventions are critical. OPA supports the work of the Senior Practitioner in striving for a team based approach to behaviour support planning, with the teams comprising inter-disciplinary professionals and significant others (family members or friends) of the person with behaviours of concern.[448]

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[445] Office of the Senior Practitioner (OSP) (2008) *Senior Practitioner Report: Report and recommendations on behaviour support plans and restrictive interventions for 1 July to 30 December 2007*. Department of Human Services, Victorian Government, Melbourne, p.23. Note: PRN is medication prescribed by a medical practitioner to be used when required.

[446] OSP, *Senior Practitioner Report*, p.23 [see Footnote 445].

[447] Office of the Senior Practitioner (OSP) (2009) *Report on the use of restrictive interventions, behaviour support plans and supervised treatment orders for the period 1 July 2008 – 31 December 2008*. Department of Human Services, Victorian Government, p.2.

[448] *Submission* 100, p.45 (OPA).

	Recommendation
9.2	That the Victorian Government prioritises the introduction of a multidisciplinary approach to staffing SSA facilities with a high use of restrictive interventions.

9.1.3   Complaints mechanisms in the disability sector

Interconnected with the issue of quality service systems are mechanisms for handling complaints. The provision of quality services involves understanding the needs of those who use the services. In the context of the disability service system, in addition to people with a disability, often the families of people with a disability are key users of the service system. Complaints can provide valuable information regarding the needs of people who use a service system. This information can contribute to processes of continuous improvement, which is a critical component of a quality service system.

The *Disability Act 2006* created a new statutory role to provide mechanisms for handling and processing complaints in the disability services system – the Disability Services Commissioner. The Commissioner works with people with a disability to resolve complaints about disability service providers, and works with disability service providers to improve outcomes for people with a disability. The Commissioner encourages and assists the resolution of complaints in a variety of ways including informal discussions, conciliation processes or, under certain circumstances, formal investigation. As well as the work directly focused on resolving individual complaints, the Commissioner has a range of other functions, including conducting education, training and research to improve disability services complaints systems.

The Disability Services Commissioner, Mr Laurie Harkin, told the Committee that in its first reporting period (2007-08), the Office received 311 complaints, and that 'the second year has been characterised by a 30 per cent increase in the number of issues that have come to us in the second year versus the first'.[449] The Commissioner explained that of the complaints received by the Office, 'the most significant number of concerns that are expressed to us happen to come from people in the shared supported accommodation circumstance'.[450] Furthermore, of the people who make complaints, according to the Disability Services Commissioner, a 'significant proportion of the concerns that are brought to us ... involve people with a mental illness or dual disability'.[451]

The types of issues that are generally raised with the Commissioner include:

- Concerns regarding compatibility of residents
- Alleged assaults by either staff or co-residents

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[449]   *Committee Transcript*, 25.8.09, p.2 (Disability Services Commissioner).
[450]   *Committee Transcript*, 25.8.09, p.2 (Disability Services Commissioner).
[451]   *Committee Transcript*, 25.8.09, p.3 (Disability Services Commissioner).

- Quality of care issues

- Competency and consistency of staff

- Capacity to meet specific needs, particularly for people with autism and dual disability with mental illness

- The involvement of families in service and decision-making

- A small number of complaints relate to physical condition of facilities.[452]

The Commissioner advised the Committee that in general only 4 per cent of people who have an issue with their service actually bring a complaint.[453] A key reason for this is that people are often fearful of making a complaint. Mr Harkin stated his view to the Committee that:

> it is unsatisfactory that people are afraid to complain. The driver for not complaining is … the fear that something will happen, something will be withdrawn from me. There may be retribution of some kind because I have said something.[454]

The Commissioner advised that he and his Office are working on minimising this fear of complaining. He noted that in the recent reporting year more people with a disability are making complaints.

A number of individuals and organisations that provided evidence to the Committee expressed concerns that, despite these recent developments in the disability services sector, complaints mechanisms are ineffective and lack transparency. They told the Committee that certain processes have to be pursued before the option to raise complaints with the Disability Services Commissioner becomes available. The Carers and Parents Support Group explained that 'you actually have to go through the … DHS grievance process first before you actually go to the commissioner'.[455]

Others concurred with the Commissioner, indicating that people with a disability are reluctant to use the Disability Services Commissioner. For example, the Regional Information and Advocacy Council (RIAC) told the Committee that:

> Clientele are a bit reluctant to go to the likes of the Disability Service Commissioner. It's a huge decision for them to go to that step…

> We are client driven so we give that option to the client, if they want to take that track. A lot of them don't want to.[456]

Effective complaints processes, therefore, need to be simple and to provide avenues that make it easy for individuals to pursue issues of concern.

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[452] *Committee Transcript*, 25.8.09, pp.3-4 (Disability Services Commissioner).

[453] *Committee Transcript*, 25.8.09, p.4 (Disability Services Commissioner).

[454] *Committee Transcript*, 25.8.09, pp.5-6 (Disability Services Commissioner).

[455] *Committee Transcript*, 18.11.08, p.14 (Carers and Parents Support Group).

[456] *Committee Transcript*, 18.11.08, pp.4-5 (RIAC).

The Committee heard that in addition to fears related to complaining or finding the complaints mechanisms confusing, some participants in the Inquiry felt they had not achieved successful resolution regarding their complaints, and feel a need to continually persist with their complaints. The Disability Services Commissioner indicated that he uses conciliation processes to resolve some of these types of issues.

Disability Services Commissioner – information provided on conciliation and investigation processes

What is involved in conciliation?
Conciliation is where the person making a complaint, the service provider involved and the Commissioner (or a representative) have an opportunity to talk about the complaint and come up with a solution. The Commissioner (or a representative) will always be involved in these discussions to assist the person making a complaint and the service provider reach a resolution.

Most complaints are resolved through conciliation however if a resolution can't be reached, the Commissioner may undertake an investigation to determine the best course of action.

What is involved in an investigation?
An investigation is where the Commissioner looks into the details of the complaint to determine the best course of action. It's a serious process used to reach an outcome when other options such as informal discussions or conciliation have failed to reach a resolution.

When is the Commissioner unable to assist with a complaint?
In some circumstances, the Commissioner may not be able to consider a complaint, for example if the matter is already before a court or if the complaint has not been made in good faith.

The Commissioner is also unable to assist with complaints that fall outside his area of responsibility or powers of authority.

Where possible, the Commissioner will provide details of other services that may be available to assist in resolving a complaint.

Source: Disability Services Commissioner website, http://www.odsc.vic.gov.au.

The Commissioner advised the Committee that some of the areas that fall outside his area of jurisdiction include individual support packages (ISPs), services provided to people with a disability in supported residential services, and matters relating to the built environment and transport.[457] The Committee found that there is a lack of clarity regarding complaints and appeal processes for ISPs. The Victorian Government advised the Committee that where an ISP

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[457]   *Committee Transcript*, 25.8.09, pp.2-3, 9 (Disability Services Commissioner).

involves support provided by a disability service registered under the Disability Act, these services can be subject to DHS complaints processes and, if required, the Commissioner. Other non-registered providers, such as home help, are subject to scrutiny by Consumer Affairs Victoria and the Victorian Civil and Administrative Tribunal (VCAT). ISPs themselves, however, are not subject to a complaints process.

Furthermore, the Victorian Government advised that decisions relating to the allocation of ISPs are not subject to appeal. In circumstances where a person believes they require additional funding to the amount allocated, they are directed to seek approval from the region.[458] The Committee heard that these processes are complicated and there are inconsistent understandings regarding appeals and complaints processes, particularly in relation to the Disability Support Register (DSR).

In situations where complaints have not been possible to resolve through existing mechanisms, some complaints-handling agencies have turned to a multi-disciplinary, case management approach for resolving disputes or persistent complaints. In 2006, the Commonwealth Ombudsman, for example, suggested that 'mechanisms of oversight and accountability that are pluralist and representative in nature' are important.[459] He suggested that there is a 'need to give increased emphasis to non-traditional mechanisms of dispute resolution'.[460]

One such strategy is a multi-disciplinary case management approach to dispute resolution. While this has broadly been used in the legal system as a means of reducing adversarial approaches, there is scope to adopt a similar approach in the disability sector. A case management approach would involve a team of experts working with the complainant and seeking to pursue alternative strategies to resolve the dispute or complaint.

As noted above, the Disability Services Commissioner advised that many complaints relate to compatibility, service capacity to meet specific or complex needs (including behaviours of concern) and the level of involvement of people in caring relationships in decision making. In situations where a resolution cannot be reached, a multi-disciplinary case management approach may assist to resolve the complaint or dispute and also to identify solutions to new system gaps that have emerged through the expansion of the eligibility for disability services.

In addition to concerns about unresolved complaints, some participants expressed the view that the Disability Services Commissioner is a 'toothless tiger': 'There is no truly independent complaints process with effective teeth to

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458 Victorian Government (2009) Supplementary data provided to the Family & Community Development Committee.

459 McMillan, J. (2006) The role of the Ombudsman in protecting human rights. Address to conference on 'Legislatures and the Protection of Human Rights', University of Melbourne, Faculty of Law, p.7.

460 McMillan, The role of the Ombudsman in protecting human rights, p.7 [see Footnote 459].

ensure that care policy standards and values are maintained'.[461]   Currently the Commissioner has the authority to 'provide advice generally on any matter in respect of complaints relating to disability services to the Minister'.[462]   There is no compulsion for the Minister to act on the advice.

The Disability Services Commissioner highlighted the importance of using the complaints process to inform continuous improvement in service provision. The Commissioner indicated that this is one of the 'proactive' objectives he is engaged in with his office and stated that the delivery of education and training by his office to service providers has 'influenced organisational and cultural change'.[463]   The significance of continuous improvement as an outcome of complaints was also raised by individuals and organisations that provided evidence to the Committee. For example, a family carer expressed his view that the Department 'does not use systemic complaints to improve the service, so individual complaints are revolving doors; parents are continually bringing up individual complaints'.[464]

Recommendations

9.3   That the Victorian Government develops a communication strategy to assist individuals, families and the community to better understand the complaints process in the disability service system.

9.4   That the *Disability Act 2006* is amended to require the Department of Human Services to address all complaints referred by the Disability Services Commissioner.

9.5   That the Victorian Government broadens the jurisdiction of the Disability Services Commissioner to include complaints about individual support packages.

9.6   That the Victorian Government develops a case management coordination approach to respond to conflict resolution for those complaints where all avenues have been explored and a resolution cannot be reached.

9.2   Mental health quality services and systems

Since 1996, significant efforts have been made at both the national and state level to introduce service and practice standards with a view to enhancing the quality of mental health services. These standards inform the provision of both clinical and non-clinical residential treatment and support services in the specialist mental health sector.

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[461]   *Committee Transcript*, 22.10.08, p.2 (H. & T. Tregale).

[462]   *Disability Act 2006*, Section 17(d)(iii), p.31.

[463]   *Committee Transcript*, 25.8.09, p.2 (Disability Services Commissioner).

[464]   *Committee Transcript*, 22.10.08, p.2 (H. & T. Tregale).

The two arms of the sector have separate, but consistent standards. 'Public mental health' services are provided within National Standards established in 1996. The National Standards were developed with a focus on outcomes, rights, dignity and empowerment and guided by the United Nations Principles on the Protection of People with Mental Illness.

The psychiatric disability rehabilitation and support services (PDRSS) sector has its own standards that are based on the National Standards. The non-clinical focus of the PDRSS sector is expressed in modifications of terminology and emphasis of the National Standards, in particular Standard 11 relating to delivery of care. The following table outlines the National Standards, the Victorian standards and the quality framework that informs public mental health services.

Table 9.2–1: Standards informing clinical and non-clinical mental health services in Victoria

National Standards for Mental Health Services (Victorian clinical services)		Victorian PDRSS standards (non-clinical services)	
1)	Rights	1)	Rights
2)	Safety	2)	Safety
3)	Consumer and carer participation	3)	Participant, community and carer involvement
4)	Promoting community acceptance	4)	Promoting community acceptance
5)	Privacy and confidentiality	5)	Privacy and confidentiality
6)	Prevention and mental health promotion	6)	Prevention and promotion of mental health
7)	Cultural awareness	7)	Cultural and gender awareness
8)	Integration – service integration – integration within health system – integration with other services	8)	Integration – service integration – integration within health system – integration with other services
9)	Service development	9)	Service development
10)	Documentation	10)	Documentation
11)	Delivery of care – access – entry – assessment and review – treatment and support – community living – supported accommodation – medication and other medical technologies – therapies – inpatient care – planning for exit – exit and re-entry	11)	Delivery of support – accessibility – access – assessment and review – rehabilitation and support – community living – residential or home–based rehabilitation and support – psychosocial rehabilitation and support – planning for leaving the PDRSS – leaving and re-entering the PDRSS

Source: National Standards for Mental Health Services (1996) & Victorian PDRSS Standards (2004).

The National Standards for Mental Health Services are used to inform:

- A national accreditation program
- Monitoring by the states through service and funding agreements
- Mental health service development
- Mental health service quality improvement
- Expectations of consumers and carers.

The PDRSS standards are intended for the use of services in their planning and to encourage the objective of moving towards the goals under each criterion.

There is a specific national standard requiring supported accommodation to be provided and/or supported in a manner that promotes choice, safety and maximum possible quality of life for the consumer. This falls within the scope of standards guiding the clinical-based mental health services in Victoria.

The National Standards inform the *Victorian strategy for safety and quality in public mental health services, 2004-08*. The core goals of this strategy are:

- Outcome 1 – consumer and carer focused mental health care
- Outcome 2 – improved safety and quality of practice
- Outcome 3 – system improvement and accountability.

The recently released Victorian mental health reform strategy is also consistent with the National Standards and states its intention to progress issues directly related to improvements in standards and quality of mental health services, and in increasing accountability. For example, in April 2009 the Victorian Government released an action plan to strengthen consumer participation in public mental health services.

9.2.1   Experiences and perspectives

The Committee heard less concerns about quality of care in the mental health services sector than it did in relation to the disability services sector.

There are a number of reasons for this:

- The Terms of Reference for the Inquiry focus on 'supported accommodation' and in the context of mental health, many participants turned their attention to the lack of supported accommodation rather than the quality of existing residential clinical and non-clinical based services in mental health
- In view of the shortage of supported accommodation options in the mental health sector, many sought to highlight issues of quality of care in the supported residential service (SRS) industry, where people with a mental illness are often accommodated following discharge from residential clinical based services

▪ Some components of the mental health sector were considered to have greater quality of care than others.

In its 2009 Annual Report, the Community Visitors noted that the quality of treatment and support in community care unit (CCU) and forensic services are of a good standard. It identified issues, however, in secure extended care unit (SECU) and adult acute settings. Very broadly, these related to medication, treatment by staff, safety issues, legal issues regarding treatment and discharge plans. While the Community Visitors broadly acknowledged a willingness on the part of the Department to work through these issues to reach a successful resolution, they did indicate that some of the issues have been ongoing.[465]

A key concern of participants in the Inquiry related to compliance with mental health standards and the consistency of service. For example, the consumer representative body, the Victorian Mental Illness Awareness Council, stated that:

> we have a non compliance with profession specific and generic standards of practice;… we have non compliance with Chief Psychiatrist guidelines; we have non compliance with government policy; …we are discharging patients from hospital whilst still unwell without adequate clinical and non clinical follow up in the community and sometimes into very inappropriate accommodation…[466]

Ballarat Health Services expressed its view that despite practice standards in the mental health sector, 'one of the ironies in their supports is that there are 22 area mental health services, and you can go to all of those area mental health services and see different models of clinical care'.[467] Notably, the National Standards aim for consistent quality not necessarily consistent practice. Quality and practice, however, are very closely aligned, which is highlighted in the 2002 National Practice Standards for the Mental Health Workforce.

The Committee observed that the Victorian Government needs to further explore issues relating to compliance with mental health standards in both clinical and non-clinical bed-based mental health services.

9.2.2 Seclusion and restraint

Similarly to disability services, Inquiry participants expressed concern about the use of seclusion and restraint in clinical-based residential services in the mental health sector. This extended beyond the mental health sector and into the SRS industry. In view of the Committee's Terms of Reference extending to SECU, this issue falls within the scope of the Inquiry and is briefly touched on here.

The Chief Psychiatrist collects statistics and reports on the use of seclusion and restraint. As in the disability sector, these are interventions of last resort in instances when a person is highly disturbed and unable to be treated in a less

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[465]   Community Visitors, *Annual Report 2008-09*, pp.28-29 [see Footnote 438].

[466]   *Committee Transcript*, 30.4.09, p.3 (VMIAC).

[467]   *Committee Transcript*, 20.11.08, p.10 (Ballarat Health Services).

restrictive way. They are defined and sanctioned by the *Mental Health Act 1986* (currently under review).

The OPA recommended that restraint and seclusion use needs to be reduced in Victoria.[468] In 2007, the Chief Psychiatrist initiated a project in partnership with the Quality Assurance Committee and the Victorian Quality Council to strengthen and support safety in acute settings. It is known as the *Creating Safety: Addressing Seclusion and Restraint Practices project*, which is connected to broader national efforts to reduce the use of seclusion and restraint.

In 2005, a national project was initiated with the goal of reducing and, where possible, eliminating the use of seclusion and restraint in public mental health services. This objective is aligned with the *National Safety Priorities in Mental Health: a National Plan for Reducing Harm*. The National Mental Health Seclusion and Restraint Project is a collaborative initiative between the Australian Government and State and Territory Governments.

Operationally, the Project intends to develop and test resources that can be used to support long-term change in workforce culture and practice leading to less use of seclusion and restraint. In Victoria there are two 'Beacon sites' that are piloting new strategies to reduce the use of seclusion and restraint. These are Peninsula Health Psychiatric Service and Forensicare. In May 2008, Peninsula Health Psychiatric Service reported success in reducing the use of seclusion and restraint.[469]

9.2.3   Complaints

In the mental health sector, the key avenue for complaints is the Victorian Health Services Commissioner. In addition, the Chief Psychiatrist has the authority to inquire into the treatment and care of any individual and to investigate complaints or concerns. In view of this, the Chief Psychiatrist maintains statistics relating to the complaints received by the office. The Mental Health Review Board also has a role, and reviews circumstances where people with a mental illness are subject to involuntary treatment and have concerns regarding the decisions relating to the treatment.

Both the Health Services Commissioner and the Chief Psychiatrist note that the majority of complaints received related to treatment and care. The reasons for these complaints relate to changing a doctor or case manager, issues with communication between clinicians and consumers, disagreement about diagnosis, lack of discharge arrangements and expected follow-up care. In addition, complaints were also received in relation to access to services,

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468   *Submission* 100, p.17 (OPA).

469   Newton, R. (2008) 'Changing the way we care: Reducing seclusion and restraint', Presentation to the National Forum of the National Mental Health Seclusion & Restraint Project. Accessed from <http://www.nmhsrp.gov.au/c/mh?a=da&did=1003613> on 13 October 2009.

involuntary treatment, legislation and policy and statutory practices (such as electroconvulsive therapy).

In regard to access to services, a recurring complaint was about inadequacies in the desired level of service and support at the time it was needed, particularly relating to supported residential accommodation.[470]

9.3   Community Visitors

In the context of bodies that observe and monitor the standard and delivery of services, the Committee heard that Community Visitors in Victoria have a key role. Community Visitors have statutory responsibilities in both the mental health and disability sectors. They are independent volunteers whose role is to safeguard the interests of people with a disability and/or mental illness. In the mental health sector, visits are made to patients and residents in clinical mental health facilities that provide 24 hour nursing care. In the disability sector, visits are conducted to congregate care and community based facilities for people with a disability. In addition, Community Visitors also visit registered SRSs.

The Committee heard from many individuals and organisations that Community Visitors are an important component of the system, and a key independent 'watchdog'. For example, SRS Proprietor, Ms Karen Eccles, expressed her view regarding the important role that Community Visitors play. In addition to the SRS Regulations, she felt that 'on top of this our facility is visited monthly by Community Visitors representing the Office of the Public Advocate, who ensure that our residents' needs are being met'.[471] Kew Cottages Parents Association stated that it is important to have 'somebody who visits regularly and actually is in a sense the outside eyes, like community visitors are, but is in regular contact with the individual, to be able to monitor things'.[472] The Association also pointed out that:

> Community visitors perform an increasingly important role. The strengthening of their rights… through the recent Disability Act is a very positive thing because at the moment they are the monitoring body.[473]

Not all people felt satisfied that that Community Visitors were effective independent monitors; a range of views indicated their potential limitations. For example, the Barwon disAbility Resource Council told the Committee:

> While the community visitor is one resource that acts as a watchdog, unfortunately, it is only as good as the volunteers it attracts. I remember when the question of abuse arose at the establishment that Glenda talked about

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[470]   Mental Health and Drugs Division (2009) *Chief Psychiatrist's annual report, 2007-08*.
Department of Human Services, Victorian Government, p.26.

[471]   *Submission* 131, p.1 (K. Eccles).

[472]   *Committee Transcript*, 22.10.08, p.11 (Kew Cottages Parents Association).

[473]   *Committee Transcript*, 22.10.08, p.11 (Kew Cottages Parents Association).

> earlier we spoke to the community visitor, and she told me she was concerned that towels were being left on the floor. That was her main focus — that the place was untidy — when actually physical abuse was occurring, and to us that was obviously more important.[474]

A couple who care for a family member with a disability and have themselves been Community Visitors expressed their views regarding the limitations of the role:

> We have been community visitors; we were community visitors for six years when the legislation first came out. We find that they are ineffective in getting down to the detail of why a person does not have quality of life. They are quite good at looking at basic care, but when it comes down to the real details of why someone does not have quality of care, we find them quite ineffective.[475]

In Annual Reports produced by the Community Visitors over a number of years, concerns relating to the cleaning, maintenance and refurbishment issues have been dominant themes. This is evident in its 2008 report, which revealed that in disability services 38 per cent of issues were concerned with maintenance, cleaning and facility environment. Similarly, in mental health services, 42 per cent of issues raised by Community Visitors related to amenities and facility environment.

In the report on supported accommodation for people with a disability, VAGO made similar observations regarding the narrow focus of many Community Visitors:

> Many SSA support staff valued this program but saw it as focusing on micro, rather than macro, issues… The reports of community visitors mainly focused on physical condition issues, with very few focusing on residents needs (such as their support plan and their compatibility with other residents). Although the community visitors annual report (tabled in Parliament) raises more substantive issues, neither DHS nor CSOs are required to act on the recommendations in the report.[476]

This finding by the Auditor-General is consistent with a report conducted by the Community Visitor program itself.[477] When reviewing the Community Visitor Annual Reports over a number of years, there are common themes indicating that the issues raised and recommendations made have not been directly addressed by the Victorian Government. In its 2009 Annual Report, Community Visitors refer to their 'disappointment that many of the recurring themes reported by Community Visitors are having an acute effect on people

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[474] *Committee Transcript*, 23.10.08, p.26 (Barwon disAbility Resource Council).

[475] *Committee Transcript*, 22.10.08, p.2 (H. & T. Tregale).

[476] Victorian Auditor-General (2008) *Accommodation for people with a disability*. Victorian Auditor-General's Office, Victorian Government Printer, p.40.

[477] Office of the Public Advocate (2009) 'Two steps forward, one step back: an analysis of five years of Community Visitor annual reports, 2003–2007', Melbourne. Accessed from <http://www.publicadvocate.vic.gov.au/file/file/Research/Discussion/2009/Two-steps-forward-one-step-back-FINAL.pdf> on 23 September 2009.

with a disability in their everyday lives and often remain unresolved for an indeterminate time'.[478]

These issues regarding the role of Community Visitors in the system are not limited to the disability sector. In the consultation report on the review of the *Mental Health Act 1986*, the review panel similarly noted that 'the roles currently performed by … Community Visitors do not adequately meet monitoring requirements' and that 'Community Visitors, while valued, do not have sufficient powers or expertise to resolve issues'.[479]

These opinions demonstrate the paradoxical nature of community volunteers in roles such as the Community Visitors. While valued as the 'eyes of the community', the Committee heard that the skill levels required for the role performed by Community Visitors in visiting and engaging with people with a disability and/or mental illness is unique. As highlighted in the next section on workforce, working with people with a disability and/or mental illness requires specific skills and training.

In approximately 1998, the OPA conducted an internal review of the Community Visitor program. Former Public Advocate Mr Julian Gardner referred to this review in 2007, noting that there was 'significant change in the Community Visitors Program as a result of … that review. For example, there has been a major change in training, which has been greatly increased in quantity and quality'.[480]

The OPA provides training and support for its 590 Community Visitors to undertake over 5,500 visits every year. In its 2008 Annual Report, the office states that:

> Training is essential to the quality of the program to ensure that it can continue to provide appropriate training for volunteers in the state. This year, the program provided a total of 44 training sessions to approximately 590 volunteers, with sessions conducted in regional cities.[481]

The Annual Report also highlights the significance of continuous improvement in the context of Community Visitors. Over the year, improvements were focused on providing more up-to-date resources (such as IT software and equipment) for Community Visitors to perform their role more effectively.

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[478]   Community Visitors, *Annual Report 2008-09*, p.22 [see Footnote 438].

[479]   Department of Human Services (DHS) (2009) *Review of the* Mental Health Act 1986*: Community consultation report – July 2009*. Mental Health and Drugs Division, DHS, Victorian Government, Melbourne, p.68.

[480]   Gardner, J. (2007), Address to the Community Visitor AGM, Accessed from <http://www.publicadvocate.vic.gov.au/file/file/Research/Forums/2007/ CommunityVisitors/Address_from_Julian_Gardner_Former_Public_Advocate.pdf> on 23 September 2009.

[481]   Office of the Public Advocate (2008) *Annual Report, 2007-08*. Office of the Public Advocate, Victoria, p.41.

While the Community Visitor program was reviewed internally in 1998, since that time there have been significant changes in the provision of both mental health and disability services. As the next section on the workforce outlines, there are significant challenges for any workforce in a context where service practices are changing. For example, significant legislative and policy changes have occurred since that time, changing the way that services in both the mental health and disability sectors are provided. The *Charter of Human Rights and Responsibilities Act 2006* and the *Disability Act 2006* have been introduced, with the *Mental Health Act 1986* currently in review.

New policy frameworks in mental health and disability services are re-orienting services to more individualised approaches. It was not clear to the Committee whether consideration has been given to the implications of these changes to the Community Visitor role. Responding to culturally diverse communities, for example, is an area that has had significant focus over the past eight years. Concerns were raised, however, regarding the capacity of Community Visitors to respond effectively to people from diverse cultural backgrounds. Action on Disability in Ethnic Communities commented that:

> From our experience and from the knowledge we gain from our carers, community visitors find it difficult to advocate and actually report issues of breaches of human rights. Not only that, there is too much dialogue that goes on between community visitors and staff, and situations that come to the attention of community visitors become totally watered down.[482]

Considerations regarding the need for a review of the role of Community Visitors in light of changes to service paradigms over the past decade are not limited to the material received by the Committee. For example, in the consultation report for the review of the *Mental Health Act 1986*, the review panel quotes a submission stating that 'a review about the clarity of these roles is necessary to assist in the complaints process'.[483]

The Community Visitors clearly play an important role in advocating for the rights of people with a disability and/or mental illness. There is scope, however, to revisit what recent changes in legislation and policy mean in the context of more individualised approaches to providing support and accommodation. There is potential merit in exploring how other states manage the equivalent to the Community Visitor in Victoria. Again, the panel reviewing the Mental Health Act have noted the possibility of considering alternatives used in other states. The panel notes that in the context of mental health services, 'one option to improve monitoring functions could be through the introduction of official visitors, consistent with many other Australian jurisdictions'.[484]

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[482]   *Committee Transcript*, 30.4.09, p.3 (ADEC).

[483]   DHS, *Review of the Mental Health Act 1986: Community consultation report – July 2009*, p.62.

[484]   DHS, *Review of the Mental Health Act 1986: Community consultation report – July 2009*, p.68.

Recommendations

9.7   That the Victorian Government commissions an external review of the Community Visitor program to assess the effectiveness of the current model in the context of significant legislative and policy changes of the past decade, and that this review considers models and practices in other jurisdictions and makes recommendations for the future strengthening of the program.

9.8   That the Victorian Government amends legislation to require government to respond to the Community Visitor annual reports within six months of the tabling of their reports.

9.4   Workforce

Since the commencement of the Inquiry, the Victorian Government has introduced workforce strategies in both the Mental Health and Disability fields. The Committee heard that workforce capacity is essential to the provision of quality supported accommodation services for Victorians with a disability and/or mental illness. The Health and Community Services Union (HACSU) highlighted this point in its submission:

> Sound workforce capacity and skill level underpin any quality and productive service system…
>
> In terms of quality outcomes for service users there is a direct correlation between service adequacy and the capacity of service management, service governance, and the support and training given to all staff. These are critical factors in determining the quality of service delivery.[485]

Other participants expressed similar views regarding the importance of the workforce in providing quality care and high standards of support. The following broad comments were made in regard to the links across quality of the workforce, the quality of service and the outcomes for people with a disability.

> **Golden City Support Service**
>
> Within a quality of life framework, support provided by staff should enable people to be self-determining to experience a sense of productivity, a sense of contribution to both their family, to their friends, and to the community, to have a sense of purposefulness and to be functional…
> The way staff provide support is key to whether the outcome of being functional in a sense of quality of life occurs.[486]

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485   *Submission* 121B, pp.6, 29 (HACSU).
486   *Committee Transcript*, 19.11.08, pp.3, 5 (Golden City Support Service).

> **Kew Cottages Parents' Association**
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> The quality of the current physical accommodation for former KRS residents is consistently high…   However, the quality of care and support being received by individuals in the houses is variable…   The improved physical environment in which all former KRS residents are living does not necessarily compensate for this variability … in the standard of care and support that is being received…[487]
>
> **Yooralla**
>
> For people with complex medical needs or behaviours of concern — and this is the growing population — we need a more sophisticated approach to service delivery that recognises that the fundamental quality of the service is predicated on consistent, skilled and dedicated staff.[488]

The Committee heard that in both the mental health and disability sectors, there are workforce issues impacting on the delivery of services. Concerns were expressed about the capacity of the workforce in both sectors to meet current practice and support requirements. Workforce capacity relates not just to the numbers of staff, but also to the level of staff expertise and skill, the roles and career structures, the degree of motivation within the workforce and the structure of the workforce.

The Committee received different views and evidence relating to experiences regarding the mental health workforce from the disability services workforce. In particular, issues relating to workforce shortages and the need for increased capacity to respond to complex needs were raised. It is important to note that the skill and expertise required in clinical services differ significantly from those in non-clinical specialist mental health services. In addition, the workforce issues across the two service arms of the mental health sector are also different.

In both disability and mental health services, the workforce has experienced dramatic shifts in models of service delivery over the past two decades as a consequence of the closure of institutions. Considerable research has been conducted on the processes of closing institutions in both the Victorian mental health sector and the disability sector. Emerging from this is an insight into the different approaches taken in the two sectors to developing workforce capacity following the development of new service models in the 1990s.

Chapter One outlined the process of closing institutions in the Victorian mental health sector. Over a four-year period from 1994 to 1998, the State's mental health system underwent a major overhaul. According to Valerie Gerrand in her recent research into the process, 'the changes were striking in both pace and

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[487]   *Committee Transcript*, 22.10.08, p.5 (Kew Cottages Parents Association).
[488]   *Committee Transcript*, 22.10.08, p.4 (Yooralla).

magnitude'.[489] The new service system was re-oriented to a community care approach, with management of public mental health services moved to the general health system.

In evaluating the success of a process of deinstitutionalisation, Gerrand argues that a key measure is that the 'selection and training of staff should ensure that they have the right set of skills for a community-oriented service system, and in particular, the readiness to work in partnership with service users'.[490] She explains that in Victoria, recognition of the need to focus on workforce capacity was a critical component of the reform to the mental health service system.

From 1994 to 1996, the first phase in the reform, a state-wide staff training unit was established to build the capacity of the mental health workforce to enable it to adapt to the changed approach to service provision. For example, new skills were required in the provision of community treatment and engaging with consumers and their families. Despite the importance of workforce capacity, the training unit was disbanded in 1996. Gerrand suggests that this was 'arguably premature'.[491]

While the development of workforce capacity in the mental health sector might have potentially been cut short during the transition from institutionalised mental health services to community treatment, this recognition of the significant change and commitment to developing new skills for the workforce demonstrates a significantly different approach from the approach taken in the disability sector in the context of closing institutions.

The process of closing institutions in the disability sector has occurred over a longer period and has tended to focus on the closure of individual facilities rather than the service system as a whole. In view of the different approach and timeframes, the development of workforce capacity has been different in the disability sector.

This chapter addresses the two workforces separately, in view of the different sector experiences in adapting to the closure of institutions and the different nature and context of the services provided. The Committee heard a greater amount of evidence from those participants involved with the disability sector. As outlined earlier in this chapter, a potential reason for this has been the uncertainty of some participants regarding the scope of the Committee's Inquiry.

While the issues across the two sector workforces are notably different, evidence received by the Committee suggested there are core components necessary to effectively achieve the workforce capacity required to deliver quality services.

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[489]   Gerrand, V (2005) 'Can deinstitutionalisation work? Mental health reform from 1993 to 1998 in Victoria, Australia'. *Health Sociology Review*, Vol.14(3), p.256.

[490]   Gerrand, 'Can deinstitutionalisation work?', p.263 [see Footnote 489].

[491]   Gerrand, 'Can deinstitutionalisation work?', p.266 [see Footnote 489].

These components were consistent to both mental health and disability sectors. They are:

- Importance of building workforce capacity and ensuring appropriate workforce structures

- Importance of workforce strategy

- The need for investment in workforce

- The importance of pay, employment conditions, job security and appropriate recognition

- The need to recognise changed policy and practices will impact on workforce capacity (eg. closure of institutions)

- The need to support the workforce – through professional development, safe environments, coaching.

9.4.1   Disability workforce

The workforce in disability SSA (and in other support contexts) comprises Disability Development and Support Officers (DDSOs). The three main areas of work in the disability workforce are defined as – Accommodation Services, Day Programs and Individual Support.

The Committee found that the disability workforce is a broadly flat structure. There are no distinctions between skills required for these differing roles. DDSOs work in all three settings. The qualification often required (but not mandatory) to undertake these roles is a Certificate IV in Disability Work. In the government sector, the majority of staff hold a Certificate IV. In community service organisations (CSO) sector, there are lower numbers of qualified staff. The workforce relies heavily on part-time and casual staff (in 2005, 48 per cent part-time and 17 per cent casual staff).[492] Notably, in view of the way that information is collected about the workforce, there is greater information about the profile of the DHS workforce than the CSO workforce.

Victorian Government workforce strategy

In April 2009, the Victorian Government released the *Workforce Strategy – Improving supports for people with a disability.* In doing so, it aimed to demonstrate its recognition that the workforce is a critical agent in the change process and requires support to effectively assume this role.

The development of a workforce strategy in Victoria was also part of a national commitment to building the capacity of disability workforces across all jurisdictions. In the consultations that informed the development of the strategy, Disability Services Division acknowledged the issue of workforce capacity in the disability sector is a critical issue. It stated that:

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[492]   Department of Human Services (2005) *Disability Services Workforce Study.* DHS, Victorian Government, Melbourne.

Workforce capacity has been identified as a priority to be addressed by all jurisdictions as part of the next CSTDA [Commonwealth and State/Territory Disability Agreement].[493]

Disability Services also acknowledged that the change in service provision requires support for the workforce to adapt, stating that the State Disability Plan 'represents a shift away from the traditional skills and roles of the disability workforce and a change in the type of work, skills and attributes required of the future workforce'.[494] Direct service provision has moved towards person-centred approaches focusing on the needs of the individual. This includes ISPs (often for people considered more 'independent') and person-centred planning (used in the context of supported accommodation).

The *Workforce Strategy – Improving supports for people with a disability* outlines four priority areas for building the capacity of the disability services workforce.

- Strategic approach to workforce improvement
- Attracting workforce
- Enhancing job satisfaction
- Learning, development and support.

In view of the very recent release of the strategy, it is too early for the Committee to comment on the likely effectiveness of the strategy. The Committee identified a need for an improved plan that provides clear timelines and accountability in the roll-out of the strategy.

As noted in earlier chapters, the disability services sector is working through a period of reform in the delivery of services. In addition to the continued closure of institutions, the *State Disability Plan, 2002-12* and the *Disability Act 2006* represent a fundamentally new direction in the approach to the provision of disability services. The new focus relates to person-centred support and an increased emphasis on providing opportunities for people with a disability to live independently in the community with adequate support.

Recruitment and retention

The Committee heard that a major issue for the disability workforce relates to staff shortages and the interlinked challenge of recruiting and retaining skilled and experienced staff. This is not unique to the disability sector. Many workforces within the community services sector experience issues with recruitment and retention. Importantly, however, there are implications for quality of support resulting from the high turnover of staff in disability services.

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[493] Department of Human Services. (2008) *Disability workforce planning and development strategy, 2008-13: Draft for consultation*, p.3. Accessed from <http://www.dhs.vic.gov.au/disability/improving_supports/industryplan> on 7 April 2009.

[494] Disability Services Division (2009) *Workforce Strategy: Improving supports for people with a disability 2008-13 and beyond.* Department of Human Services, Victorian Government, Melbourne, p.4.

HACSU told the Committee that the disability support services workforce faces considerable future challenges. It further suggests that there are particular challenges for the disability sector within the broader community services sector:

> Every level of government and non government service provider has a major attraction, retention and skills issue facing them; however, problems are particularly chronic in the non government disability sector.495

The OPA also acknowledged that 'issues of recruitment and retention are … affecting the ability of services in the disability sector to maintain consistent standards of care and to ensure a knowledgeable and skilled workforce'.[496] Further to this, the Community Visitors note in their 2008 Annual Report that the increasing employment of short-term, casual and agency staff is affecting the continuity of care of residents.[497] In its 2009 Annual Report, the Community Visitors 'report with regret that the staffing issues identified in last year's report remain unchanged'.[498]

Karingal noted that high turnover of staff in SSA has implications for consistency of service provision and affects the nature of the relationships built between staff and residents. Karingal stated that in its experience 'sometimes staff come and go so quickly that they do not get to know the people they are caring for'.[499]

Participants also highlighted shortages of staff in specific areas of disability support services where residents have multiple and complex needs. Karingal noted that there is a shortage of staff with specialist skills or prepared to undertake shift work:

> There is a need for active night support; sleepover support is often not adequate for those with high and complex support needs. There is a requirement for access to medically qualified staff within disability support services.[500]

Interchange Loddon Mallee Region noted that 'many of the community residential units are not staffed during the day, so people who feel sick or don't want to go somewhere for the day can't stay home because there is not going to be anyone there to look after them or support them'.[501] The Community Visitors 2009 Annual Report also highlighted the staff-to-resident ratio.

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[495]   *Committee Transcript*, 5.11.08, p.6, (HACSU).

[496]   *Submission* 100, p.51 (OPA).

[497]   Community Visitors (2008) *Annual Report 2007-08*. Office of the Public Advocate, Victorian Government Printer, p.37.

[498]   Community Visitors *Annual Report 2008-09*, p.26 [see Footnote 438].

[499]   *Committee Transcript*, 23.10.08, p.8 (Karingal).

[500]   *Committee Transcript*, 23.10.08, p.5 (Karingal).

[501]   *Committee Transcript*, 19.11.08, p.3 (Interchange Loddon Mallee Region). See also *Committee Transcript*, 23.10.08, p.5 (Barwon disAbility Resource Council).

Based on the evidence received, the Committee recognises the need for increased numbers of disability workers. The Victorian Government's workforce strategy targets the issue of recruitment and retention. The Committee considers that improved staff-to-resident ratios are important to more effectively facilitate person-centred approaches. In particular, in situations where residents have multiple and complex needs, these ratios are particularly important.

Recommendations

9.9   That the Victorian Government increases the ratio of appropriately qualified staff to residents in shared supported accommodation facilities that accommodate people with high, complex and changing needs.

9.10   That the Victorian Government increases the staff-to-resident ratio to enable greater flexibility for those people with a disability in shared supported accommodation unable to attend day placements.

Recognition and remuneration

A number of participants in the Inquiry expressed a view that low pay and working conditions have implications for staffing levels – that is, in both recruiting and retaining workers in the fields of disability and mental health.

HACSU told the Committee that some of the drivers relating to the challenges in recruiting and retaining the disability workforce in Victoria relate to wages and the extent to which the work is valued in the community:

> Wages are poor; there is low recognition and valuing of care work; care work is not seen as part of the productive economy and as a result they don't leverage higher pay.[502]

National Disability Services (NDS) supported this view, commenting that 'it is difficult to recruit and retain staff who are on low salaries and whose jobs are not highly regarded within the Victorian community'.[503] CSO providers similarly indicated that they find it difficult to attract staff in a competitive environment. Gateways Support Services, for example, explained that to overcome this they:

> work very hard to be a friendly community organisation that actually values its staff, so I suppose we try to find other ways to make ourselves an attractive employer, because we cannot compete when the pay rates are significantly higher.[504]

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[502]   *Submission* 121B, p.29 (HACSU).

[503]   *Committee Transcript*, p.3, 5.11.08 (NDS).

[504]   *Committee Transcript*, 23.10.08, p.10 (Gateways Support Services).

It was not only service providers that called for increased wages to assist with recruitment and retention. Families in caring relationships with people with a disability also expressed their concern regarding wage levels for disability support workers. For example, the Carers and Parents Support Group in Benalla stated that:

> Parents believe the staff should be well-respected as good workers and rewarded with an appropriate wage. Better wages and respect will increase the retention of workers who deliver best practice service for people with disabilities.[505]

Similarly, a family carer stated that as parents 'we would like staff to be resourced, supported and paid appropriately to assist the continuity and retention of staff within that sector'.[506]

In CSOs, payment for wages is integrated into the broader allocation of funds to services. The Committee heard that the allocation of funds to services is complex and that there are no specific requirements regarding how 'price indexation' increases for CSOs are transferred within the organisation. The DHS uses 'price indexation mechanisms to ensure funding provided to organisations through service agreements keeps pace with predictable and one-off cost increases, principally wage and non-wage movements'.[507] The NGO price index is guaranteed for the 2009-12 service agreement. The indexation rate is based on the following formula:

- 85 per cent of the index for wages in line with Government wages policy at the time (3.25 per cent). NB, the DHS website notes that Government wages policy is now 2.5 per cent, but the guaranteed index will apply for three years based on previous wages policy.

- 15 per cent of the index for operational cost increases, based on the Departmental Funding Model (DFM) for CPI (2.5 per cent).

Therefore, the CSO price index is rounded up to 3.14 per cent (which is the 3.25% x 85% plus 2.5% x 15%). These adjustments are known as price indexation, and are processed automatically by the DHS at the beginning of each financial year.[508] There is a payment schedule and service agreements can contain specific requirements for using funds. On the whole, however, CSOs broadly allocate their funds as they require.

In regard to price indexation, HACSU expressed its view that:

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[505] *Committee Transcript*, 18.11.08, p.4 (Carers and Parents Support Group Benalla).

[506] *Committee Transcript*, 23.10.08, p.2 (Dawn Accommodation).

[507] Department of Human Services (2009) *Funded Agency Channel: Price Index 2009-12,* Accessed from <https://fac.dhs.vic.gov.au/home.aspx?TabID=content&type=4&contentID=6159> on 3 December 2009.

[508] Department of Human Services (2009) *Service Agreement Information Kit for Funded Organisations: 3.4 Price Indexation.* Accessed from <http://www.dhs.vic.gov.au/facs/bdb/fmu/service-agreement/3.payments-to-organisations/3.4-price-indexation/_nocache> on 3 December 2009.

there has been a pattern of many, usually smaller, NGO's not passing on wage growth funds to employees; this is exacerbating workforce attraction and retention problems in the sector and expanding wage disparity problems.[509]

NDS, however, highlighted the complexity of remuneration, attracting workers and providing quality services to people with a disability. NDS acknowledged that 'recruitment and retention difficulties are compounded by the low salary levels for disability support work'.[510] It also stressed that 'organisations need increased resourcing to train, lead and motivate staff, to enable workers to provide the support critical to a good quality of life [for people with a disability]'.[511]

Based on the evidence it received, the Committee considers there is scope for the Victorian Government to consider reviewing the contractual requirements in regard to the allocation of funds towards disability support workers. In particular, the Committee considers that service agreements should stipulate that a specific portion of the 85 per cent of price indexation increases is directed towards wage increases and professional development for disability support workers.

Furthermore, as noted in earlier chapters, the 2009 price review of out of home disability services conducted by PricewaterhouseCoopers (PwC) identified that both government and CSOs face significant, yet different, cost pressures and challenges related to the transition to a new service delivery approach. PwC recommended that three components of funding be considered:

- A price adjustment to existing unit prices to reflect recurrent service needs

- Unbundling of the unit price to reflect significant variations in cost pressure

- Other funding to support service transition and capability building to meet government direction of service reform and compliance.[512]

Recommendations

9.11   That the Victorian Government increases remuneration for Disability Development and Support Workers to reflect the level of expertise and skills required in working with an increasingly diverse and complex client base.

9.12   That the Victorian Government reviews service agreements with a view to establishing contractual requirements to allocate specific proportions of price indexation increases to wage increases, and training and support for disability support workers.

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509   *Submission* 121B, p.29 (HACSU).
510   *Submission* 120, p.6 (NDS).
511   *Submission* 120, p.6 (NDS).
512   PricewaterhouseCoopers (2009) 'Department of Human Services: Price Review Out of Home Disabiltiy Services Final Report', p97. Accessed from <http://www.dhs.vic.gov.au/disability/improving_supports /industryplan/pwc> on 20 October 2009.

Recommendations

9.13   That the Victorian Government adopts the recommendations made by the PricewaterhouseCoopers price review and adjusts the base price to reflect the actual cost of service delivery.

Work environment

Issues relating to the work environment and the support provided to staff in the mental health and disability sectors were raised in the evidence received. The Committee heard of some concerns relating to safety. Karingal provided an example of one issue their organisation faces in view of the rural travel expected of their workers:

> One of the issues that some of our staff are finding, too, is some of the pockets in the Otways still have black spots for mobile phones. For those people who are actually travelling, we provide an after hours call service, 24 hours a day, seven days a week. So for staff who are called out at 2 o'clock in the morning and they are at risk of hitting a black spot with their mobile phone, that is a real issue for our staff.[513]

The Carers and Parents Support Group in Benalla also highlighted safety issues associated with a lack of skills and training. They noted that 'support workers are often not properly trained to deal with people with behaviours of concern. This leads to serious safety issues for residents and workers'.[514]

Other participants told the Committee of challenges for workers who are very isolated in their day-to-day work, particularly in SSA. Yooralla explained that: 'It is an isolated environment with poor opportunities for interaction with other colleagues'.[515] Kew Cottages Parents Association suggested that 'staff working with these individuals also have increased support needs and risk suffering from the stress and isolation of working in a small CRU [community residential unit] remote from others'.[516]

Support for staff

Interlinked with the issue of environment is the issue of support for staff. In particular the value of mentoring and practice coaching were raised in the context of supporting staff to adapt to changing service approaches and ideologies.

One worker in the sector stated that the nature of the work created the potential for burnout and stress.[517] Others indicated that for good practice, supervision

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[513]   *Committee Transcript*, 23.10.08, p.11 (Karingal).

[514]   *Committee Transcript*, 18.11.08, p.4 (Carers and Parents Support Group Benalla).

[515]   *Committee Transcript*, 22.10.08, p.7 (Yooralla).

[516]   *Committee Transcript*, 22.10.08, p.5 (Kew Cottages Parents Association).

[517]   *Committee Transcript*, 23.10.08, p.2 (Name withheld).

and coaching were essential. Ultimately, however, many agreed that the quality of service to people with a disability is dependent on the levels of support invested in the workforce. NDS, for example, stated that:

> We are relying on staff who are, by and large, out in the community working with clients to make good judgements and decisions and we need to be able to be in dialogue with them to support them and see how they are going with that.[518]

Golden City Support Services talked about the need to maintain levels of practice coaching to ensure that staff maintain their skill levels. The CEO, Mr Ian McLean, referred to research indicating 'that if you do practice coaching on shift, then the skills will be implemented for up to about three to nine months. But if you stop practice coaching, then that skill actually wanes again. And we, observably, see that'.[519]

Numerous individuals and organisations that provided evidence to the Committee stressed the significance of effective training and professional development to contribute to workforce capacity. The Centre for Developmental Disability Health Victoria suggested that in disability services 'staff will often have very basic skills as carers and often struggle with the extra demands that come with people with physical and mental health problems'.[520] Kew Cottages Parents Association expressed strong views about the need for more trained staff:

> The great shortage of skilled and trained support staff must be addressed as a matter of urgency; service management must provide more active support to house staff; funding needs to be allocated to provide high quality courses to offer the necessary qualifications and training; … more effort must be made to increase the qualification and training of casual, part time and permanent staff.[521]

Other participants expressed similar views, for example Dawn Accommodation stated that there is 'a need there for appropriately trained staff to provide support and care, staff to be based and be a part of local community, particularly when in crisis or out of hour needs, the support is required'.[522]

The issue of appropriately skilled and qualified staff was highlighted by the Victorian Auditor-General's 2008 report into accommodation for people with a disability. The report made significant mention of the capacity and expertise of service providers in the disability sector. The Auditor-General found that service providers:

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[518]   *Committee Transcript*, 5.11.08, p.7 (NDS).

[519]   *Committee Transcript*, 19.11.08, p.9 (Golden City Support Services).

[520]   *Submission* 62, p.2 (Centre for Developmental Disability Health Victoria).

[521]   *Committee Transcript*, 22.10.08, p.6 (Kew Cottages Parents Association).

[522]   *Committee Transcript*, 23.10.08, p.2 (Dawn Accommodation).

are struggling to meet their existing obligations for supporting residents, particularly in the time required to provide individualised support. Their capacity to provide additional individualised support is limited. There is considerable variation in staff skills and qualifications, which results in variability in service provision.[523]

In addition to the variability of skills and expertise identified by VAGO, HACSU further commented that the disability support service system is experiencing skills atrophy. It suggested that this is in addition to a 'skills recession', which is caused by the challenges in recruitment and retention and an ageing workforce. According to HACSU, 'skills atrophy is a continual decline in those workers who are currently working in the system' and is largely a consequence of the lack of accessibility of training and a system that does not prioritise training opportunities for workers'.[524] As discussed below, the Disability Services Division has recently prioritised the training of staff in the disability workforce.

Mr Ian McLean, CEO of Golden City Support Services, explained that the link between quality of life for people with a disability and the level of skills and expertise of staff is not limited to training. He stated that 'the reason why Eric Emerson's research shows that there is very little correlation between training and quality of life outcomes is because the application of that skill is limited'.[525] Golden City Support Services advocate for a more extensive model that incorporates ongoing supervision and coaching. Mr McLean stated that 'coaching practice, leadership, the sense of assessment of what we're doing on the job, is of key importance for our organisation' and proposes:

> [a] service system that is prepared to invest in, practice frameworks of support that staff get skilled in, training that includes not just training that is upfront but job coaching on an ongoing basis to maintain the application of skill … And the constant recognition and feedback.[526]

In addition to the need for improved training opportunities and adequate practice coaching to maintain the 'application of skill', the disability services sector is clearly facing considerable challenges to bring its workforce into alignment with new models of practice.

These practices involve more person-centred approaches and working with a broader range of disability types and dual and multiple disabilities. Many individuals and organisations emphasised the need for improved training in specialist skills, for example, to work with dual disability and behaviours of concern. Karingal advised the Committee that:

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[523]   Victorian Auditor-General (2008) *Accommodation for people with a disability*, Victorian Government Printer, p.2.

[524]   *Committee Transcript*, 5.11.08, p.6, (HACSU).

[525]   *Committee Transcript*, 19.11.08, p.9 (Golden City Support Services).

[526]   *Committee Transcript*, 19.11.08, p.9 (Golden City Support Services).

> We are finding that staff are not skilled or equipped to work with people with dual disabilities, and that may be someone with a mental illness who also has an intellectual disability and/or autism. This is a really highly specialised area, and we are finding that staff are not as skilled as we would like them to be. Certainly Karingal is making an effort to offer training for staff in that area.[527]

The Centre for Developmental Disability Health Victoria also explained that in the disability sector, 'houses dealing with complex social, medical and behavioural issues are unlikely to be well managed if the supervisor for the carers works off site'.[528] This was also raised by Goulburn Valley Centre Disability Services, who stated that 'a lot of young children who are surviving now who have complex medical needs, obviously they might live 40 or 50 years so obviously for trained staff – that's an issue in trying to get nursing – as to trying to attract nursing staff to their profession as well within the not-for-profit sector'.[529]

Goulburn Valley Centre Disability Services identified the implications for people with a disability when the services lack the skilled staff required: 'Specialist services are often depleted and the level of care decreases'.[530] The Health and Community Sector Union expressed its view that 'we need a workforce that has specialist skills in terms of meeting people's physical and social needs'.[531] It went on further to state that 'restricted career pathways, no funding for promotion or recognition of skills enhancement and work intensification combine to create disincentive to train'.[532]

Karingal informed the Committee that staff are not well paid to undertake specialist roles with people with behaviours of concern or with multiple and complex needs. Similarly, a family carer for a young man with multiple disabilities, also expressed support for the need to fund 'the add-ons', particularly the extra skills in working with people who exhibit behaviours of concern'.[533] The following recommendation was made that to:

> Address the shortage of skilled support staff by the creation of an additional salary/wage allowance for staff working with people with recognised high support need - e.g as scored by Supports Intensity Scale or similar. This needs to be supported by suitable training.[534]

The following extract from the evidence received by the Committee provides one direct care worker's perspective on workforce issues in the disability sector.

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[527] *Committee Transcript*, 23.10.08, p.5 (Karingal).

[528] *Submission* 62, p.2 (Centre for Developmental Disability Health Victoria).

[529] *Committee Transcript*, 18.11.08, p.4 (Goulburn Valley Centre Disability Services).

[530] *Committee Transcript*, 18.11.08, p.4 (Goulburn Valley Centre Disability Services).

[531] *Committee Transcript*, 22.10.08, p.4 (HACSU).

[532] *Committee Transcript*, 5.11.08, p.7 (HACSU).

[533] *Committee Transcript*, 19.11.09, p.2 (Name withheld).

[534] *Submission* 73, p.5 (Name withheld).

One direct care worker's perspective

I am here to speak to you as a direct care worker. It is probably just a bit different perspective to what you have been hearing today. 20 years, working in the disability field, I have seen many changes...

The recruitment and retention rate of staff is … a huge issue, and it impacts on the house supervisor being constantly required to train new staff. The complex criteria for new or casual staff means not necessarily getting the right person for the right job. We have an ageing workforce. As the roster lines and the non-friendly hours mean younger staff are not attracted to positions…

The needs of the clients are becoming more complex. We have dual disabilities, medical needs. We have higher behaviours of concern that cause assaults on staff, and that is increasing…

We have insufficient powers to provide one-to-one support for clients, meaning the whole house attends an outing as opposed to individual outings. People are not getting their needs met in that regard. This causes frustration to both the clients and staff. Also many staff are gaining higher qualifications and are finding it difficult to get the recognition for this, which means that there is very little scope for career advancement…[535]

The Committee found that the Victorian Government's workforce strategy has recognised these development issues and aims to address them through its development and support strategy. This will see a competency based learning approach to all learning activities.

The key points in the strategy are:

- Sustainable, skilled and flexible workforce
- Qualification and career paths
- Confident and strong leadership
- Innovative learning and development activities
- Partnership and collaborative approaches.

Recommendations

9.14   That the Victorian Government funds service providers to employ practice coaches/coordinators to provide mentoring to staff in the development of new skills as part of its workforce strategy.

9.15   That the Victorian Government reviews the structure of the workforce to increase the proportion of permanent, trained staff/employees.

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[535]   *Committee Transcript*, 23.10.08, p.2 (Name withheld).

Recommendations

9.16   That the Victorian Government's implementation plan for the disability workforce strategy states funding commitments to achieve the proposed objectives.

9.17   That the Victorian Government introduce recruitment strategies for attracting workers in rural and regional areas.

9.18   That the Victorian Government undertakes a targeted strategy to employ more workers from indigenous backgrounds and culturally diverse communities.

9.4.2   Mental health workforce

The mental health workforce comprises a range of health and community service practitioners. Health practitioners in the mental health service system include doctors, nurses, psychiatrists, and psychologists. Community service practitioners in the mental health service system include social workers, youth workers, occupational therapists and support workers.

As outlined in earlier chapters, the mental health service system can be broadly distinguished into two categories. Clinical based treatment services is one component. In the context of supported accommodation, residential clinical services include SECUs and CCUs. These are largely staffed by the specialist health practitioners outlined above. The second category is the non-clinical specialist mental health service component, most notably providing services in PDRSS day programs, home based outreach support and residential rehabilitation. These services are generally staffed by specialist community service practitioners. Prevention and Recovery Care services are based on partnership arrangements between PDRSS and clinical services and therefore are supported by both specialist health and community practitioners.

Victorian Government workforce strategy

In its recently released mental health strategy, *Because Mental Health Matters*, the Victorian Government has acknowledged that:

> the implementation of many of the strategic directions identified in the mental health reform strategy are contingent on the development of robust, adaptable and skilled workforces with the sufficient capacity to maintain and expand service delivery and respond to the changing and diverse needs of consumers.[536]

A key reform area within the strategy, therefore, relates to workforce and innovation, with an emphasis on building skills, leadership and knowledge.

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[536]   Department of Human Services (2009) *Because Mental Health Matters: Victorian Mental Health Reform Strategy, 2009-2019*, Mental Health and Drugs Division, DHS, Victorian Government, Melbourne, p.125.

The Strategy sets out four goals to achieve the objective of improving workforce capacity, skills, leadership and knowledge. The goals are:

- Building a sustainable, flexible and dynamic specialist mental health workforce

- Developing work practices and cultures that support high quality, effective care

- Improving the mental health competency of other key workforces in the sector

- Creating state-wide research and knowledge management capacity.

Similar to the disability sector, the strategy highlights some key goals in its challenge to build workforce capacity without committing to a plan of implementation with clear timelines. Furthermore, with no embedded evaluation, it will be difficult to measure the progress of the strategy.

In September 2009 the Victorian Government released its mental health workforce strategy — *Shaping the Future: The Victorian Mental Health Workforce Strategy Final Report.* The three key areas for attention are:

1) Supply and distribution

2) Skill and training

3) Organisational environments.

The strategy indicates a commitment by the Victorian Government to adopt a more strategic approach to developing the capacity of the disability services workforce. This involves a commitment to increasing the level of information collected about the workforce, and includes a best practice 'ideas bank'. A further goal is to undertake an evaluation of the workforce through a gap analysis.

The Committee commends this intention to increase the understanding of the disability workforce. Gaining a clearer picture of the workforce through the development of databases and understanding the gaps is a critical step in moving towards a new future. Based on the evidence it received, the Committee has found that determining the next steps once that information has been analysed is the key goal to filling the identified gaps.

Furthermore, the critical challenge for the Victorian Government will be in the implementation of the strategy. While it declares that it will achieve a number of improvements in workforce capacity by 2013, the intentions for implementing and evaluating these achievements are not contained within the strategy.

As noted above, the two arms of the mental health sector – the clinical and the non-clinical – have different staff profiles and therefore different workforce requirements. HACSU suggests that in clinical services, where the focus is on

> treating and managing a client's clinical symptoms… [the] structure and staffing of these services is also designed to manage behavioural problems such as those who have repeated self harm issues, ongoing substance abuse and aggressive behaviour.
>
> Non clinical accommodation services … are not staffed or structured to manage the behaviours that clinical bed based services deal with…. PDRS focus on managing disability, assisting residents with community and social integration, and promoting recovery.[537]

This comment indicates the different needs and requirements of the two sections of the mental health workforce. It also alludes to the different issues experienced and confronted across the workforce. These differences were briefly explored in regard to the standards informing the two components of the workforce.

Recruitment and retention

Participants in the Inquiry raised issues relating to staff shortages, recruitment and retention in mental health services. Similarly to the disability services workforce, the reality of an ageing workforce is creating challenges for the mental health sector. HACSU made the following observation:

> This applies in particular to the staffing of clinical bed-based services. Mental health nurses comprise the core staffing component of these services, yet the nursing workforce is ageing and not being sufficiently replenished with new recruits.[538]

HACSU also acknowledged that 'workforce problems are also relevant to the PDRSS sector, where inadequate salary rates and career structures make it difficult to attract and keep skilled and experienced workers'.[539] Ms Lyn Douglas told the Committee that 'there is one PDRSS service that visits my son in his home three quarters of an hour a week, but if they, again, have one or two staff ill then a spanner gets thrown in the works'.[540]

The issues highlighted by individuals and organisations that provided evidence are consistent with findings of the recent Senate inquiry. In 2008, the Senate Standing Committee on Community Affairs conducted an inquiry into mental health services and highlighted the challenges confronting the mental health workforces across all jurisdictions. It found that 'workforce shortages around Australia are affecting mental health services. Governments have invested money, and initiatives are in place to try to supply more workers to the sector,

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[537] *Committee Transcript*, 5.11.08, p.3 (HACSU).
[538] *Committee Transcript*, 5.11.08, p.3 (HACSU).
[539] *Submission* 121A, p.18 (HACSU).
[540] *Committee Transcript*, 21.10.08, p.5 (L Douglas)

but competition remains stiff, workloads are heavy and in many areas remuneration non-competitive'.[541]

In its analysis of the Victorian rehabilitation and recovery care service system for people with a severe mental illness and associated disability, the Department also acknowledges that there are significant issues relating to workforce shortages in Victoria. It states that there are:

> Existing and projected shortages in the skilled mental health workforce, particularly in the nursing and medical workforce. Shortage in skilled staff, driven by recruitment and retention difficulties, significantly impact on the ability to expand the service system and maintain key positions in some areas.[542]

The Victorian Government's response to the issue of recruitment and retention is discussed below.

Workforce development

Participants also identified workforce development and continuous improvement as key areas to focus on in the mental health workforce. Part of this relates to adapting to changing approaches in the mental health sector, including the increasing focus on recovery and prevention. Ballarat Adult Community Psychiatric Service stated that:

> What we can and should be providing are the very … well-established, well-known, evidence-based clinical treatments that affect the course and outcome of a significant mental disorder. The kinds of outcomes such as the chronically psychotic, socially dysfunctional, disengaged person who has marked levels of disabilities and handicaps, is and should be on the wane.[543]

Ballarat Adult Community Psychiatric Service maintained that mental health services need to tackle the problem of incompetent, unskilled clinical staff who no longer provide a service but are still in the role of providing care.[544] One individual told the Committee that the lack of suitably trained staff in CCUs impacts on the support provided to her son. She told the Committee that 'there is no one-on-one for him, so he is basically left to his own devices, because their staffing level is 1 to 30, and their staffing is not psych trained'.[545]

In mental health services, shifts in policy are affecting how practitioners respond to mental illness. As noted in earlier chapters, policy developments from 2005

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[541] Senate Standing Committee on Community Affairs (2008) *Towards recovery: mental health services in Australia.* Commonwealth of Australia, Senate Printing Unit, Parliament House, Canberra, p.xii.

[542] Department of Human Services (2007) *An analysis of the Victorian rehabilitation and recovery care service system for people with severe mental illness and associated disability: Project report.* Mental Health Branch, DHS, Victorian Government, Melbourne, p.2.

[543] *Committee Transcript*, 20.11.08, p.9 (Ballarat Adult Community Psychiatric Service).

[544] *Committee Transcript*, 20.11.08, p.9 (Ballarat Adult Community Psychiatric Service).

[545] *Committee Transcript*, 5.11.08, p.2 (A McGuinness).

have seen a strong focus on early intervention and prevention. More recently, policy development in mental health is starting to emphasise 'recovery' in the treatment of people with more serious mental illnesses. Like disability services, this approach requires a stronger focus on the individual in mental health settings. HACSU argued that inadequate provision of staff development exacerbates mental health workforce problems, stating that:

> There is an urgent need to ensure all staff have ready access to regular training programs related to their work. These programs should enable all staff to keep informed about evidence-based practice and service innovations.[546]

Services in rural and remote communities pointed out that there are often significant difficulties in accessing appropriate training. Murray Malley Community Mental Health Services indicated that in Mildura there are significant issues recruiting staff into the mental health sector. The Director of Clinical Mental Health advised the Committee that he currently has 'about 50 EFT at the moment. I would say I have got about eight vacancies'.[547] He explained that there are particular challenges in securing staff in specialist areas of mental health, but that in general the problem is across all services. The Director also went on to say that 'to try and find more experienced staff to come here is very difficult, and our workforce is mainly made up of the less experienced staff or staff who have been here for many years'.[548] The organisation noted that the issues were more difficult in clinical services than PDRSS due to the specific qualification requirements to work in clinical settings.

The Committee notes that the Victorian Government workforce strategy aims to address issues relating to workforce distribution across the State.

Work environment

Support to work in safe environments was also identified as an issue, particularly by some PDRS services providing support in community settings. Pathways Homeless Outreach Psychiatric Service provides services in the Barwon region. The clinical coordinator explained to the Committee that:

> Within the community mental health teams high-rise density public housing has required staff to attend these premises in pairs for safety. The assessed risk factors for staff, let alone client safety, impinge on the level of support able to be provided.[549]

Ms Leesa Cornthwaite, a former medical officer at a SECU, told the Committee that the complexity of patient's needs in units such as SECUs highlights the need for adequate medical, nursing and allied health staffing levels to facilitate

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[546]   *Committee Transcript*, 5.11.08, p.5 (HACSU).

[547]   *Committee Transcript*, 6.11.09, p.9 (Murray Mallee Community Mental Health Service). Note: EFT – effective full-time.

[548]   *Committee Transcript*, 6.11.09, p.9 (Murray Mallee Community Mental Health Service).

[549]   *Committee Transcript*, 23.10.08, p.5 (Pathways).

appropriate and comprehensive risk assessments and psycho-education.[550] She maintained that:

> Medical and nursing staff can find themselves dealing with crises, without any significant opportunity for therapeutic work or increasing patients' awareness of their illness. This reactive rather than proactive clinical involvement by staff can exacerbate patient frustration.[551]

The conflict between providing an adequate level of service for people with a mental illness whilst ensuring safe working environments for staff is one that the sector confronts on a daily basis.

9.5   Mix of service providers

As required by the Terms of Reference, the Committee inquired into the mix of service providers involved in the provision of supported accommodation for Victorians with a disability and/or mental illness. As outlined in Chapter Four, service providers in these sectors include government (in disability services), health and community services (in both mental health and disability sectors) and private industry (supported residential services). The role of SRS in service provision is discussed in detail in Chapter Eleven.

The Committee received evidence from participants regarding a range of aspects related to the mix of service providers. Concerns focused broadly on the mix of providers in the disability support sector; that is, government operated services and CSO operated services. In the disability sector, the issues of consistency and quality of service provision were recurring concerns. The right of people with a disability to receive a quality service regardless of the service provider was at the heart of the issues raised before the Committee.

Ensuring consistency of service provision across different providers led to concerns about three key issues:

- Quality service provision (in particular, consistency in standards and practices)

- Disparities across service models (including training, salaries and service costs)

- Issues in relation to the multiple roles of government in service provision, funding and regulation (perceived conflict of interest).

The solutions varied and included:

- Transferring all service provision to CSOs

- Maintaining the current mix of providers.

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[550]   *Submission* 7, p.2 (L. Cornthwaite).
[551]   *Submission* 7, p.2 (L. Cornthwaite).

9.5.1 Quality service provision

One of the central issues regarding the mix of service providers related to the level of quality provided by government operated disability services and CSO operated disability services. For example, Action on Disability within Ethnic Communities (ADEC) suggested that the government sector does not adhere to the same rigour with regard to disability standards and compliance as non-government providers. Western Region Disability Network told the Committee that generally families who have individuals in CSO managed SSAs are more positive about the quality of care provision and the way they are treated as families than are others in DHS facilities.[552]

HACSU, on the other hand, expressed its view that the Victorian Government has a key role in service provision. It informed the Committee that the State Government has a long history in providing services to people who are Victoria's most vulnerable and in greatest need.[553] HACSU suggested that these services are at the core of government's responsibilities and that it should continue to provide services.

Furthermore, HACSU suggested to the Committee that government provided services are scrutinised at a higher level than CSO services.[554] HACSU commented that government services are subject to freedom of information (FOI) legislation and to internal scrutiny by the Auditor-General and Community Visitors.[555] In addition, however, CSOs can be subject to FOI, to performance audits by the Auditor-General (as in the recent review of disability accommodation services) and to visits by the Community Visitors to SSA providers.

In addition, HACSU told the Committee that there are a number of quality and accountability measures with which government providers must comply. HACSU argued that the non-government sector is not subject to the same accountability or quality measures.[556]

With the introduction of the new *Quality Framework for Disability Services in Victoria*, both government operated services and CSO operated services are subject to external monitoring based on the same quality framework.

The Committee recognised that this framework represents a new direction that will potentially align the quality and standards across the service system more effectively.

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[552]   *Submission* 22, p.7, (Western Region Disability Network).
[553]   *Submission* 121B, pp.4, 21-22 (HACSU).
[554]   *Committee Transcript*, 5.11.08, p.8 (HACSU).
[555]   *Committee Transcript*, 5.11.08, p.8 (HACSU).
[556]   *Committee Transcript*, 5.11.08, p.8 (HACSU).

9.5.2   Service comparisons – costs, training, salaries

NDS is of the view that only one support system is needed, rather than the current two parallel systems, which produce a lack of parity in services provided.[557] Citing the 2007 Productivity Commission Report, NDS pointed out that government operated disability services received $39,413 more funding per service user/annum than non-government provided accommodation services.[558] NDS recommended that 'the transfer of the 531 government operated group homes to the non-government sector would create the opportunity to fund disability supports for many people currently waiting for service'.[559]

However, the Committee identified significant barriers against making comparisons between CSO and government service providers. The evidence to date (in particular in the UK, where most work has been done) is mixed. While there has been some attempt to compare efficiency, in the form of average cost estimates, this has involved using the total spend, divided by the number of beds, to develop a 'cost per bed'.[560] However, this doesn't account for costs that are borne by the organisation, in terms of financial outlays and staff resources and other capacity; there is substantial anecdotal evidence that these are raised disproportionately through (if nothing else) the processes arising from management of service agreements and contract requirements. Comparisons of effectiveness (service delivery quality or outcomes achieved) similarly find mixed results across different organisation and service types.

The recent Public Accounts and Estimates Committee (PAEC) report breaking down funding provided to both government and CSO organisations in the disability sector also highlights the difficulties in making comparisons relating to 'cost per place'.

PAEC 2009 Report on 2009-10 Budget Estimates

In a Public Accounts and Estimates Committee Report, a breakdown of funding provided to the non-government disability sector in relation to residential accommodation services and DHS services is given. In 2007-08, DHS services were allocated $382.5 million for residential accommodation services while the non-government sector received $214.7 million.[561] The greater expenditure in DHS services than non-government services was qualified by:

▪   DHS has a larger service delivery capacity and therefore incurs a higher level of expenditure

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557   *Committee Transcript*, 5.11.08, p.7 (NDS).

558   *Submission* 150, p.13 (NDS).

559   *Submission* 150, p.13 (NDS).

560   Boston Consulting Group (2006), *Improving Mental Health Outcomes for Victorians: the Next Wave of Reform*. Boston Consulting Group, p.52.

561   Public Accounts and Estimates Committee (PAEC) (2009) *Report on the 2009-10 Budget Estimates – Part Two*. Parliament of Victoria, Melbourne, 15 October, p.324.

- DHS expenditure relates to a full cost that includes Capital Asset Charge, depreciation, client related costs and corporate infrastructure and other costs attributed to the Residential Accommodation Support output

- Non-government organisation staff are not covered under the same wage award as DHS staff, and the exemption of non-government organisations from payroll tax contributes further to the cost difference.[562]

In addition, the report provides further data which indicates that an indicative average 2007-08 cost per place of non-government organisations is approximately $91,000 compared to approximately $119,000 for a DHS place.[563]

The comparability of an average cost per place of non-government versus DHS is not possible given that:

- Costs vary significantly depending on service model, configuration and complexity relating to age, behaviour, medical and specific support needs of residents

- The DHS indicative average cost per place is based on full direct service cost to DHS whilst non-government cost per place is not a full cost as it reflects only revenue from government funding

- The DHS indicative average cost per place includes places in Residential Institutions

- Non-government organisation staff are not covered under same wage award as DHS staff and non-government organisations are exempt from payroll tax.[564]

The issue of funding more services through the non-government sector based on the cost differential between government and non-government services was proposed to Mr Arthur Rogers, Executive Director of Disability Services Division. Mr Rogers told the Committee that cost differential work has not been undertaken by DHS so he was unable to provide comment.[565]

Some organisations also suggested that there are differences in workforce capacity with regard to training and wage disparities. As discussed earlier in this chapter, the disability sector faces retention and skill capacity problems. This occurs in both the government and non-government services. HACSU told the Committee that the problem is particularly chronic in the non-government sector. HACSU explained that the non-government service providers have not leveraged funding models that enable capacity building around workforce and skill development.[566] HACSU claimed that larger organisations have more

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[562] PAEC, *Report on the 2009-10 Budget Estimates – Part Two*, p.324 [see Footnote 561].

[563] PAEC, *Report on the 2009-10 Budget Estimates – Part Two*, p.324 [see Footnote 561].

[564] PAEC, *Report on the 2009-10 Budget Estimates – Part Two*, pp.324-325 [see Footnote 561].

[565] *Committee Transcript*, 10.12.08, p.12 (A. Rogers, DHS).

[566] *Committee Transcript*, 5.11.08, p.5 (HACSU).

scope to provide training to staff than smaller organisations. In comparison, HACSU suggested that 'the government sector has fared better since 2000, due mainly to the better leverage of a single workforce, greater capacity of a single management and greater ownership and investment by government as the employer'.[567]

Yooralla supported the view that the different funding models enable government providers to deliver better staff training opportunities and working conditions than non-government services. The organisation maintained that they are constrained by their funding, which limits their capacity to provide equal training and wage rates as those in the government sector.[568] They argued that:

> the conditions are far superior in the government sector. They have many more full-time positions, which are far more attractive to staff over a long time. They have better maternity leave, better training leave, so when it all adds up it is actually quite a substantial difference. There is no difference in the quality of service.[569]

At the same time, however, making comparisons across services within the CSO sector is difficult in view of the wide variations among CSOs. The nature of CSO providers was discussed in Chapter Four.

9.5.3   Multiple roles of government and perceived conflict of interest

Some participants suggested that the Victorian Government's range of roles generates a conflict of interest in its role as a provider of services when mixed with its policy-making, funding and regulatory roles.

For example, ADEC stated that governments cannot be a provider as well as a regulator and funder:[570]

> You are either a funder and a regulator or you are a provider, because there is a huge conflict of interest there. I know that people work hard, but sooner or later the government is going to have to bite the bullet. I appreciate the political problems involved with that, but it is either going to be a funder and regulator or it is going to be a provider and put the regulation to a completely independent body at arm's length from the government. It cannot do both.[571]

Gateways Support Services indicated its views that in relation to funding and the prioritisation of limited resources, the complexity of the Victorian Government's role was a concern. The CEO, Ms Rosemary Malone, expressed

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[567]   *Committee Transcript*, 5.11.08, p.5 (HACSU).

[568]   *Committee Transcript*, 22.10.08, p.8 (Yooralla).

[569]   *Committee Transcript*, 22.10.08, p.8 (Yooralla).

[570]   *Committee Transcript*, 30.04.09, p.6 (ADEC).

[571]   *Committee Transcript*, 30.04.09, p.6 (ADEC).

her view that due to these complexities, CSOs tend to be excluded from decisions about the prioritisation of limited resources:

> So resources are always limited, and in terms of prioritising, a lot of those discussions are held internally.

> There is not always consultation about priorities for funding. So in terms of who is consulted about the priorities, you will be consulted if you are within the department and you will not be consulted if you are outside the department. I think it is about access to providing input, and I suppose it is just that we are outside those processes. And there are limited resources.[572]

The Committee's attention was drawn to developments that have been occurring in other states regarding clarifying the role of CSOs and government in the provision of disability services. The Committee learnt that other jurisdictions are increasingly considering the multiple roles of government, with some transferring the provision of disability services from governments to CSOs.

In Western Australia, almost 60 per cent of disability services are administered by CSOs. This has occurred over a number of years, with the gradual contracting of CSOs to administer disability services. The Committee was advised that the WA Government is soon to release its Economic Audit Committee Report and in doing so will provide greater clarify on its position regarding the extent to which services currently provided by government will be administered by CSOs. In November 2009, National Disability Services Western Australian issued a media release announcing its support of the WA Government's achievement in transferring disability services to CSOs.[573]

Recently, KPMG undertook a review of disability services on behalf of the Tasmanian Government. The review recommended that the responsibility for delivery of services in Tasmania be devolved to the NGO sector over a three-year period.[574]

It is important to note that service delivery in Tasmania is different from Victoria and making comparisons needs to be done with caution. Approximately 75 per cent of service delivery in Tasmanian disability services already rests with CSOs, and the focus on government service provision has been declining for some time.[575] In Victoria, on the other hand, the government provides more than 50 per cent of disability services. HACSU told the Committee that:

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572   *Committee Transcript*, 23.10.08, p.11 (Gateways Support Services).

573   National Disability Services Western Australia (2009) 'News Update: NDS WA supports transfer of government services', Email circulated on 18 November 2009; See also NDS WA (2009) 'Media Release: Disability peak supports transfer of government services', 5 November 2009. Accessed from <http://www.nds.org.au/WA/Archive/2009/mr-5nov09.pdf> on 10 December 2009.

574   KPMG (2008) *Review of Tasmanian Disability Services – Final Report*. Report produced for Department of Health and Human Services, Tasmania, p.50.

575   KPMG, *Review of Tasmanian Disability Services – Final Report*, p.26 [see Footnote 574].

> Recent references by CSO lobbyists to Tasmania contracting out the government supported accommodation services to the CSO sector need to be qualified with the detail… It is clearly not possible to compare and apply insight from 2 such differently sized and configured service systems.[576]

The purpose of the KPMG review was to assess the current and future directions of Tasmanian disability services. A key finding of the review is that Tasmanian disability services have not moved with contemporary policy developments, as have some other states. KPMG noted that:

> Tasmanian Disability System has not kept pace with contemporary disability practice, with limited evidence of consistent development, implementation or use of contemporary policy, procedures and systems in disability support provision. Significant system re-orientation is required to allow Tasmanians with a disability to receive a similar level of support as that received in other jurisdictions such as Victoria and Western Australia.

So while there is some value in looking to approaches used in other states in regard to clarifying the roles of government and CSOs in service provision, it is also important to be mindful of the differences in the service systems and the reasons underlying reforms in other states.

A key reason underlying the KPMG recommendation to devolve services to CSO providers is that 'a high degree of involvement in direct service delivery is seen to detract from DHHS [Department of Health and Human Services] capacity in terms of strategic leadership, contemporary policy development and service system planning'.[577] At this stage of the development of Tasmanian services, the Tasmanian Government appears to require a strong focus on reforming its disability services and moving away from direct service provision.

The Tasmanian experience is valuable in demonstrating the types of considerations given to the implications of government holding multiple roles, including the provision of services. In its 2006 Industry Development Plan for the provision of disability services, the Victorian Government also identified the need to consider the multiple roles government has in the disability sector. In 'Key result area 1: Creating individualised support responses', the Victorian Government has identified that a priority area is to:

> Examine the changing roles of government as a provider of support services, policy developer, funding source and regulator.[578]

The Victorian Government's progress relating to this priority area was not made clear to the Committee.

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[576] *Submission* 121B, pp.23-24 (HACSU).

[577] KPMG, *Review of Tasmanian Disability Services – Final Report*, p.26 [see Footnote 574].

[578] Department of Human Services (DHS) (2006) *Partnering for the future: The Victorian Industry Development Plan for the provision of support for people with a disability*. Department of Human Services, Victorian Government, p.6.

9.5.4   Consistency of service provision

The Committee heard that a critical issue underpinning the discussion regarding the mix of service providers relates to the consistency of service provision and the right of people with a disability to receive the same service regardless of the provider they access the service from.

Western Region Disability Network (WRDN) suggested that people's experiences of supported accommodation differed and were dependent on the commitment and quality of staff regardless of service provider.[579] The Network advised the Committee that 'WRDN members do not generally care who provides the services so long as they are of high quality'.[580]

HACSU commented that the issue of the service provider mix is a distraction and the main issue should be about the quality of service provision.[581] It stated that:

> The focus should be on expanding service availability and service capacity across both the non-government and government sectors in a balanced and organised way and that it is only through future investment that we will be able to meet the needs of our most vulnerable citizens in this state.[582]

The evidence indicates that when the argument about transferring disability service provision to the non-government sector was explored in detail with organisations and individuals, the Committee found it was based on quality and standards in accommodation and support facilities. Quality in disability service provision, as the evidence suggests, is variable and not specific to one service sector.

The Committee heard that concerns exist within the community sector regarding parity and the cost of services. Based on the evidence received relating to the mix of service providers, however, the Committee determined that it is not possible to make recommendations regarding any alterations to the mix of providers without further exploration of the consistency of service provision across providers and the development of a more accurate method of comparing cost of service provision across providers.

Recommendations

9.19   That the Victorian Government develops a methodology and publishes a comparison of the cost of service provision across government and CSO service providers.

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579   *Submission* 22, p.7 (Western Region Disability Network).
580   *Submission* 22, p.7 (Western Region Disability Network).
581   *Submission* 121B, p.4 (HACSU).
582   *Committee Transcript*, 5.11.08, p.8 (HACSU).

Recommendations

9.20   That the Victorian Government commissions an external review to assess the consistency of quality service provision across both government and CSO service providers in the disability sector.

9.21   That following a review of cost and consistency in disability service provision; the Victorian Government makes a public statement regarding the future role of government as a service provider, policy-maker, funder and regulator of disability services.

Chapter Ten: Caring relationships and people with a disability and/or mental illness

Committee findings

- That caring relationships underpin the system of community care in Victoria for people with a disability and/or mental illness. **(Section 10.1)**

- That many families and friends assume responsibility for providing the support and care for people with a disability and/or mental illness. **(Section 10.2)**

- That families in caring relationships seek recognition and respect for the contribution that they make in caring for people with a disability and/or mental illness. **(Section 10.2)**

- That considerations relating to families in caring roles need to be balanced with the needs and aspirations of people with a disability and/or mental illness. **(Section 10.2)**

- That families in caring relationships are not always in a position to maintain a caring role to support a person with a disability and/or mental illness to live in the community. **(Section 10.3)**

- That people with a disability and/or mental illness often aspire to live independently from their family in the community with appropriate support. **(Section 10.3)**

- That without appropriate support, the demands of the caring role can have detrimental effects on the physical, emotional and financial wellbeing of families in caring relationships. **(Section 10.4)**

- That families in caring relationships require tailored solutions that provide the levels of support for their unique circumstances. **(Section 10.5)**

- That the resilience of families in caring roles is not inherent, static or absolute and that it can be nurtured through external support. **(Section 10.5)**

- That respite is a critical component of support options for families in caring relationships. **(Section 10.5.1)**

- That current processes for measuring demand limit the capacity of people with a disability and their families and social networks to plan effectively for the future. **(Section 10.6)**

- That there is disillusionment amongst families who participated in the Inquiry regarding the Victorian Government's level of engagement and support of families in caring relationships with a person with a disability and/or mental illness. **(Section 10.6)**

- That the Victorian Government has identified the significance of caring relationships in its carer action plans. **(Section 10.7)**

- That implementation and mechanisms for evaluation of existing carer action plans are unclear. **(Section 10.7)**

T he Committee's combined Terms of Reference for the Inquiry into Supported Accommodation for Victorians with a Disability and/or Mental Illness seek an exploration of the impact of the provision (and lack) of supported accommodation on people who care for a person with a disability and/or mental illness. As outlined in earlier chapters, the Committee's focus is on families in caring roles, as distinct from care purchased in the market.

A large proportion of the oral and written evidence received by the Committee has been from families in caring relationships. The Committee has therefore received a wealth of information from the perspective of carers. Importantly, the role of families in caring relationships cannot be understood in isolation from the needs and rights of the person with a disability and/or mental illness.

The Committee found that many families in caring roles who gave evidence to the Inquiry were disillusioned and disappointed with the provision of supported accommodation for Victorians with a disability and/or mental illness. These carers expressed a loss of faith in the system, suggesting a need for the relationship between them and the government to be strengthened.

As with other aspects of supported accommodation, families in caring roles who are involved with the mental health sector have both different and similar experiences to those involved with the disability sector. Furthermore, the responsibilities for people caring for a person with a mental illness can be significantly different from someone caring for a person with a disability. These differences are highlighted throughout the chapter.

The Victorian Government has identified the important contribution that families in caring roles make to the community. In 2006, the Department of Human Services (DHS) released a policy framework to reconceptualise the 'caring relationship' on a whole-of-department basis. The overarching principles contained in this document provide a sound framework in which to consider the issues raised by families and others in the context of supported accommodation. That is, support, respect, recognition and participation.

This chapter considers the responses of those participants who provided evidence to the Committee relating to the caring relationship in the context of supported accommodation. These include the importance of:

- Recognition of and respect for the caring relationship
- Involving families in planning and service delivery
- Supporting the caring relationship
- Acknowledging the implications of the imbalance between the supply and demand of community care
- Providing timely and relevant information to families in caring roles
- Providing options for people in caring roles who are ageing.

10.1   Caring relationships

In 2006, the DHS released a policy framework that reconceptualised and acknowledged the importance of 'caring relationships'. The framework, *Recognising and Supporting Care Relationships,* was based on a whole-of-department foundation.. The document outlines a set of overarching principles and aims to provide the foundation for action plans in relevant departmental program areas.

The objective of the policy framework is to move carer policy towards a relationship-focused model that emphasises the dynamic interconnections between people in caring relationships. The aim is to move towards an integrated approach in carer policy and with a focus on the relationship as opposed to the specific needs of carers or the people being cared for. A critical issue is determining how to get the appropriate balance between the needs and rights of both carers and carer recipients.

The policy recognised the significant shifts in caring for a person with a disability and/or mental illness as a consequence of the move away from institutional and residential care to an emphasis on care in the community. It states that:

> Over the last two decades in Australia, the health, aged care, disability services and child welfare sectors have experienced significant structural change, shifting from institutional models of care to a more broadly-based system that emphasises the principles of community care.[583]

The policy also acknowledged that the caring relationship underpins the community care system, a system that 'encourages people who need assistance to remain in their own homes or in the community wherever possible'.[584]

As noted above, the Committee's focus is limited to the experiences of those in caring relationships, as opposed to carers who provide paid care. This relationship is defined as a 'caring relationship based on personal and familial connections' and provides a 'context for engaging and addressing the potential tension between competing rights and needs of people within caring relationships'.[585] In considering the caring relationship, the Committee has also sought to be mindful of the relationship history, including risks within the relationship. As noted by the Department's policy framework on caring relationships, 'recognition needs to be given to the fact that some care relationships are going to be difficult or even inappropriate due to the relationship history'.[586]

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[583]   Department of Human Services (DHS) (2006) *Recognising and supporting care relationships: A Department of Human Services policy framework*. DHS, Victorian Government, Melbourne, p.3.

[584]   DHS, *Recognising and supporting care relationships*, p.3 [see Footnote 583].

[585]   DHS, *Recognising and supporting care relationships*, p.3 [see Footnote 583].

[586]   DHS, *Recognising and supporting care relationships*, p.12 [see Footnote 583].

10.2   Recognition and respect of caring relationships

The Committee heard from participants that it is critical to provide recognition and respect for the caring relationship. This includes recognition and respect of the carer as well as the person needing care, and of the relationship that exists between them. The Committee acknowledges that the Victorian government has sought to do this in a number of ways – the policy context specific to the disability and mental health sectors is discussed later in this chapter.

Participants in the Inquiry informed the Committee that many families and other people gain significant rewards from the caring relationship. Many people assume the responsibility of providing support required by a person with a disability and/or mental illness who they have a familial or personal connection with. This person is integrated into their life and the needs and aspirations of the person with a disability and/or mental illness are responded to as they emerge at different stages of their life. Yooralla explained that:

> Some people really do want to keep their son or daughter at home. In fact that is why we have so many ageing carers. They have done the system and their young person an incredible favour keeping them at home, looking after them and really enjoying family life.[587]

The caring relationship between a carer and a person with a mental illness has its own unique features. Carers Victoria explained that:

> Although many family members who care for a person with a mental illness may not cohabit with them, they continue to provide emotional and financial support, advocacy and crisis accommodation. In particular, they provide crisis accommodation and care for their relative when symptoms of illness emerge or when their relative is discharged early from an acute or clinical setting.[588]

In view of the commitment made to care for a person with a disability and/or mental illness, the decision to relinquish that responsibility (or the thought of it) can be very difficult. Interchange Central Gippsland highlighted that:

> many families experience an overwhelming state of distress when they are finally in a position where they are unable to care for their child. Families love their child and many have a strong wish and determination to remain involved in their child's life. It is often with the deepest sadness and regret that they experience, that they have diminished capacity to continue to care for the family member. The experience is heart wrenching and soul destroying for many carers.[589]

A large number of families engaged in caring relationships provided evidence to the Committee. Of those who identified the nature of the disability and/or

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[587]   *Committee Transcript*, 22.10.08, p.6 (Yooralla).
[588]   *Submission* 61, p.15 (Carers Victoria).
[589]   *Committee Transcript*, 21.10.08, p.6 (Interchange Central Gippsland).

mental illness of the person they care for, 40 people were caring for someone with a disability and 24 for someone with a mental illness. Approximately six people said they were caring for someone with dual or multiple disabilities.

The Committee heard from carer support organisations that the level of recognition and respect for the caring relationship needs to be improved.[590] In particular, these organisations pressed for a strengthening of recognition of the caring relationship in key legislation relating to people with a disability and/or mental illness. For example, Carers Victoria suggested that 'there is very little in the *Mental Health Act 1986* that actually supports involvement of carers'.[591] The Victorian Government's current review of the legislation is discussed later in this chapter. It is timely to note here, however, that the panel reviewing the *Mental Health Act 1986* has made some specific suggestions regarding the involvement of carers in the context of a caring relationship. Carers Victoria makes the point that from a carer's perspective, these seeming absences of recognition lead to the feeling amongst carers that 'carers and family members do not count in terms of the work that they do'.[592]

Similarly in the disability sector, concerns have been expressed that the legislation does not support the involvement of families in caring relationships to the extent that it might. For example, Kew Cottages Parents Association states that 'the Disability Act, we believe, fails to make provision for or adequately define the role of families or advocates in the lives of their disabled relatives, particular in decisions affecting them'. It argued that 'there needs to be greater recognition in legislation, policy and practice of the role of families', stressing that the sense of being unacknowledged or under-recognised is 'that frequently families end up feeling isolated and unsupported, and too often find themselves in an adversarial role with house staff or regional management'.[593]

The *Disability Act 2006* outlines principles that are specific to the role of families in caring relationships. Section 5(3) states that disability services should:

> (h) Consider and respect the role of families and other persons who are significant in the life of the person with a disability;
> (i) Acknowledge the important role families have in supporting persons with disabilities;
> (j) Acknowledge the important role families have in assisting their family member to realise their individual physical, social, emotional and intellectual capacities;
> (k) Where possible strengthen and build capacity of families who are supporting persons with a disability.

In addition, the Disability Services Division in the DHS is currently developing a Carers Charter. According to a recent consultation paper, the 'objective of the

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[590] For example, see *Submission* 61 (Carers Victoria); *Submission* 52 (Gippsland Carers Association).

[591] *Committee Transcript*, 22.10.08, p.11 (Carers Victoria).

[592] *Committee Transcript*, 22.10.08, p.11 (Carers Victoria).

[593] *Committee Transcript*, 22.10.08, pp.3, 6 (Kew Cottages Parents Association).

Carers Charter is to assist carers in becoming more involved in decision making and the development of policy, and to provide an opportunity for government agencies and the community to become more aware of carer's needs'.[594]

In regard to the recognition of families in caring relationships, recent legislation in Victoria creates the opportunity for families in caring relationships to register their relationship. Attorney-General Rob Hulls stated that this is for the specific purpose of

> recognising registered caring relationships in Victorian legislation where there has previously been no such recognition and by according them with a range of legal rights and obligations.
> … registration of a caring relationship will provide conclusive proof of the relationship where caring relationships are recognised under Victorian law.[595]

The legislation is known as the *Relationships Act 2008*. It defines a registrable 'caring relationship' to mean a

> relationship (other than a registered relationship) between two adult persons who are not a couple or married to each other and who may or may not otherwise be related by family where one or each of the persons in the relationship provides personal or financial commitment and support of a domestic nature for the material benefit of the other, whether or not they are living under the same roof, but does not include a relationship in which a person provides domestic support and personal care to the other person –
> (a) for fee or reward; or
> (b) on behalf of another person or an organisation (including a government agency, a body corporate or a charitable or benevolent organisation).

Importantly, for such a relationship to be eligible, both participants in the relationship need to provide consent to register the caring relationship. This legislation, therefore, is not applicable to families in caring relationships with a person who has a decision-making disability and is unable to provide consent.

In situations where people have a decision-making disability, there is the possibility of assuming the role of guardian. Generally, a person can become a guardian for a person who has a disability and as a consequence of the disability is unable to make decisions about their own personal and lifestyle affairs, such as where they will live or health treatment they might require. Like the *Disability Act 2006*, the *Guardianship and Administration Act 1986* seeks to uphold existing family relationships and to consider the wishes of close family members.[596]

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594   Department of Human Services (DHS) (2009) *Proposal for a Victorian carers reward card – options for the implementation and delivery of the card: Consultation Paper*. DHS, Victorian Government, Melbourne, p.4.

595   *Victorian Parliamentary Debates* 2008 (12 November 2009) Legislative Assembly, Volume 482, p.4572.

596   *Guardianship and Administration Act 1986* (Victoria), s.22(2)(b) and (c).

Some carer groups acknowledged the challenges that confront policy and legislators in the context of caring relationships. The Program Manager of Policy and Research at Carers Victoria, for example, acknowledged that:

> it is worth saying that in the disability sector there is tension between the disability rights movement and issues to do with family carers. It is very difficult to unpack boundaries in that issue where of course people with disabilities where possible should have the right to self determination in decision making and all that sort of stuff. When capacity is an issue, then the rights of the family become more important. I do not think the sector has teased that out.[597]

The issue of capacity and family involvement is very complex. Developments in supported decision making are informing some of these changes and potentially indicate a shift away from older concepts of substitute decision making. The involvement of families in these discussions is critical.

As Carers Victoria notes, these issues regarding decision making are yet to be fully teased out in regard to mental health and disability services. They are, however, very current. Furthermore, as Carers Victoria suggest, they are inter-linked with increased efforts to ensure people with a disability and/or mental illness are supported to have the greatest degree of choice and autonomy in their decision-making, regardless of their capacity.[598] In 2007, the Department of Health in the United Kingdom developed a guide to best practice in supported decision making stating:

> The governing principle behind good approaches to choice and risk is that people have the right to live their lives to the full as long as that does not stop others from doing the same. Fear of supporting people to take reasonable risks in their daily lives can prevent them from doing the things that most people take for granted. What needs to be considered is the consequence of an action and the likelihood of any harm from it.
>
> By taking account of the benefits in terms of independence, well-being and choice, it should be possible for a person to have a support plan which enables them to manage identified risks and to live their lives in ways which best suit them.[599]

Victoria is currently tackling similar issues about capacity, decision making and risk with the Department of Justice review of the *Guardianship and Administration Act 1986*. These issues will continue to be explored in that context, which is outside the scope of this Inquiry. It is important, however, to acknowledge that these discussions will inform the approach to the caring relationship.

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[597] *Committee Transcript*, 22.10.08, p.11 (Carers Victoria).

[598] *Committee Transcript*, 22.10.08, p.11 (Carers Victoria).

[599] Department of Health (2007) *Independence, choice and risk: a guide to best practice in supported decision making.* United Kingdom Department of Health, London, pp.3-4.

Recommendation

10.1 That the Victorian Government legislates for the appropriate involvement of families in caring relationships in the planning, treatment and support of the person they care for.

10.3 Imbalance between the supply and demand of services

The caring relationship is inevitably affected by the imbalance between the supply and demand of support and accommodation services in the mental health and disability sectors. Earlier chapters have outlined this imbalance. The range of services sought, but often unable to be accessed in a timely way, include mental health clinical and non-clinical services, respite services, disability shared supported accommodation (SSA) and individual support packages (ISPs).

Interlinked with the availability of services are the significant ideological changes over the past two decades regarding the opportunities to live independently in the community that ought to be available for people with a disability and/or mental illness. As mentioned earlier, the Victorian Government policy regarding the caring relationship is informed by these significant structural shifts away from institutional models of care to increased care in the community. While these moves have been largely applauded, there are ongoing demands for supported accommodation for people with a disability and/or mental illness when care in the community is not an option.

As noted in Chapter Four the Committee heard that there is a range of reasons why people are sometimes unable to provide support and accommodation for family members with a disability and/or mental illness. In addition, other families in caring relationships expressed awareness that while they may be willing to continue to provide support for the person they cared for, this might not be the aspiration of that person. Yooralla identified this issue with its client group.

> Another driver of demand is the changing expectations of the younger clients and their families. They have increased expectations of a 'normal' life with standard patterns of development and emerging independence. For many young people in their twenties, this means moving away from home to a more independent lifestyle.[600]

This was supported by Ms Mary Kooloos, a family carer of her 30-year-old son. She informed the Committee that 'they don't want to be living with their parents all the time, they want to live independent, they want to be like everybody else, that's what they crave, and we as parents are, or their carers are falling down if we don't allow them that independence'.[601]

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[600] *Submission* 77, p.2 (Yooralla).
[601] *Committee transcript*, 21.10.08, p.2 (M. Kooloos).

So while people with a disability and/or mental illness may require ongoing support, the Committee heard that care in the community may involve living independently from people they are in caring relationships with. Access to appropriate accommodation and support to achieve independent living in the community was highlighted as a critical factor to achieving this. Participants also emphasised the importance of choice in that support and accommodation. Yooralla expressed this in its submission to the Committee, stating that 'optimally individual responses demand a system that would enable those with high or intermittent support needs to effectively choose to live in the situation of their choice, be it alone, with family or friends, in accessible and appropriately fitted residential settings'.[602]

The Committee observed that expectations to achieve such independent living and increased choice have been raised in the disability sector with the introduction of ISPs. Despite these expectations participants also told the Committee that there are concerns regarding the adequacy of ISPs. Yooralla explained that these uncertainties will potentially contribute to an ongoing demand for SSAs:

> While carers can welcome the prospects of individual packages, they worry about the sufficiency of those packages, about where the 'safety net' is and how flexible those support arrangements will be if personal needs change. For these reasons, shared supported accommodation remains a preferred arrangement for many carers, particularly for those whose family member has intellectual disability or multiple and complex disabilities.[603]

10.4 Demand on families in caring relationships

Individuals and organisations told the Committee there are numerous implications for families in caring relationships when demand for support and accommodation requirements cannot be met.[604] Participants expressed similar experiences of pressure on their health and wellbeing, their capacity for social participation and, for families, on the family unit.

The Committee heard many emotional and compelling stories of personal experiences of caring relationships. People spoke of their exhaustion from sleep deprivation, their high blood pressure and depression from stress related conditions. Others spoke of the impacts of their caring role on their relationships and their social networks. Some told the Committee of their financial challenges resulting from their inability to work due to caring responsibilities. Interchange Central Gippsland explained that:

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[602] *Submission* 77, p.7 (Yooralla).

[603] *Submission* 77, p.9 (Yooralla).

[604] For example, see *Submission* 129 (M. Ryan); *Submission* 9 (L. Evans); *Submission* 102 (Kew Cottages Coalition); *Submission* 61 (Carers Victoria).

> Many parents suffer total exhaustion and extreme sleep deprivation after trying to meet demands of the care needs of children with complex health issues, multiple disabilities, and challenging behaviours.[605]

The Committee also heard about the financial challenges experienced by families in caring relationships. For some families, their caring responsibilities mean they cannot work full-time. One family carer, Mr Les Evans, told the Committee that 'full time is not an option for some, workloads and work commitments are compromised due to lack of availability of care, some parents unable to even access employment. No flexibility in work commitments'.[606] Ms Judi Hollingworth explained that for carers

> pensions are lucky to cover board and lodging and perhaps some travel. Things like household maintenance, garden upkeep, support for additional needs, equipment and dare I say leisure and holidays are simply in the dreams of a person on a pension.[607]

Parents of a 35 year old women with an intellectual disability told the Committee that 'the financial burden is completely prohibitive' of covering the costs of rent and care in private accommodation.[608]

Due to the financial disadvantage experienced by many families in caring relationships, many are eligible for income support from the Commonwealth Government. At the end of 2008 there were 34,834 recipients of a Centrelink Carer Payment in Victoria. The payments differ for singles and couples. Singles receive $671.90 per fortnight and couples receive $506.50 per fortnight. They are also eligible for additional supplements and a range of concessions. To be eligible for a Carer Payment, the person in the caring relationship must be caring for someone with a severe disability aged 16 years or older.

Some families in caring relationships, however, are in receipt of Carer Allowance only (just over $100.00 per fortnight), and are not eligible for the same concessions as those on a Carer Payment. At the end of 2008 there were 36,642 recipients of Carer Allowance in Victoria. Both Carer Payment and Carer Allowance provide for situations where it is anticipated that the need for care will be ongoing, rather than short-term or episodic.

In addition, there are also 2,200 Victorian Foster Carers who receive benefits and concessions.[609] People who provide foster care receive varying benefits depending on the age of the person they care for and the level of complexity of their needs.

Levels of Commonwealth and State income support, therefore, vary considerably for families in caring relationships. The amount of financial

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[605] *Committee Transcript*, 21.10.08, p.5 (Interchange Central Gippsland).

[606] *Submission* 9, p.1 (L. Evans).

[607] *Submission* 5, p.3 (J. Hollingworth).

[608] *Submission* 48, p.1 (P. & S. Dick).

[609] DHS, *Proposal for a Victorian carers reward card*, pp.4-5 [see Footnote 594].

support they receive will depend on the financial status of the person and the level of care they provide.

In May 2009, the Victorian Government released a consultation paper outlining options for the introduction of a Carers Reward Card. This is intended to provide some financial relief to families in caring relationships. The proposed benefits of the Carers Reward Card are considered to be discounts on a range of government and community services, venues and activities. Some limited public transport concessions are also intended.

In addition, as mentioned in Chapter Four the Committee noted with interest that the Commonwealth Government has asked the Productivity Commission to undertake a feasibility study into a national disability insurance scheme.

The following case study provides the story of one family struggling to support a person with a disability.

The Tonissen family experience

We care for our adult son with severe Autism who is non-verbal, not toilet trained and has the intellect of about an 18 month-2 year old. Caring for him 24 hours a day assisting him with all daily needs, with constant supervision for his safety and our physical exhaustion leaves us unable to function like a normal family. We run a farm and also have 2 other daughters, one of whom is at Uni. Over the years they have had to go without and 'normal' things like a family holiday are non-existent.

Many parents are full time carers and are ageing and struggling to support their sons and daughters who have high support needs. The role of caring leaves them exhausted emotionally, physically and financially and will require permanent accommodation for their child, now or in the near future. Many parents we know are currently suffering from depressive symptoms and also taking medication daily just to cope with day to day pressures...

Younger parents battle to keep their families and marriages together, protect siblings from neglect and discrimination and run a 'normal' life. With the responsibility of full time care of their disabled adult son or daughter, they have little time to focus on their other children or have time to themselves.[610]

The Committee heard that there is a need for increased support options for families in caring relationships to assist them with the demands of their caring responsibilities.

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[610] *Submission* 89, p.1 (M. & R. Tonissen).

Recommendations

10.2　That the Victorian Government provides counselling services and support options to families in caring relationships.

10.3　That the Victorian Government works with the Commonwealth Government to increase financial support to families in caring relationships accessing specialist disability supports and services.

10.4　That the Victorian Government provides financial counselling options for families in caring relationships experiencing difficulties with the financial demands associated with the cost of disability.

10.5　Family resilience and the importance of support

The Committee heard from participants that support for families in caring relationships was an important factor in maintaining their resilience.　For example, Annecto stated

> That if you are looking at supporting the care recipient, you need to be supporting the carer. Talking from our experience … obviously if carers get ill care recipients sometimes end up in hospital or they both end up in hospital and it causes further grief for the family unit and extended family. We have found that in our practices, particularly in aged care and now within disability, supporting a carer is the way that we have been actually able to assist the family group because you are not just looking at the carer, you are also looking at the relatives, the other family, the significant others in the person's lives. I think that is really important to look at. Obviously it is a package deal. You cannot separate them out.[611]

The Committee heard that while many families in caring relationships are committed to their responsibilities resilience is important in caring roles. Resilience is 'having the ability to function effectively or positively "in adverse circumstances"'.[612]　In a recent research project that explored family resilience in situations where families have a child with a disability, family resilience was identified to be a 'process that will change over time and exists on a continuum of levels.　Family resilience ... can be described by three steps: adversity, resources/strengths and adaptability'.[613]　Importantly, it is not 'a trait, static entity or an absolute'.　To nurture and sustain such resilience, research suggests that external support is critical.　While focused on the resilience of families with a young child with a disability, notably these concepts are transferable to families in caring relationships with an adult with a disability and/or mental illness.

In a service provision context where care in the community is the dominant and preferred approach to providing accommodation and support to people with a

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[611]　*Committee Transcript*, 6.11.08, pp.3-4 (Annecto).

[612]　Social Policy Research Centre (SPRC) (2008) *Family resilience where families have a child (0-8) with disability: Final report*. Report prepared for the Disability Policy and Research Working Group, Social Policy Research Centre, UNSW, p.28.

[613]　SPRC, *Family resilience where families have a child (0-8) with disability*, p.30 [see Footnote 612].

disability and/or mental illness, the Committee found the role of families in caring relationships has become increasingly significant. To enable people to undertake caring roles and to participate in caring relationships, support will often be required to develop the foundations of resilience. Resilience might also involve recognising the individual needs and aspirations of a person with a disability and empowering them with independence and choice to take risks as other members in the community. Shepparton Access, for example, suggested that support for families in caring roles needs to start early:

> I think that if we could put the models in a lot earlier and [support] people who [determine] that they [need or want] accommodation because of their family circumstances … when they're in their twenties, when they have the ability to increase their skills…, it would be cheaper to support those longer term and you will have an increase in skills.[614]

Some families in caring relationships informed the Committee that they do not have the levels of support they feel they need to continue in their caring roles. Interchange Central Gippsland explained its view that 'the current system is not responding at the same pace that the families need support'.[615]

The Victorian Government recognises the need to support care relationships. In addition to respite, this can include providing information and advice, one-on-one support and counselling and assistance to develop and maintain carer support groups. The types of support provided, however, vary across sectors.

Research has found that families in caring roles for a person with a disability often have a store of protective factors that make them resilient to the stresses of caring. Some of these factors include good communication and problem solving skills, capacity to balance family relationship, social support, routines and time for family, hope and flexibility, good health and strong financial management skills.[616]

According to the same research, however, a number of issues can threaten that resilience. In particular, resilience is affected by unresolved fears for the future of a person with a disability, including their future health and safety, what opportunities they will have to participate in the community in the future and who will support and advocate for them after the carers pass away. In addition, issues relating to financial stress, difficulties accessing services and balancing the needs of all family members puts further pressure on the protective factors that families in caring relationships need to maintain resilience.

As noted, the Social and Policy Research Centre at the University of New South Wales found that access to formal supports and services is frequently essential to families in caring relationships. Consistent with findings from the evidence

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[614]   *Committee Transcript*, 18.11.08, p.6 (Shepparton Access).
[615]   *Committee Transcript*, 21.10.08, p.3 (Interchange Central Gippsland).
[616]   SPRC, *Family resilience where families have a child (0-8) with disability*, pp.4-7 [see Footnote 612].

received by the Committee, the research found there is a range of areas where service providers both facilitate and hinder family resilience. These include

- Being supported through transitional periods
- Having access to relevant and timely information
- Being eligible for services and supports and having timely access to them
- Having confidence in service quality and treatment
- Having access to service coordination.[617]

The research project identified strategies for strengthening families caring for a person with a disability. These included providing support to

- Problem solve and communicate
- Balance the needs of family members
- Have family time
- Facilitate and build social supports
- Identify realistic goals and work towards them.[618]

The ideas and suggestions provided to the Committee by individuals and organisations were consistent with these research findings. Arguments were presented for greater support, respite and understanding of the needs of families in caring relationships and for involving them in decision making. For example, Interchange Central Gippsland explained that families in caring roles often need a broad range of supports, depending on individual circumstances:

> The support they often need might have been out of home respite, or in-home respite, supported community access for the child, intensive behaviour management support, or just a coordinated and planned response to their needs.[619]

Gateways Support Services explained that families in caring relationships in different circumstances require different levels of targeted support, particularly emphasising the needs of people who are ageing in their caring roles, and people caring for someone with autism or complex physical and/or behavioural needs.[620]

Carers Victoria also noted the need to support carer resilience, suggesting the importance of a holistic approach, and noting it is

> essential that government provide an early investment in the provision of appropriate respite for families and also the other holistic supports required. Again, it is not about supported accommodation or respite in home or out of home in isolation. You have to make sure there is a holistic package provided

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[617]   SPRC, *Family resilience where families have a child (0-8) with disability*, pp.9-11 [see Footnote 612].
[618]   SPRC, *Family resilience where families have a child (0-8) with disability*, pp.12-14 [see Footnote 612].
[619]   *Committee Transcript*, 21.10.08, p.3 (Interchange Central Gippsland).
[620]   *Committee Transcript*, 23.10.08, p.7 (Gateways Support Services).

that really provides the family with the resilience and capacity to continue as a family unit.[621]

Interchange Central Gippsland concurred with this, telling the Committee that 'we recommend that families need a comprehensive range of supports to sustain them in their caring role'.[622] Significantly, the Committee heard that individual families have diverse needs and that a range of supports specific to those needs are critical.

Some of the specific types of support participants raised with the Committee related to learning management strategies for responding to behaviours of concern for children with a disability. Sunraysia Residential Services explained that 'we also provide a program called Signposts, which is a program designed by the Parenting Research Centre, formerly the Victorian Parenting Centre, for the development of confidence and skills in parents who are caring for someone with a disability who displays difficult behaviour'.[623]

The organisation stated that the Department of Human Services no longer funds this program[624] but that they 'continue to provide that service, because with professional support families can learn to manage difficult behaviour and become resilient, and they deserve that opportunity'.[625] An evaluation of this program revealed that it had made a significant difference to the lives of participant parents and their children. Parents emerged from the program with greater confidence in managing the behaviours of children with a disability, resulting in reduced anxiety and depression for parents. It also led to improved behaviours in children.[626] The Committee considers there is scope to explore such a program for families in caring relationships with adult family members who demonstrate behaviours of concern.

Interchange Central Gippsland pointed out the considerable benefits of strategies that assist families in caring relationships to work through issues relating to behaviours of concern:

> There's many families that want to keep their child within their home. However, if they had one week's break, that that child lived out of home for a week, and in that week they got intensive behaviour support, they were taught how to control their behaviours, and then they came back in the home for a week, that would reduce costs for supported accommodation, but it would also provide respite to families, and it would also provide management strategies for the person with a disability.

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[621] *Committee Transcript*, 20.10.08, p.6 (Carers Victoria).

[622] *Committee Transcript*, 21.10.08, p.3 (Interchange Central Gippsland).

[623] *Committee Transcript*, 6.11.08, p.4 (Sunraysia Residential Services).

[624] The Signposts program is now funded by the Department of Education and Early Childhood Development.

[625] *Committee Transcript*, 6.11.08, p.4 (Sunraysia Residential Services).

[626] Victorian Government (2009) Supplementary data provided to Family & Community Development Committee.

The Committee heard that the skills to manage behaviour are learned, not inherent, and that people require support in building such abilities. The residential program that Interchange Central Gippsland suggestion is a similar concept to mother-baby units, where people can learn skills during an intensive one-week residential program. The Committee considered that there is benefit in giving further consideration to programs based on this residential model for families in caring relationships to learn the skills to manage behavioural concerns.

In addition to the nature of support, Carers Victoria highlighted the financial burden experienced by families in caring relationships:

> there are numerous studies that indicate that given the level of financial disadvantage parents are placed in — not grudgingly whatsoever — the reality is they are having to operate at a far lower financial level because of the costs incurred to maintain their child within their family unit.[627]

As indicated in the research outlined above, financial stresses are significant in threatening the resilience of families. People told the Committee of their inability to work due to their caring responsibilities and the subsequent implications for their financial circumstances.

Recommendations

10.5   That based on evaluation outcomes, the Victorian Government develops a variation on the Signposts program to support families in caring relationships with an adult family member who demonstrates behaviours of concern.

10.6   That the Victorian Government expands residential programs that provide support and skills development for families in caring relationships responding to behaviours of concern.

10.5.1   Respite

Regardless of the preference and willingness of families to provide the support needed by their family member with a disability and/or mental illness, to maintain resilience families often need time to build social networks, specific 'family time' or time to have some rest. The Committee heard that access to respite is a key ingredient in the mix of supports that families in caring relationships require. Interchange Central Gippsland explained that families 'often need breaks from the demands of care'. The organisation explained that it provides:

> the support aimed at assisting families to cope with the demands and the isolation that they may feel as a result of providing full-time care for a child and

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[627]   *Committee Transcript*, 20.10.08, p.6 (Carers Victoria).

a person with a disability. As we all know, the research shows planned respite can make a difference by giving parents and caregivers time off for their own needs. And respite within Interchange is given through a range of options, and its lots of choice of options, lots of flexibility, lots of social options'.[628]

The Committee's Terms of Reference do not require that it look at the issue of respite. The evidence received by the Committee, however, revealed that there is a demand for timely, available and appropriate respite that is not being met.

There are various respite options for families and carers of a person with a disability and/or mental illness in Victoria, which differ in nature across the mental health and disability service systems. In the disability sector, support is provided through a range of respite supports, including in-home respite and out-of-home respite. The delivery of respite services to individuals with a disability and their families and carers is provided by the DHS and community service organisations.[629]

In the mental health sector, planned respite options, whether in the home or out-of-home, occur in three main ways: planned and regular respite, occasional planned respite, and short notice respite.[630]

In comparison with the disability sector, respite in the mental health sector is delivered solely by the non-government psychiatric disability and rehabilitation and support services (PDRSS).

Families in caring relationships indicated a need to take time out occasionally – for a holiday, to meet with friends for a meal, to do errands.[631] Yet the Committee heard that this is not always possible. Yooralla noted that there has been 'very little investment in out of home facility based respite in a very long time'.[632] For families caring for a person with high and complex needs, Yooralla stated that they 'will often get their support from a number of different sources. They may be using a range of facility based respite, in home respite, recreational respite and brokerage, and they pull it together to try and make it into one big package. Yes, that does work for some people, and it certainly does not for others'.[633]

The Victorian Government has acknowledged the need to increase respite options. In its 2008-09 Budget it allocated an additional $3 million ($12.5 million over four years) to deliver 330 episodes of respite. It stated that these episodes would be designed to be flexible and responsive to individual and carer needs and would be based on individualised planning.

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[628] *Committee Transcript*, 21.10.08, p.3 (Interchange Central Gippsland).

[629] Department of Human Services (2009) *Disability Services Policy and Funding Plan: 2008-2009 Annual Update*. DHS, Victorian Government, Melbourne, p.110.

[630] Department of Human Services (2004) *Information for families and carers of people with a mental illness*. DHS, Victorian Government, Melbourne, p.20.

[631] For example, see *Submission* 9, p.1 (L. Evans).

[632] *Committee Transcript*, 22.10.08, p.7 (Yooralla).

[633] *Committee Transcript*, 22.10.08, p.7 (Yooralla).

The Committee has found that the system of respite is disparate, with provision occurring across three levels of government and no adequate methods of capturing information regarding use of respite services. The Committee considers there is a need for a more streamlined approach and acknowledges the Victorian Government's initiative to provide $1 million over two years to enhance on-line respite information services and enable access and coordination of respite services.

The Victorian Government has committed to introducing a state-wide approach to on-line respite information services for Disability Services including links to other State and Commonwealth funded respite services. This will better inform and enable individuals and their carer networks to get advice and access the range of respite services when and where needed.

The Committee is of the view that this state-wide approach should go a step further and lead to the development of a central respite register to further assist families in caring relationships to navigate the respite service system.

Recommendations

10.7 That the Victorian Government develops a respite strategy to outline current respite services available across all three levels of government and intentions for future development of respite services.

10.8 That the Victorian Government develops the respite sector to provide an increased range and availability of respite services to families in caring relationships, particularly in rural and regional areas.

10.9 That the Victorian Government measures use of respite services by families in caring relationships for someone with a disability and/or mental illness and uses this information for planning purposes.

10.10 That the Victorian Government introduces a central respite register to coordinate access to respite services in Victoria.

10.5.2 Timely and relevant information to families in caring roles

An additional factor raised by participants was the importance of timely and relevant information to support them in undertaking their role. This is interlinked with involving families in caring relationships in planning and service delivery, discussed in the next section.

The Committee heard that family inclusion in treatment processes is variable. For example, some family members felt they were called only on rare occasions when the system 'needed them', even when they might be in a position to provide valuable information regarding the health of their relative.

Kew Cottages Parents Association told the Committee that

> Provision of information to families is highly inadequate, which means that many families do not feel sufficiently informed and therefore empowered to advocate effectively for their disabled relative.[634]

Recommendation

10.11   That the Victorian Government introduces a communication strategy to ensure the provision of timely, targeted, accessible, relevant and culturally appropriate information to families in caring relationships.

10.6   Involving carers in planning and decision-making

The Committee heard from many individuals and organisations about the need for families in caring relationships to be involved in planning and decision making relating to service delivery for people with a disability and/or mental illness. This included planning at an individual level and at a systems level. A critical issue identified by those providing evidence was an apparent lack of planning to address the needs of ageing carers, including transition planning into alternative support and accommodation arrangements for people with a disability and/or mental illness.

Participants told the Committee that families in caring relationships are often not included in systems and policy planning, despite the important role they play. For example, Gippsland Carers Association argued passionately that:

> we have a right to expect the government will support us to ensure that we have a place at the policy and planning table, that we are on an equal footing with funded disability self advocacy, and that we are on an equal footing with funded service providers, each of which have government funding at the federal and state level to provide them with advocacy services and peak bodies. Families have no such privilege.[635]

The Committee has observed that there is a challenge in getting the balance right between acknowledging the independence of people with a disability and/or mental illness and also acknowledging the key role played by families in caring roles and encouraging their involvement.

As noted in the research regarding family resilience, one of the key factors hindering resilience is the fear of what the future holds for the person they are in a caring relationship with. It suggested this fear may be heightened by uncertainty and lack of planning. The Committee heard consistently about the lack of a planned approach to work with the individual needs of people with a disability who will always require a level of support, and about the critical role families in caring relationships play in the process of planning.

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[634]   *Committee Transcript*, 22.10.08, p.6 (Kew Cottages Parents Association).

[635]   *Committee Transcript*, 21.10.08, p.5 (Gippsland Carers Association).

Previous chapters have discussed the issue of planning, particularly at a structural and systems level. This section gives attention to the needs of people at an individual level, and particularly in the context of future needs. Carers Victoria emphasised the importance of governments seeing carers as partners in planning.[636]

The involvement of family carers in planning and decision making in the context of service delivery is discussed in Chapter Five, particularly in connection with the Disability Support Register.

Recommendations

10.12   That the Victorian Government develops a strategy regarding older families in caring relationships, with the objective of providing greater certainty regarding the future for people with a disability and/or mental illness with older carers.

10.13   That the Victorian Government improves consultation with families in caring relationships by actively involving them in the review of relevant policy and legislation.

10.6.1   Planning and decision making in service delivery

Organisations and carers suggested there is a lack of long-term planning involving families, to ensure a holistic and integrated response to supported accommodation needs.[637] The evidence suggests that planning at the individual level is necessary in order to provide adequate support to individuals with a disability and/or mental illness at different stages of their lives.

Karingal believes that families in caring relationships should be considered as partners who make a valuable contribution to support plans.[638] The Committee heard that often those in caring roles have the most informed understanding of what accommodation and support someone with a disability will need in the future. Carers Victoria suggested that 'parents and other family members must constantly be included in those processes of planning and actual implementation on individual levels'.[639]

Planning that considers the ongoing and changing needs of an individual over an extended period of time is critical in ensuring a continuity of care if and/or when a crisis or emergency situation occurs. The Committee was told that early planning is crucial to ensure individual needs are adequately supported over the course of their lives. Interchange Central Gippsland said that more timely planning mechanisms need to be in place for young people with a disability

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[636]   *Committee Transcript*, 22.10.08, p.4 (Carers Victoria).

[637]   *Committee Transcript*, 22.10.08, p.5 (Carers Victoria); *Committee Transcript*, 23.10.08. p.7, (Karingal).

[638]   *Committee Transcript*, 23.10.08. p.8 (Karingal).

[639]   *Committee Transcript*, 22.10.08, p.5 (Carers Victoria).

and/or mental illness and their families to develop plans based on individualised choices in the earlier years rather than when a crisis is about to happen.[640] Sunraysia Residential Services argued that families themselves are the best people to plan for the future.[641] They told the Committee that:

> Families as planning partners need and deserve to be educated and supported to develop the specific skills and confidence to plan well. Younger families will benefit from engaging in the planning process as early as possible and from having an opportunity to experience success in planning. It will avoid some of the perils of the past where older families have been engaged in planning and things just have not worked out the way that they had planned.[642]

The effectiveness of planning and service delivery at the individual level is dependent on resourcing. Interchange Central Gippsland advised the Committee that adequate resources need to be available throughout the planning and implementation stages,[643] and Karingal stated that 'the most aspirational and detailed plans are of little value without the resources necessary to implement them'.[644]

Many organisations and individuals expressed a view that when families in caring relationships are no longer able to provide support to the person they care for, the experience of moving to an unfamiliar setting can be stressful and even traumatic for a person with a disability and/or mental illness. For this reason, organisations suggested that people with a disability and/or mental illness would benefit from transitional units or options so they can develop skills and confidence to live independently.

Bernadette Ransom told the Committee that there should be 'a transition period where our sons and daughters might be able to stay one day a week, then two, and have that opportunity to slowly leave the home. So it is not such a dramatic loss of family like it is when there is a crisis in the family'.[645] Similarly, DAWN maintained that a transitional training unit would support skill development of people choosing to live in the wider community.[646]

Other participants raised similar concerns with the Committee. Ms Lois Brown, for example, explained that 'we are now in our seventy's and are finding it increasingly difficult to care for him… We should not have to worry about what happens to Phillip when one of us has to care for the other, or one or both of us die'.[647] Ms Stephanie Mortimer made the same point in her submission to the Committee. Ms Mortimer expressed her concern for her parents who continued

[640] *Committee Transcript*, 21.10.08, p.6 (Interchange Central Gippsland).
[641] *Committee Transcript*, 6.11.08, p.5 (Sunraysia Residential Services).
[642] *Committee Transcript*, 6.11.08, pp.4-5 (Sunraysia Residential Services).
[643] *Committee Transcript*, 21.10.08, p.7 (Interchange Central Gippsland).
[644] *Committee Transcript*, 23.10.08. p.7 (Karingal).
[645] *Committee Transcript*, 19.11.08, p.4 (B Ransom).
[646] *Committee Transcript*, 21.10.08, p1, (DAWN).
[647] *Submission* 13, p.1 (L. Brown).

to care for her sister and who feared dying and 'not knowing what will happen to their loved one when they die'.[648]

Recommendation

10.14 | That the Victorian Government provides transition planning for families in caring relationships with a person with a disability and/or mental illness where the person with a disability might experience changed circumstances.

10.6.2 Planning for ageing

During the course of the Inquiry, a number of organisations and individuals expressed significant concern for the plight of older families in caring relationships. For example, Yooralla stated that current planning is not sufficient to meet the future needs of older people caring for someone with a disability:

> because the current disability support register only registers a current need, if people are saying "Yes, it is working for me, but in five years I am going to be 80, and I no longer want to manage this way", they cannot register for a need.[649]

Along with other individuals and organisations, they raised a range of concerns relating to the issue of ageing carers. These issues are discussed below.

One concern is that many older carers have never accessed the system in order to receive support services; however they will not be in a position to care for their family member with a disability and/or mental illness on an ongoing basis. Goulburn Valley Area Mental Health Service described a situation where:

> People will have kept their child with a disability at home. They would never have accessed services from government services. They become frail. They become aged. They become demented. They require services. They're no longer able to care for their child with a disability and they may also come in because they've got a psychiatric disability on top of it. They've never been to IDS. There's nowhere that these people can be accommodated. No special service that caters for them and if they can't go back home, because parents may have been placed in nursing homes, we are often in dire trouble.[650]

The Carers and Parents Support Group told the Committee that families in caring relationships need time out from their caring as they are getting older and can't do it anymore.[651] Similarly, Barwon disAbility Resource Council argued that 'parents should be able to retire at a reasonable age without going into their

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648   *Submission* 3, p.4 (S. Mortimer).

649   *Committee Transcript*, 22.10.08, p.9 (Yooralla).

650   *Committee Transcript*, 18.11.08, p.4 (GV Area Mental Health Service).

651   *Committee Transcript*, 18.11.08, p.13 (Carers and Parents Support Group).

80s and 90s still being desperately worried about what will happen to their offspring'.[652] Ms Jean Tops, Gippsland Carers Association, told the Committee:

> We're talking about the 30,000 or so people with a severe or profound disability who are currently living with ageing parent carers in their state. 30,600 according to the ABS/SDAC survey. All of those families who have cared for those people for 30 years and more have the right to say, 'We don't want to do this any more', and they have the right to say, 'We think it is in the best interest of our son or daughter that they live in their own accommodation'.[653]

The Committee heard that since carers are unable to register their future need, the system is not planning for the crisis that will occur when older carers can no longer carry out their caring role.[654] Families in caring relationships with someone with a disability want to plan for the future so they know what will happen to that person after they are no longer able to provide care. Gellibrand Residential Services told the Committee that there is no process for this to occur.[655]

Carers Victoria told the Committee that 'it should not be assumed that informal and ongoing care will be available or desirable when the long-term primary carer is no longer able to care'.[656] The organisation suggested a need for planned, supported transition from individual or parent care, alongside building system capacity for emergency or sudden transitions of people with a disability and/or mental illness.

Kew Cottages Coalition argued that not enough is being done to provide relief to ageing carers from the responsibility of full-time care.[657] Carers Victoria told the Committee that 'there is a need to consolidate existing programs and resources for ageing parent carers into a program of 'Planning for the Future', which ensures the needs of ageing parent carers are systematically and proactively targeted'.[658]

Sunraysia Residential Services argues that information about the immediate and future needs of many ageing carers has not been captured; the only way carers get help is through presenting as a crisis.[659] As already highlighted, many people are being supported by ageing carers who are in their 70s and 80s but, as Yooralla claims, no one is necessarily aware of such situations as the system does not collect data about emerging need.[660] Yooralla told the Committee:

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[652]   *Committee Transcript*, 23.10.08, p.4 (Barwon disAbility Resource Council).

[653]   *Committee Transcript*, 21.10.08, p.10 (Gippsland Carers Association).

[654]   *Committee Transcript*, 21.10.08, p.10 (Interchange Central Gippsland).

[655]   *Submission* 45, p.3 (Gellibrand Residential Services).

[656]   *Submission* 61, p.11 (Carers Victoria).

[657]   *Submission* 102, p.1 (Kew Cottages Coalition).

[658]   *Submission* 61, p.12 (Carers Victoria).

[659]   *Committee Transcript*, 6.11.08, p.9 (Sunraysia Residential Services).

[660]   *Committee Transcript*, 22.10.08, p.9 (Yooralla).

> If they cannot register for a need, then no-one is planning for it and no-one is funding it. The problem is that we are getting into a cycle where they cannot show they need something until one year before they need it, and the system simply does not allow a response within one year.[661]

Melbourne City Mission told the Committee that some services had been set up to work with ageing carers to plan for the future accommodation needs of people with a disability and/or mental illness. The organisation argued, however, that these services provide no options at the end of the planning process.[662] In order to address the deficiency of relevant data about the real need for supported accommodation of ageing carers, Scope said that the government needs to partner with carers and supported accommodation providers to facilitate effective local planning for future accommodation and support needs.[663]

The Committee heard that because of the lack of planning and lack of available supported accommodation, the current approach to ageing carers is reactive and crisis driven. A survey undertaken by Scope on the needs of ageing carers indicated that over one-third of ageing carers supported by Scope have an immediate need for supported accommodation.[664] Yooralla stated that it is too late to find out about the needs of carers when they are at crisis point:

> It is too late then. We need to find out before, and that means we need to work with the division of general practitioners to identify people who are in this position, and to offer good case planning and support to allow such mechanisms to be developed. They are then connected to the system; they know where to go, and someone checks on them about every three months just to say, 'How is it going? Are you coping okay?' Then you are going to pick it up earlier. The investment in that type of support is incredibly low.[665]

Importantly, organisations and individuals informed the Committee that older carers are a particularly vulnerable group as they are not accustomed to asking for help. Sunraysia Residential Services claimed that older carers are thankful for everything they receive but some of those carers will just keep going until they fall over.[666]

The issues facing ageing carers from CALD backgrounds are further complicated. National Disability Services (NDS) pointed out that the service system needs to be reconsidered to reflect the needs of particular cultural groups with regard to accessing supports and information. NDS told the Committee that there are a number of individuals with a disability from CALD backgrounds who are 'living with ageing parents, who perhaps are not in the system and do

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661   *Committee Transcript*, 22.10.08, p.9 (Yooralla).

662   *Submission* 124, p.6 (Melbourne City Mission).

663   *Submission* 97, p.10 (Scope).

664   *Submission* 97, p.8 (Scope).

665   *Committee Transcript*, 22.10.08, p.10 (Yooralla).

666   *Committee Transcript*, 6.11.08, p.6 (Sunraysia Residential Services).

not have any contact or understanding of the possibilities for them until their ageing parent or ageing carer dies'.[667]

In addition to the issues raised above for older carers, a number of individuals and organisations expressed concerns about the implications of the lack of planning and transitional arrangements on the person with a disability and/or mental illness.[668] Some of the implications raised included:

- The dramatic adjustment to group living at the age of 50 or 60 as a consequence of an older parent no longer able to provide care

- The risks involved in living with older parents with ailments and/or unable to provide the level of care required.

10.7 What is the Victorian Government doing for families in caring relationships?

As noted earlier in this chapter, the Victorian Government has established a whole-of-department policy on caring relationships with the intention of reconceptualising caring as that based on a personal relationship. It identifies three overarching principles providing the foundations for the development of carer plans at the divisional level. These overarching principles are:

- Recognition and respect

- Support

- Participation.

Both the mental health and disability sectors have given consideration to the role of families and carers in the provision of support to people with a disability and/or mental illness. Both sectors have encapsulated the overarching principles identified above in the development of individual action plans. The action plans encompass:

- Existing services that recognise and support the caring relationship

- Innovative directions in conceptualising and focusing policy and program development based on mutually beneficial and supportive caring relationships

- Where necessary, reframing existing service models to fit within the new policy context.

The carer action plans for the disability and mental health sectors are discussed separately below.

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[667]   *Committee Transcript*, 5.11.08, p.13 (NDS).

[668]   *Committee Transcript*, 23.10.08, p.4 (Barwon disAbility Resource Council); *Committee Transcript*, 18.11.08, p.4 (Carers and Parents Support Group); *Committee Transcript*, 22.10.08, p.2 (M Shilton).

10.7.1   Disability

In July 2006, the disability sector released its carer plan titled *Disability Services Carer Action Plan: Recognising and supporting care relationships*.   The policy acknowledges the informal support and care provided by people in personal relationships with a person with a disability.   It also seeks to outline future directions for policy and program development to more adequately reflect a relationship-focused model of caring.[669]

The *Disability Act 2006* does not explicitly address the informal carer relationship. Disability Services seeks to outline this relationship in a policy context as opposed to a legislative context. The action plan outlined future policy and program directions that more adequately reflect a relationship-focused model of caring.

The key future policy actions that the Disability Services Division identified in 2006 in regard to carer relations include:

- Develop a carer participation plan

- Develop quality outcomes for carers to incorporate into the quality framework

- Ensure recognition and respect for carers' issues and views in developing the implementation plan for the *Disability Act 2006*

- Assist government departments to develop disability action plans that reflect recognition, respect and partnership with families and carers

- Review existing policies and information provided by the DHS and accessed by families and carers, to ensure they provide practical information to empower families and carers to be active and informed partners in care and support planning.[670]

In addition, Disability Services have identified a number of programs and services that provide supports to enable carers to maintain their caring role and the person with a disability to live in the community. In 2006, it proposed future program actions to enhance caring relationships. These include the following:

- Broaden implementation of the ISP approach consistent with the Victorian State Disability Plan 2002-12

- Review current training strategies for staff on working with parents, families and carers and develop a staff development package focusing on working in partnership with families and carers

- Implement the Disability Support Register to better target resources and support to families and carers

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[669]   Department of Human Services (DHS) (2006) *Disability Services Carer Action Plan: Recognising and supporting care relationships*. DHS, Victorian Government, Melbourne, p.1.

[670]   DHS, *Disability Services Carer Action Plan*, p.8 [see Footnote 669].

- Review and document examples of good practice in working in partnership with parents, families and carers, including those with additional needs

- Review Disability Accommodation Services practice instructions to reflect the principles of recognising and supporting care relationships.[671]

10.7.2 Mental health

The Mental Health Branch of DHS released a carer action plan titled *Caring together – An action plan for carer involvement in Victorian public mental health services* that was active from 2003-08. It aimed to 'improve the participation of carers of people with a mental illness in the planning, development, implementation, delivery and evaluation of mental health services in Victoria, including clinical mental health services and the psychiatric disability rehabilitation and support services (PDRSS) sector'.[672]

More recently, in March 2009, the Mental Health Strategy was released, and this now informs the role of carers in the mental health service system. The Strategy seeks to actively include carers and families in decisions about care and to value the 'important role they play in supporting someone with mental health issues'.[673]

This goal is outlined in Reform Area 4: Specialist Care:

- Goal 4.1 Build a more responsive system of specialist mental health care geared to early intervention, relapse prevention and recovery through improving participation for consumers and carers.

The new strategy does not discuss carers separately from consumers, but instead carer participation is integrated into the goal of increased participation for consumers.

The *Mental Health Act 1986* is currently under review and the role of carers has been explicitly considered with regard to recognition of the caring role.

The review panel has highlighted the challenges in getting the right balance between the rights of people with a mental illness and people in a caring relationship with them. It acknowledged the important role of carers in the treatment and care of people with a mental illness and recommended that formal recognition of carers in the new Act would be in line with the government's mental health strategy.[674]

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[671] DHS, *Disability Services Carer Action Plan*, p.11 [see Footnote 669].

[672] Department of Human Services (2006) *Caring together – An action plan for carer involvement in Victorian public mental health services*. DHS, Victorian Government, Melbourne, p.5.

[673] Department of Human Services (2009) *Because mental health matters: Victorian Mental Health Reform Strategy 2009-2019*. DHS, Victorian Government, p.47.

[674] Department of Human Services (DHS) (2009) *Review of the* Mental Health Act 1986*: Community consultation report – July 2009*. Mental Health and Drugs Division, DHS, Victorian Government, Melbourne, p.5.

The review also highlighted the concerns of carers with regard to inadequate information sharing. The panel acknowledged the need for an appropriate balance between the right to privacy and carers' need for information. The panel recommended that where a person does not have the capacity to consent to the disclosure of information, the new Act should require the disclosure of information to a recognised carer who requires the information to perform their caring role. This does not apply to family members who do not provide care.[675]

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[675]   DHS, *Review of the* Mental Health Act 1986, p.56 [see Footnote 674].

Part D:

Alternatives

Chapter Eleven: Consequences of the imbalance between supply and demand

Committee findings

- That the options for people with a disability and/or mental illness who cannot access specialist supported accommodation are not always suitable to their needs. **(Section 11.1.2)**

- That the experiences of people with a disability unable to access specialist supported accommodation options are different from the experiences of people with a mental illness. **(Section 11.1.2)**

- That the options for people with a disability and/or mental illness unable to access specialist supported accommodation can be inappropriate, and include residential settings such as aged care, respite, supported residential services, caravan parks, motels, and rooming houses. **(Sections 11.2—11.6)**

- That the Committee heard concerns regarding the suitability of supported residential services as a model for supporting and accommodating people with a disability and/or mental illness. **(Section 11.2.1)**

- That people with a disability and/or mental illness who cannot access suitable support and accommodation options will sometimes live with families who are unable to provide the support they require. **(Section 11.7)**

- That people with a disability and/or mental illness who cannot access suitable support and accommodation options can find themselves in situations of homelessness or incarceration. **(Sections 11.8 & 11.9)**

- That people with a disability and/or mental illness will sometimes choose to live in situations that others might not consider appropriate to their needs. **(Section 11.3.4)**

- That the Victorian Government's *my future, my choice* is a positive initiative that aims to provide better living options for younger people with a disability living in, or at risk of entry to, residential aged care. **(Section 11.4.1)**

I n previous chapters, the issue of demand for supported accommodation exceeding supply in Victoria has been examined at a range of levels. This chapter shifts attention to the outcomes of that disparity between demand and supply. It aims to explore and discuss where people with a disability and/or mental illness live and how they access support when they are unable to secure a placement in the specialist supported accommodation system.

A key question that arises is whether support and accommodation options accessed by people with a disability and/or mental illness in these situations meet their individual needs and aspirations. To explore this question the chapter focuses on the adequacy of accommodation and support options for people with a disability and/or mental illness who cannot access the specialist system. The Committee received a substantial amount of evidence regarding the experiences of people unable to secure a placement that meets their specific needs, and notes with concern that people with dual or multiple disabilities are disproportionately represented in this group. Many people who provided such information outlined their concerns regarding the adequacy of these options for people with a disability and/or mental illness.

The Committee found that the experience of people with a disability unable to access the specialist system of supported accommodation differs from the experience of people with a mental illness. While both groups experience difficulties accessing specialist services, the different accommodation and support options available when individuals cannot access appropriate placement results in different outcomes for the two groups.

11.1 Specialist and non-specialist support and accommodation

The terms of reference specifically require the committee to inquire into the system that provides specialist support and accommodation to people with a disability and/or mental illness. The combined terms of reference adopted by the committee require it to make inquiries into the adequacy and appropriateness of care and accommodation provided in various government, private and community facilities that accommodate clients with a disability and/or mental illness when they cannot access the specialist system. In particular the combined terms of reference requires the committee to inquire into the adequacy and appropriateness of supported residential services, boarding houses, public hospitals, nursing homes and supported accommodation assistance program (SAAP) funded services when used as alternatives to the specialist supported accommodation system.

11.1.1   Specialist support and accommodation

Chapter Four outlined the nature of the specialist support and accommodation services available to people with a disability and/or mental illness and the roles of key individuals and organisations in the system. The services provided vary across the disability and mental health sectors.

In the disability sector, the provision of state-funded accommodation and support includes shared supported accommodation (SSA) (small and large), residential care and support to live independently in the community (for example, with an individual support package (ISP)). In the mental health sector, adequate support and accommodation includes a range of options across the specialist mental health service system, including residential clinically based treatment and step-up, step-down services, and non-clinical services such as residential rehabilitation and support to live independently in the community, for example, home based outreach support (HBOS) and residential rehabilitation services (RRS).

11.1.2   Non-specialist alternative support and accommodation options

In some instances when people with a disability and/or mental illness are unable to access specialist support and accommodation options they seek alternative options, such as residential services, rooming houses, respite and aged care. These options, however, do not always meet the specific needs and aspirations of people with a disability and/or mental illness. For other people who are unable to access the specialist service system, this might mean staying in situations that are not meeting their individual needs, such as continuing to live with families who, for a range of reasons, are unable to provide the levels of support required.

Individuals and organisations presented arguments to the Committee suggesting that many of the options for accommodation and support outside the specialist system are inadequate, and do not provide opportunities to assist people with a disability and/or mental illness live a quality life or to work towards a recovery goal.

Determining what is considered adequate versus what is inadequate accommodation and support can be a subjective process. The Committee heard that adequate supported accommodation and support has the following key features:

- Accessibility

- Specificity

- Flexibility

- Sustainability

- Consistency

- ▪   Expert provision.

Many of the alternative options to the specialist system were identified as lacking a number of these factors, to the extent that they could be viewed as inadequate accommodation and support to meet the individual needs and aspirations of people with a disability and/or mental illness. This has negative implications for their capacity to live a quality life or to achieve a recovery goal.

It is important, however, to be mindful that some people with a disability and/or mental illness might prefer to live in accommodation that others would consider inadequate to meet their needs. It is worth noting that as the Committee did not receive a significant amount of information from people with a disability and/or mental illness regarding their needs and aspirations it has therefore relied on comments made by representative organisations and others who emphasise the importance of choice and the 'dignity of risk'. The concept of dignity of risk is used in both the disability and mental health sectors and acknowledges the fact that with every endeavour there will be an element of risk and that every opportunity for growth carries with it the potential for failure. All people learn through a process of trial and error. Similarly, people with a disability and/or mental illness learn through taking risks and trying new things and often learn as much from their mistakes as from their successes.[676]

The Centre for Developmental Disability Health Victoria outlined some key issues that arise for people with a disability and/or mental illness residing in accommodation and receiving support that is inadequate in meeting their needs. These included:

- ▪   Over medication and sedation
- ▪   Physical harm to the individual due to unsafe environments
- ▪   Physical or mental harm due to inadequate supervision
- ▪   Inadequate management of medications and health care
- ▪   Poor follow-through on management advice from professionals
- ▪   Self-harm or harm to other residents/carers
- ▪   Substantial and repeated property damage
- ▪   An impoverished, restricted 'locked-down' home environment
- ▪   Limitations in accessing community activities, personal freedom, open spaces, financial resources, and making choices
- ▪   Stress on families and carers causing family breakdown
- ▪   Repeated moves with a downwards cycle of unsuitable placements
- ▪   Isolation from family and community
- ▪   Culturally inappropriate settings

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[676]   Parsons, C. (2007) *Dignity of risk: Challenges in moving on.* NEAMI Ltd presentation to 17 Annual The MHS Conference, Melbourne, p.1. Accessed from <http://www.neami.org.au/publications/documents/TheDignityofRiskarticleversion.doc> on 4 December 2009.

- Involvement of police and criminal justice system.[677]

Alternative support and accommodation options that may be accessed when specialist services are not available fall into five broad categories:

1) Semi-permanent and permanent access to privately owned accommodation (sometimes including 'support'), such as supported residential services, rooming houses, motels and caravan parks, and aged care facilities

2) Using respite facilities as long-term accommodation

3) Living with families in circumstances when it is no longer appropriate to do so, such as living with ageing parents or parents in ill-health, living in situations of abuse or neglect, and with families unable to provide the levels of full-time support required.

4) Existing in inappropriate circumstances of incarceration, including inadequate alternative options and inadequate support in incarceration.

5) Existing with minimal or no accommodation, such as on the streets, in homelessness hostels, and temporary, transitional housing arrangements (including Supported Accommodation and Assistance Programs – SAAP)

These categories are discussed individually in the sections below.

11.2   Privately owned accommodation

Some privately owned accommodation options for people who have been unable to access a place in the specialist service system provide accommodation only and others provide accommodation and a level of support. The types of support and accommodation discussion in this section are:

- supported residential services (SRSs)
- Rooming houses
- Motels and caravan parks.

A finding from the evidence is that people with a mental illness are more inclined to resort to these forms of accommodation than people with a disability due to lack of specialist supported accommodation options in the mental health system.

11.2.1   Supported Residential Services

The committee received information regarding SRSs as an alternative model of support and accommodation, much of it expressing concern that these cannot provide adequate support and accommodation for people with a disability and/or mental illness. Issues were raised relating to lack of sustainability of SRS accommodation in terms of cost, security, tenancy rights, the inadequacy of

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[677]   *Submission* 62, p.7 (Centre for Developmental Disability Health Victoria).

support in meeting specific individual needs, the incompatibility of some residents, lack of privacy, and staffing capacity.

Some individuals and organisations, however, acknowledged that in a context where there is a disparity between demand and supply of specialist supported accommodation, the SRS sector has a role to play. They emphasised the need for improvements to regulation of SRSs and sanctions for non-compliance. In addition, these participants highlighted the need to support SRSs to meet regulatory requirements and to improve their services and support. The argument was made that to enable SRSs to meet the needs of people with a disability and/or mental illness, the government needs to invest further in them.[678]

11.2.2   Overview of the SRS industry

SRSs emerged in the early 1970s to accommodate and provide 'personal care services', with a particular focus on providing a service to Victorians who were older than 60 years and who had a disability requiring support with activities of daily living, but not to the level of intensity that would be provided in an aged care facility. SRSs were originally termed 'special accommodation houses' to distinguish them from other boarding houses that did not provide any form of care.

The current definition of an SRS is legislated under the *Health Services Act 1988* and placements are no longer restricted to those over 60 years. The Act defines SRSs as premises where accommodation and special or personal care are provided or offered for persons for fee or reward. The support provided by an SRS can include assistance with showering, personal hygiene, toileting, dressing, meals and medication as well as physical and emotional support as needed. These services are required to be provided in a 'home-like environment'.[679]

SRSs are owned by a person or a company and are regulated by the State government. The SRS industry is generally categorised into two groups: pension-level and above-pension level facilities. Pension-level facilities are currently defined by the Victorian Government as those in which 80 per cent or more of residents are charged pension-level rates or less. In March 2009, this rate was $329.90 per week. Above pension-level facilities are not restricted in the rates they charge.

In October 2008, there were 181 SRSs operating and registered with the Victorian DHS. They range from small facilities accommodating as few as five people to larger facilities that can accommodate up to 80 people. Unlike other forms of accommodation and support for people with a disability and/or mental illness, SRSs are frequently larger facilities that accommodate more than 25 people. According to the *2008 Census of Supported Residential Services* prepared for

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[678]   *Submission* 57, p.4 (Brotherhood of St Laurence).

[679]   *Health Services Act 1988 (Vic)*, s.10.

DHS, the average number of residents per SRS is 28, with a range of 4 to 77. Almost 40 per cent of SRSs contain between 20 and 29 residents, followed by 22 per cent that house between 30 and 39 residents and 22 per cent that house between 10 and 19. Nine per cent of SRSs accommodate between 40 and 49 residents.[680]

11.2.3 Resident profile of SRSs

A key role of SRSs is to cater for the needs of people who can no longer live independently at home and need assistance with day-to-day tasks. They provide care for older people, for people with a mental illness and people with a disability (including, but not limited to, physical disability, intellectual disability and acquired brain injury).

The 2008 census provides a profile of residents in SRSs based on a sample taken in August 2008. The census provides information about a range of characteristics of people who live in SRS facilities (including age, gender, type of disability), the differences across pension-level and above pension-level facilities, and how this profile has been changing over time. This information is valuable for gaining insights into factors underlying the adequacy or inadequacy of SRSs as an option for people with a disability and/or mental illness.

Despite the increasing numbers of young people living in SRSs, the average age reported in the 2008 census is 70 years (with a range from 19 to 110 years). There are significant differences between pension-level and above pension-level relating to gender, health, disability type and behavioural issue. For example, there are a greater number of women than men in above pension-level SRSs, whereas men make up approximately 60 per cent of residents in pension-level SRSs.

The 2008 census identified that nearly 90 per cent of residents in SRSs have at least one disability (with the figure increasing to 96 per cent in pension-level facilities). Significantly, the majority of those in pension-level facilities have a psychiatric disability. Of the residents with a disability, 38 per cent have a psychiatric disability, 38 per cent have aged-related frailty, 17 per cent have dementia, 14 per cent have a physical disability, and 14 per cent have an intellectual disability.[681] Residents of pension-level SRSs are more likely to be male, younger, and have psychiatric, intellectual, acquired brain injury and/or issues with substance use compared with residents in above-pension facilities who are generally older, female and have dementia or aged-related frailty or physical disabilities.

As highlighted in the evidence, resident compatibility in pension-level SRSs frequently causes difficulty in sustaining tenancies. This can be the result of

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[680] The Social Research Centre (SRC) (2009) *2008 Census of Supported Residential Services – Report.* Department of Human Services, p.114.

[681] SRC, *2008 Census of Supported Residential Services*, p.156 [see Footnote 680].

behaviours of concern (sometimes arising from the nature of people's disability) and, at times, alcohol and other drug use. The lack of specific support for these types of issues can contribute to unsustainable and insecure living environments.

11.2.4 Perspectives on SRSs

The view of many individuals and organisations giving evidence to the Committee was that SRSs are not an option that can adequately meet the accommodation and support needs of people with a disability and/or mental illness. The Health and Community Services Union (HACSU), for example, expressed a view that 'continuing problems with SRSs over time demonstrate this is not a service model warranting endorsement'.[682] Similarly, an advocacy worker from Barwon disAbility Resource Council stated that SRSs 'are not an ideal way for people to be living in our community'.[683]

The reasons provided regarding the inadequacy of SRS accommodation for people with a disability and/or mental illness are discussed in this section, in particular the lack of sustainability (affordability, safety, security), lack of support to meet specific needs, and lack of specialist support. This section also considers the compatibility of residents with regard to gender, age, and type of disability and how these factors affect people's compatibility with one another.

The lack of sustainability was seen as a major issue, with individuals and organisations highlighting the expense of SRSs for people with a disability and/or mental illness, and the lack of safety and security.

Support

Individuals and organisations provided evidence relating to the nature of the support provided in SRS accommodation – in particular the lack of knowledge and expertise of staff and the lack of capacity to provide support tailored to the needs of individuals. Each SRS is required to employ a qualified personal care coordinator who coordinates care for all residents. The regulations require there to be at least one staff member for every 30 residents, extra staff to provide adequate levels of care for residents and sufficient staff onsite overnight to respond to the residents' care needs and to ensure the safety of residents.

Participants in the Inquiry expressed concerns about the levels of expertise of SRS proprietors to meet the support needs of residents in SRSs. The reasons provided included lack of staff expertise and high levels of residents to staff. Melbourne City Mission stated that SRSs accommodate a large number of diverse people but the staffing ratios are inadequate to meet the needs of such a large number of residents.[684] Likewise, Inner South SRS Network stated that inadequate staffing ratios in pension-level SRSs do not enable input to care

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682   *Submission* 121A, p.6 (HACSU).
683   *Committee Transcript*, 23.10.08, p.2 (Barwon disAbility Resource Council).
684   *Submission* 124, p.10 (Melbourne City Mission).

plans, in particular behaviour management. The Network told the committee that in these situations, staff and management are more likely to resort to chemical means of restraint to address behaviours of concern.[685] The Office of the Public Advocate (OPA) indicated the importance of staff capacity to intervene effectively when residents display behaviours of concern. It suggested, however, that staff in pension-level SRSs are often not equipped to manage these behaviours.[686]

The Committee was also told that there is a lack of adequate support for the specific needs of people with a disability and/or mental illness in SRSs. Although the majority of individuals living in pension-level SRSs have a mental illness, there are insufficient psych-trained staff to meet these individuals' needs.[687] Barwon disAbility Resource Council told the Committee that pension-level SRSs are an inappropriate accommodation option for people with a mental illness as 'people are being discharged from acute services straight to these very under-resourced and unsophisticated support services'.[688] The Committee heard that residents in SRSs can benefit from outreach support from a specialist mental health service, given that SRSs are often not equipped to support people with a mental illness. SRS staff often don't have the skills or qualifications to provide the level of support required.[689]

A number of organisations were of the view that flexible funding packages need to be provided to people with a disability living in SRSs in order to meet their specific needs. The rationale for this was that with funding tailored to meet the specific needs of individuals, specific issues of these groups could be more readily addressed.[690] CareConnect told the Committee that flexible funding needed to be available to augment standard SRS staffing models so that a resident's specific needs can be met.[691]

The evidence received by the Committee suggests that the needs of people with complex and challenging behaviour are not met in pension-level SRSs. People with complex needs associated with their disability and/or mental illness are often unable to live independently in the community without adequate support. NorthWestern Mental Health stated that there is a concern that people are often placed in SRSs because they are unable to manage in less supported environments. Paradoxically, however, it claimed that the SRS environment cannot adequately meet the full range of their support needs.[692]

> It seems that the 'special or personal care' provided is limited to a bed, meals, and medication supervision, and little else. It is important to recognise that people living in pension-only SRS are in a vulnerable position because they

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[685]   *Submission* 113 p.10 (Inner South SRS Network).

[686]   *Submission* 100 p.44 (OPA).

[687]   *Committee,Transcript*, 5.11.08, p.2 (A McGuiness).

[688]   *Committee Transcript*, 23.10.08, p.5 (Barwon disAbility Resource Council).

[689]   *Committee Transcript*, 23.10.08, p.4 (Karingal).

[690]   *Submission* 62, p.9 (Centre for Developmental Disability Health Victoria).

[691]   *Submission* 58, p.3 (CareConnect).

[692]   *Submission* 119, p.7 (NorthWestern Mental Health).

have little money and often lack family and other supports. It is therefore important that the SRS is able to actively provide or link the residents into a range of other services that will meet the needs of the residents – such as health, mental health, dental, drug and alcohol services, social, recreational and other meaningful activities.[693]

Affordability

The lack of affordability of SRSs for people with a disability and/or mental illness, particularly those on Centrelink payments and with no family support, was a concern for some who submitted evidence. Some individuals and organisations expressed a view that SRS fees – including pension-level SRSs – are extremely expensive for people with low incomes.[694] For example, Neami explained that:

> The cost of living in an SRS can be extremely high. Most 'pension level' SRSs charge the consumer 85 – 90% of their income, leaving very little for discretionary spending (often this is referred to as 'cigarette money', indicating what many consumers spend their leftover money on).[695]

Several other organisations noted similar concerns. HACSU's commented that residents of pension-level SRS will often have only $5 to $20 to spend on personal items after their fees have been deducted.[696] Furthermore, some organisations suggested that the standard of care was often not equivalent to the costs paid by residents.[697]

As noted above, there are two categories of SRS accommodation – pension-level facilities and above pension-level facilities. The 2008 census found that 91 per cent of residents in pension-level facilities, and 45 per cent of all SRS facilities, are charged $329.90 per week or less. There was no further information regarding how much less than $329.90 some residents might pay.

The costs of SRSs often ruled out social inclusion for people with a disability and/or mental illness, as highlighted by the Barwon disAbility Resource Council which stated that 'the price of paying for their own supported care means that those people are no longer able to afford any kind of community access'.[698] Carers Victoria made a similar claim, stating that while SRS accommodation might appear affordable, people with a disability and/or mental illness generally do not have a high income.

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[693] *Submission* 119, p.7 (NorthWestern Mental Health).

[694] *Submission* 72, p.10 (Housing Resource & Support Service); *Submission* 75, p.2 (Neami); *Submission* 100 pp.54-55 (OPA); *Submission* 124, p.10 (Melbourne City Mission); *Submission* 65, p.1 (EACH).

[695] *Submission* 75, p.2 (Neami).

[696] *Submission* 121A, p.14 (HACSU). See also *Committee Transcript*, 20.11.08, p.3 (APROTCH Ballarat Community Health Centre).

[697] *Submission* 72, p.10 (HRSS); *Submission* 75, p. 2 (NEAMI).

[698] *Committee Transcript*, 23.10.08, p.2 (Barwon disAbility Resource Council).

Further to this, the OPA suggested that the cost of disability needed to be included in considerations regarding the financial burden of support and accommodation for people with a disability and/or mental illness.[699] Research by Peter Saunders from the Social Policy & Research Centre at the University of New South Wales on the cost of disability was also referred to. This research found that:

> Once account has been taken of the costs of disability, the differential in poverty rates between those with and without a disability increases substantially, with the poverty rate among those with a disability exceeding that of those without a disability by more than six-fold.[700]

Some individuals and organisations also expressed a view that there is a move by the Victorian government to push more services on to the private sector and away from the public sector.[701] Barwon disAbility Resource Council, for example stated that 'as a community we are saving money while people are funding their own supported care'.[702]

In its 2008 Annual Report, the Community Visitor Program (a program of the OPA) recommended that the government review the maximum SRS fee for pension-level residents, and consider it be set no higher than 75 per cent of the social security allowance to enable residents to have more disposable income for their personal needs.[703]

Safety

In addition to issues relating to lack of affordability many participants expressed concerns about the safety of SRS as an accommodation option. Carers Victoria highlighted safety concerns with regard to the mix of residents, gender, and residents with challenging behaviours. It stated that these issues can be detrimental to the health and wellbeing of a resident with a disability and/or mental illness.[704] The Committee heard from STAR, VALID, Reinforce and AMIDA that some residents' health deteriorates to a level at which their risk of self-harm increases.[705] Inner South SRS Network told the Committee that some residents are fearful of violence, including sexual assault. It expressed the view that this is a result of the diverse population living in SRSs, such as people with complex and/or behaviours of concern.[706]

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[699] *Submission* 100, p.54 (OPA).

[700] Saunders P. (2006) *The Costs of Disability and the Incidence of Poverty*. SPRC Discussion Paper no.147. Accessed from <http://www.sprc.unsw.edu.au/dp/DP147.pdf> on 19 August 2009.

[701] *Committee Transcript*, 5.11.2008, p.3 (Inner South Parents & Friends Mental Health Support Group).

[702] *Committee Transcript*, 23.10.08, p.2 (Barwon disAbility Resource Council).

[703] Community Visitors (2008) *Annual Report 2007-08*. Office of the Public Advocate, Victorian Government Printer, Melbourne.

[704] *Committee Transcript*, 22.10.08, p.4 (Carers Victoria).

[705] *Submission* 106, p.10 (STAR, VALID, Reinforce and AMIDA).

[706] *Submission* 113, p.7 (Inner South SRS Network).

The OPA suggested that female residents are particularly vulnerable to violence and exploitation given that the gender mix is predominantly male.[707] The organisation told the Committee that 'the Community Visitors Program at OPA has reported that women in these circumstances have exchanged sexual "favours" for what they perceive as basic necessities, such a cigarettes and money'.[708]

In September 2009, the Attorney-General Mr Rob Hulls responded to matters raised by the OPA in relation to safety of women in SRSs. He advised *The Age* newspaper that :

> The Public Advocate has made it clear that a lot of the material that has been put forward is anecdotal and that's because of the difficult circumstances in relation to some of the allegations whereby there has been no proof offered up.[709]

While acknowledging the challenges in gaining evidence of circumstances of sexual assault, Mr Hulls went on to state the importance of ensuring that specific allegations, such as those relating to the safety of residents in SRSs, should be referred to and investigated by police.[710]

In addition, a resident's safety can be exacerbated by low staffing levels and limited staff with relevant experience and qualifications to manage difficult situations.

Rights

The lack of tenancy rights in SRSs was also raised as a factor impacting on its sustainability as an accommodation option. A number of individuals and organisations referred to the importance of security of tenure or tenancy rights for people with a disability and/or mental illness. Some organisations argued that legislation should be developed to provide a level of tenure security for SRS residents, equivalent to that of rooming houses.[711] This would include a breaching process that would occur before a person can be evicted, with the right of appeal.[712] SRS residents are not protected by the *Residential Tenancies Act 1997*. The OPA explained that a consequence of the lack of tenancy rights for residents is that many are reluctant to complain about their living conditions due to a fear of reprisal or eviction.[713] The OPA stated that it is crucial SRS residents are afforded the same rights and protection comparable to other members of the community that pay rent.

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[707]   *Submission* 100, p.55 (OPA).

[708]   *Submission* 100, pp.54-55 (OPA).

[709]   McKenzie, N. & Miletic, D. (2009) 'Sex assault' in care probed, *The Age*, 25 September p.1.

[710]   McKenzie & Miletic, 'Sex assault' in care probed, p.1 [see Footnote 709].

[711]   *Submission* 119, p.5 (NorthWestern Mental Health); *Submission* 100, p.62 (OPA).

[712]   *Submission* 119, p.5 (NorthWestern Mental Health); *Submission* 100, p.62 (OPA).

[713]   *Submission* 100, p.62 (OPA).

Another major concern expressed was the frequent lack of privacy in SRS accommodation. The OPA states that residents have the right to privacy and their own space, which is accessible and reduces the risk of health and safety issues with regard to people with a disability and/or mental illness.[714] All people have the right to privacy and to feel safe in the environment they live in. However, many SRS residents share bedrooms, which significantly limits their privacy.[715] As the OPA stated that 'the complexity of needs of many of the residents, …can pose significant risks to the physical and mental health and safety of residents'.[716] The Mental Illness Fellowship argues further that the lack of access to privacy has a considerable psychological impact on individuals who are already psychologically vulnerable.[717]

Compatibility of residents

Another factor raised that influences the sustainability or otherwise of SRS accommodation for people with a disability and/or mental illness was the mix of residents and their compatibility to co-habit. Frequently the gender of individuals, the ages of residents and the different types of disability will affect the dynamic in a residential setting. Some carers state that the diverse age mix of residents is often problematic.[718] Young adults with a disability and/or mental illness in SRSs can be living with older people in their 60s and 70s. According to one carer, this situation is not ideal for either older or younger residents due to their different interests and energy levels.[719] The OPA supported this view, stating that older residents can feel unsafe around the physicality of the behaviours of younger residents, while younger residents can become frustrated and bored.[720]

The following story provides an insight into one family's experience regarding the importance of getting residents' compatibility right.

One family's experience

My son who is 25 lives at a SRS. It is not a suitable place for him to live. My son has feelings of isolation and disengagement, is a person who by nature is more comfortable participating on the fringes – ie not being the centre of activity or even participating in the main activity, but being in the company of people who are doing the activity. At the SRS, there are few people of his own age to mix and identify with. And definitely no one to assist with facilitation or engagement.

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714   *Submission* 100, p.17 (OPA).
715   *Submission* 100, p.36 (OPA); *Committee Transcript,* 5.11.08, p2 (A McGuiness); *Committee Transcript,* 20.11.08, p.3 (Ballarat Community Health Centre); *Submission* 57, p.3 (Brotherhood of St Laurence).
716   *Submission* 100, p.36 (OPA).
717   *Submission* 98, p.14 (Mental Illness Fellowship Victoria).
718   *Submission* 115, p.3 (J. Marinovic); *Submission* 38, p.1 (M.M. Shilton).
719   *Submission* 70, p.1 (Name withheld).
720   *Submission* 100, p.44 (OPA).

> Any young person may get impatient with the aged and infirm. A mentally ill person who is given psychotropic drugs may display increased impatience and agitated behaviour as a result of the drugs.[721]

Other issues

Participants from rural and regional areas sought to highlight to the Committee that the location of SRSs can be inadequate. For example, the Goulburn Valley Area Mental Health Service told the Committee that due to the limited numbers of SRSs in some areas, the location of the facilities becomes problematic due to limited public transport.[722] Goulburn Valley Area Mental Health Service explained that in the Shepparton Mooroopna region, there is only one SRS to cater for the entire area.[723]

Finally, some evidence received by the Committee suggests that people with a disability and/or mental illness who have children are placed at risk of losing their children if they reside in an SRS.[724] The Inner South SRS Network explained that SRSs are not safe environments for people with children, nor are they appropriate for visits from children. The Network also suggested that with parental access rights of individuals are compromised and difficult to maintain when contact with children is restricted.[725]

11.2.5   Regulation of SRSs

The Minister for Community Services is the responsible Minister for SRS regulation and the DHS is responsible for monitoring compliance with the regulatory scheme. DHS monitors compliance of SRS with the requirements of the *Health Services Act 1988* and Health Services (Supported Residential Services) Regulations 2001 (SRS regulations). The legislation sets minimum requirements for both the physical environment and the care provided. Authorised Officers' monitoring activities include scheduled inspections of all SRSs, supplemented by random inspections. Inspections can include both a facility audit and a care audit.

DHS registers SRSs after assessing written applications, which include detailed information about the proposed operation of the SRS, business and financial planning and care to be provided. Prospective proprietors are interviewed and assessed prior to the grant of registration and new proprietors are typically required to attend a course run by the Department on the operation of SRSs. Proprietors must re-apply for registration near the end of their registration period, when the Department will reassess the applicant to ensure all required criteria are met.

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[721]   *Submission* 70, p.1 (Name withheld).

[722]   *Committee Transcript*, 18.11.08, p.3 (Goulburn Valley Area Mental Health Service).

[723]   *Committee Transcript*, 18.11.08, p.3 (Goulburn Valley Area Mental Health Service).

[724]   *Submission* 65, p.4 (EACH); *Submission* 113, p.12 (Inner South SRS Network).

[725]   *Submission* 113, p.12 (Inner South SRS Network).

Despite the regulations, individuals and organisations expressed concern regarding standards in SRSs. The evidence suggests that a high degree of variance exists in operator standards, since inadequate facilities continue to operate.[726] Some organisations maintain that nutrition is often poor in pension-level SRS and the standard of maintenance can vary greatly.[727] In addition, Inner South Parents and Friends claim that heating in these facilities is limited and the fabric of the buildings is often extremely poor.[728]

The SRS regulations are currently undergoing a review. Notably, this review is a legislative requirement and is not an assessment of the suitability of the SRS model in the provision of support and accommodation for people with a disability and/or mental illness requiring support with activities of daily living. The SRS regulations are due to sunset 10 years after they were established on 4 December 2001, thus prompting their review.

11.2.6   Viability of the SRS sector

As indicated, some individuals and organisations noted that SRSs have a role to play in the system due to the disparity between demand and supply of supported accommodation in the specialist service system. Despite this view, the viability of the SRS industry is questionable. In advice to the DHS on SRSs (the Green Report), Associate Professor David Green stated that 'in terms of providing care to financially disadvantaged people, the SAH-SRS industry is in long-term decline.'[729] The Green Report suggests there are significant issues relating to viability, particularly for pension-level SRSs.

The Victorian Government has introduced the Supporting Accommodation for Vulnerable Victorians Initiative (SAVVI) to assist pension-level SRSs as an initiative to increase the viability of SRSs. SAVVI provides measures intended to create a stronger foundation for pension-level SRSs to improve their viability and meet the complex and diverse needs of their residents through indirect facility cost relief, health and social assessment of residents, and service coordination and support services provided by NGOs.

In 2006, the Victorian Government allocated $40.4 million over five years to establish the initiative. There remains $11.0 million to be allocated. The Victorian Government advised the Committee that there is evidence of a slow-down of the rate of viability-related closures in the pension-level sector. In addition, 700 hours of additional direct care staff hours have been provided. It

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[726]   *Submission* 65, p.1 (EACH); *Submission* 125, p.4 (Mental Health Legal Centre); *Submission* 34, p.1 (A Field).

[727]   *Submission* 112, p.2 (Inner South Parents and Friends); *Submission* 65, p.1 (EACH)

[728]   *Submission* 112, p.2 (Inner South Parents and Friends).

[729]   Green, D. (2004), *Advice to the Department of Human Services on Supported Residential Services*, Updated version, p.9. Accessed from <http://www.health.vic.gov.au/srs/downloads/srs_green_report_final.pdf> on 18 August 2009.

suggested that a range of improvements to the physical environment in SRSs have been achieved through SAVVI.[730]

The intended outcomes of SAVVI include:

▪ Less risk of SRS closing and possibility of residents having to move or become homeless

▪ Increased capacity to meet day-to-day support needs

▪ Improved access to health and community services

▪ More opportunities for social activity and participation

▪ Improved living environments.[731]

Despite the slowing numbers of closures, however, SRS facilities have continued to decline since the Green Report. The following table illustrates the decreasing number of SRS facilities from the mid-1990s.

Figure 11.2.6-1: SRS REGISTRATIONS – SELECTED YEARS 1980–2008
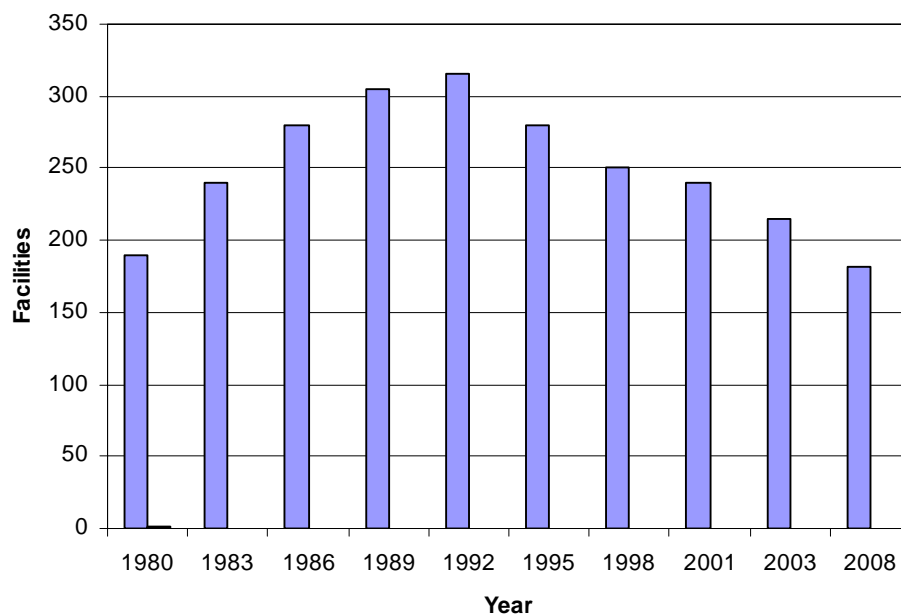
Note: Figures have been approximated, as the number of registered facilities and beds vary across any given year.

Sources: Green Report; 2003 SRS Census; 2009 SRS Census.

The Committee heard from SRS proprietors with regard to the viability of SRSs and issues related to the operation of their services. Karen Eccles told the Committee that the amount of DHS regulatory requirements is extremely onerous for proprietors.[732] Similarly, Bev and Gerard Leehane argued that the quality standards set by DHS are too high and unachievable due to the work

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[730] Victorian Government (2009) Supplementary data provided to the Family & Community Development Committee.

[731] Department of Health (2009) *The SRS Supporting Accommodation for Vulnerable Victorians Initiative*, Information sheet. Accessed from <http://www.health.vic.gov.au/srs/savvi.htm> on 2 September 2009.

[732] *Submission* 131, p.2 (K. Eccles).

involved in running the service.[733] Furthermore, proprietors maintained that the funding levels are insufficient to be able to be able to meet the required standards. The Leehanes said they are unable to maintain the standards on the current remuneration they receive.[734] Ms Eccles told the Committee that 'the provision of much better quality care and an immaculate environment would be possible if funding levels were much more realistic'.[735]

Proprietors suggested that many of their residents come to them because they cannot access other forms of supported accommodation.[736] Due to the shortage of supported accommodation, proprietors told the Committee that the government needs their facility in order to give people at pension-level somewhere to go.[737] In addition, proprietors argued that if the regulatory framework is adhered to, residents receive quality and focused care and support in a home-like environment.[738]

11.2.7   Solutions / recommendations

In view of the extensive concern expressed by participants in the Inquiry relating to SRSs, the Committee recommends broadly that there needs to be an independent review of the effectiveness of the SRS model in meeting the needs of people with a disability and/or mental illness.

The Committee acknowledges that the Victorian Government is currently undertaking a review of the SRS regulations. Importantly, however, that review will not consider the suitability of the model itself or consider possible alternatives to SRSs.

Recommendation

11.1   That the Victorian Government commissions an external review to assess the suitability of the supported residential service model and its operation as a provider of support to people with a disability and/or mental illness.

In addition, however, the Committee acknowledges that the SRS industry will continue to operate in the interim.   It has therefore made additional recommendations relating to the existing model of SRSs and suggests improvements based on evidence it received in the Inquiry. The Committee recognises that the review of the SRS regulations may address some of the concerns raised by participants in the Inquiry. The Committee was advised that the Victorian Government intended to start considering proposed regulatory

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[733]   *Committee Transcript*, 20.11.08, p.3 (G. & B. Leehane).
[734]   *Committee Transcript,* 20.11.08, p.3 (G. & B. Leehane).
[735]   *Submission* 131, p.2 (K. Eccles).
[736]   *Submission* 131, p.1 (K. Eccles); *Committee Transcript,* 20.11.08, p.4 (G. & B. Leehane).
[737]   *Committee Transcript*, 20.11.08, p.4 (G. & B. Leehane).
[738]   *Submission* 131, p.1 (K. Eccles); *Committee Transcript*, 20.11.08, p.11 (G. & B. Leehane).

reforms in late October 2009. Subject to Cabinet endorsement, the Victorian Government intends to table a Bill in Parliament in the 2010 autumn session.

Recommendation

11.2   That through the review of the supported residential service (SRS) regulations, the Victorian Government improves the SRS industry's capacity to respond to people with a disability and/or mental illness by:

- increasing the availability of support from community service organisations in supported residential services, including Individual Support Packages

- increasing accountability and sanctions for non-compliance with regulations

- improving discharge policies from both disability and mental health services into supported residential service accommodation

- establishing a requirement for documented support plans for people with a mental illness who move into these facilities following their discharge

- strengthening the safety of residents in supported residential services, particularly female residents

- increasing the minimum level of qualifications of staff in supported residential services

- strengthening the tenancy rights of residents in supported residential services.

11.3   Rooming houses

Some of the evidence received by the committee revealed that some people with disability and/or mental illness, particularly mental illness, might live in rooming house accommodation when they are unable to access appropriate specialist supported accommodation.

11.3.1   Overview of rooming houses

Under the Victorian *Residential Tenancies Act 1997,* a rooming house is defined as a building in which four or more people reside in rooms available for occupancy on payment of rent.[739] Rooming houses are generally run by commercial operators and have proliferated across Victoria since early 2000.[740] This situation occurred due to the declining affordability and accessibility of private rental

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[739]   *Residential Tenancies Act 1997,* Section 3 Definitions, p.5. Accessed from <http://www.astlii.edu.au/au/legis/vic/consol_act/rtal1997202/s3/html> on 30 September 2009.

[740]   Archer, T. (2009) 'A Short History of Today's Rooming Houses'. *Parity,* Vol. 22. Issue 5, June, p.35.

housing, creating a favourable environment in which new operators could obtain a profit from rooming houses.[741] In the 2006 Census, there were approximately 4,500 Victorians living in rooming houses.[742] The growth in rooming houses is often through the conversion of existing properties into rooming houses. Rooming houses offer an accommodation option to people who are unable to access other accommodation options. Rooming houses vary in size, ranging from small properties housing four or five lodgers up to larger buildings accommodating more than 100 residents.[743] With the growth in rooming houses, the resident mix in the houses has become complex and diverse.

11.3.2   Resident profile

There is a diverse mix of residents living in rooming houses in Victoria. Approximately 76 per cent of residents are male, with the largest group in the 35–55 age bracket.[744] Women residing in rooming houses are generally within the same age group. An Australian Institute of Health and Welfare (AIHW) report highlights that residents occupying rooming houses are generally the homeless, aged and frail, low income, single, and people with a disability.[745] The report identifies the diversity of disabilities experienced by some people living in rooming houses. They include intellectual, physical, neurological, sensory and dual disabilities. In addition, they also include mental illness and associated psychiatric disability.[746]

11.3.3   Perspectives on rooming houses

According to the evidence received from individuals and organisations, a key issue for people with a disability and/or mental illness living in rooming houses is the challenge in sustaining these living arrangements due to minimal tenancy rights, high cost of living, vulnerability to abuse and exploitation and poor living standards. Furthermore, the Committee heard that support that meets the needs of a person with a disability and/or mental illness is a significant factor in their ability to sustain their housing. Unlike SRSs, rooming houses do not provide any support to their residents.

Participants in the Inquiry questioned the appropriateness and adequacy of rooming house accommodation for people with a mental illness and/or disability who require significant support. The Committee heard that in most

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741   Archer, 'A Short History of Today's Rooming Houses', p.35 [see Footnote 740].

742   Archer, 'A Short History of Today's Rooming Houses', p.35 [see Footnote 740].

743   Enticott, J. Council to Homeless Persons website. Accessed from <http://www.chp.org.au/parity/articles/resutls.chtml?filename_num=00293> on 30 September 2009.

744   Cartmel, H. (2007) 'What is a Rooming House?' in *Parity,* Vol. 20, Issue 6, July, p.7.

745   Australian Institute of Health and Welfare (AIHW) (2007) *Community housing data collection 2005–06: results for the trial collection of unit record level dwelling and organisation administrative data.* AIHW Welfare and Housing working paper no. 56. AIHW, Canberra, p.23.

746   AIHW, *Community housing data collection 2005–06*, p.23 [see Footnote 745].

situations, support is rarely provided in rooming houses.[747] Carers Victoria explained that individuals with a disability and/or mental illness do not only require a roof over their heads; they need support and services to assist them with their personal care needs, vocational needs and social skills to enable them to participate in the community.[748] The organisation stated that 'the lack of support and the lack of health resources within those boarding houses are all detrimental to the person with the disability'.[749]

Organisations and individuals told the Committee that the living standards of rooming houses are poor. According to an article in *Parity*, many houses are overcrowded, have significant maintenance issues, as well as poor facilities such as plumbing and electricity.[750] The Community Housing Federation of Victoria stated that rooming houses are often old buildings and in need of maintenance and improvements since they are often the same rooms that provided accommodation to people 50–60 years ago.[751] NorthWestern Mental Health argued that due to limited accommodation options, individuals sometimes live in rooms not originally deemed as bedrooms, such as living rooms and rundown outer buildings.[752] In addition, there is often a very poor level of cleanliness and sanitary conditions.[753]

Participants in the Committee's Inquiry also expressed concerns about the high cost of rent in rooming houses. It is common for people with a disability and/or mental illness to pay up to $180 per week, while on a disability support pension of $575.80 per fortnight for a single person.[754] Carers Victoria stated that this form of accommodation is not affordable to people on income levels that are not high.[755] The Committee heard that some people are paying high rents for a room comparable to a linen cupboard with a mattress on the floor.[756] NorthWestern Mental Health argued that rooming house providers take advantage of their residents' marginal status and limited accommodation options.[757]NorthWestern Mental Health told the Committee that due to the limited supply of supported accommodation, Victorians with a disability and/or mental illness 'often have no alternative but to utilise this most unsatisfactory accommodation option'.[758]

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[747] *Committee Transcript*, 5.11.08, p.5 (Community Housing Federation of Victoria); *Committee Transcript,* 22.10.08, p.4 (Carers Victoria).

[748] *Committee Transcript*, 22.10.08, p.4 (Carers Victoria).

[749] *Committee Transcript*, 22.10.08, p.5 (Carers Victoria).

[750] Archer, T. (2009) 'A Short History of Today's Rooming Houses' p.36 [see Footnote 740].

[751] *Committee Transcript,,* 5.11.08, p.3 (Community Housing Federation of Victoria).

[752] *Submission* 119, p.12 (NorthWestern Mental Health).

[753] *Submission* 65, p.1 (EACH).

[754] *Payment rates of disability support pension.* Centrelink website, Accessed from<http://www.centrelink.gov.au/internet/internet.nsf/payments/pay_how_dsp.htm> on 4 September 2009.

[755] *Committee Transcript*, 22.10.08, p.4 (Carers Victoria).

[756] *Committee Transcript*, 5.11.08, p.4 (Community Housing Federation of Victoria).

[757] *Submission* 119, p.12 (NorthWestern Mental Health).

[758] *Submission* 119, p.12 (NorthWestern Mental Health).

Exposure to violence and to alcohol and other drugs was also considered another significant concern with regard to rooming houses. NorthWestern Mental Health stated that some residents experience assault, intimidation, and stand-over tactics by co-tenants or rent collectors.[759] Mr Chris Chaplan, policy and project officer at the Community Housing Federation of Victoria told the Committee that there is a high level of violence in rooming houses, particularly in private rooming houses.[760] He pointed out that people with a mental illness living in rooming houses are vulnerable to bullying or victimisation due to their mental illness. In addition, he stated that people living in this form of accommodation often have high levels of substance use. Subsequently, rooming houses can be extremely inappropriate for people with a disability and/or mental illness seeking to address their substance use.[761]

Despite the insecurity and often perilous environment of rooming houses, they are sometimes the only option available to people with a disability and/or mental illness. One witness stated that:

> It was a good change moving up to Bendigo because of all the Melbourne stuff, the negative lifestyle, but when I move out of here, I assume that I'm going to have to go back to Melbourne. My only option there is a boarding house, which means I should get back together with my violent ex-boyfriend, and start using again. Boarding houses are horrible, there's people injecting in the hallway, fights every night. You can't go to the shower without catching tinea. Yes, it's really unhygienic. I've sort of used all the options of staying with parents.[762]

Some participants advised the Committee that the lack of tenancy rights for individuals living in rooming houses impacts on its adequacy as a sustainable option for people with a disability and/or mental illness. A person residing in a rooming house is referred to in the *Residential Tenancies Act 1997* (RTA) as a resident and is defined as an individual who, with the agreement of the rooming house owner, lives in a room as their only form of residence.[763] Rooming houses should provide their residents with:

- Safety and security
- Water, toilets and power
- Quiet enjoyment
- Residency without harassment or threats
- A written notice of eviction.[764]

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[759]   *Submission* 119, p.12 (NorthWestern Mental Health).

[760]   *Committee Transcript*, 5.11.08, p.5 (Community Housing Federation of Victoria).

[761]   *Committee Transcript*, 5.11.08, p.5 (Community Housing Federation of Victoria).

[762]   *Committee Transcript*, 19.11.08, p.6 (Mind).

[763]   *Residential Tenancies Act 1997 (Vic),* s.3.

[764]   Consumer Affairs Victoria. *Rooming House Residents: Your Rights.* Accessed from <http://www.consumer.vic.gov.au/CA256902000FE154/Lookup/CAV_Publications_Ren ting/$file/rent_flyer_rooming_house_zcard.pdf> on 7 September 2009.

NorthWestern Mental Health and Neami, however, suggested that people living in rooming houses are routinely denied their legal rights under the RTA. Many individuals are subject to illegal evictions, illegal rent increases, and often do not have an opportunity to sign a lease.[765] People living in rooming houses do not enjoy full protection of their rights with regard to the RTA.

Rooming houses are not regulated in the same way that SRSs are, although Ballarat Community Health Centre stated that some rooming houses operate as SRSs by providing support in the way of overseeing medication.[766] Rooming houses, however, are unregulated and do not have Community Visitors visiting these premises to discuss the standards and care received by residents.

An effective rooming house project has been established by the Victorian Government. The Rooming House Plus Project provides long-term housing for people with low incomes and complex needs due to mental illness or challenging behaviours and who have difficulty maintaining tenure in less supported environments. The project is a joint initiative of the Office of Housing, Mental Health and Aged Care branches.

The transformation of a former motor inn in Melbourne has provided 64 modern apartments for low-income, single Victorians. The project provides a mix of housing and mental health and aged care support for residents and aims to link sustainable housing to improved health.[767]

A community housing service provides the property and tenancy management while the support component for tenants requiring assistance with daily living is funded by Mental Health and Aged Care and provided by a non-government organisation.

On 15 July 2009, the Victorian Government established a Rooming House Standards Taskforce to scrutinise rooming houses to ensure they are registered and complying with minimum standards.

Rooming House Standards Taskforce

The Terms of Reference of the Taskforce focused on standards, compliance and enforcement, registration and supply of rooming houses.

Six recommendations were made on improving rooming house **standards**. The key recommendation relates to the immediate introduction of a range of additional standards, including locks on bedroom doors, bathrooms and toilets, fire management and the provision of basic window coverings as well as the exploration of

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765   *Submission* 119, p.12 (NorthWestern Mental Health); *Submission* 75, p.3 (NEAMI).

766   *Committee Transcript*, 20.11.08, p.4 (Ballarat Community Health Centre).

767   Department of Human Services (2006) *Former motor inn rocks on as rooming house*. Accessed from <http://www.dhs.vic.gov.au/humanservices/feb06/inn.htm> on 7 September 2009.

additional standards after analysis of the impact on affordability and supply.

Eight recommendations were made on improving the **compliance** with, and **enforcement** of, rooming house regulation. The key recommendation relates to increasing the fines under the *Residential Tenancies Act 1997* as a deterrent to non-compliance with rooming house provisions. Other compliance and enforcement related recommendations include providing the Director of Consumer Affairs Victoria with greater powers to investigate and act on breaches of legislation and considering changes to the RTA to allow third parties to bring action on behalf of vulnerable residents.

Five recommendations were made on the **registration** of rooming houses. The key recommendation is the introduction of a registration process for rooming house operators to drive improved professionalism and reduce exploitative practices in the sector. Other registration-related recommendations include the establishment of a state-wide register of rooming houses that can be provided to those organisations that refer homeless people to rooming houses and phasing in restrictions on the use of Government Housing Establishment Funding so that it is only made available to registered rooming houses.

Six recommendations are made on increasing the supply of affordable accommodation. The Taskforce saw these recommendations as critical. Ultimately only increased supply of affordable housing will reduce the demand which is driving exploitative practices by some rooming house operators. The key recommendation in relation to supply involves the purchase of high quality rooming house and singles accommodation.

Finally, there are a number of recommendations that relate to **phasing in the new regulatory requirements** to limit any negative impact on rooming house residents. Specific recommendations include trialling more innovative crisis accommodation options, including the use of the Housing Establishment Fund and supporting the Registered Accommodation Association of Victoria to strengthen levels of professionalism among private operators.[768]

Recommendations

11.3   That the Victorian Government expands the 'rooming house plus project' through the establishment of one in every region.

11.4   That the Victorian Government revisits the registration, compliance and enforcement of rooming house standards and regulations in July 2011 to determine the effectiveness of the new measures.

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[768]   Chairperson's Report (2009) *Rooming House Standards Taskforce – Chairperson's report*. Victorian Government, Melbourne.

11.3.4 Motels and caravan parks

A number of individuals and organisations explained to the Committee that due to a lack of options of specialist support and accommodation, some people with a disability and/or mental illness live for extended periods in privately operated caravan parks and motels. These forms of accommodation were designed to provide temporary accommodation for travellers and tourists, not ongoing, long-term accommodation for people with support needs.

It appears that some people with a mental illness choose these forms of accommodation due to the lack of specialist supported accommodation options in the mental health sector.

The inappropriateness of these forms of accommodation for people with a disability and/or mental illness issues are similar in many respects to rooming house accommodation and, at times, SRS facilities. That is, the exposure to unsafe environments (including alcohol and other drugs and violence), the instability of the accommodation (no security of tenure or tenancy rights), and the lack of access to support. Bendigo Psychiatric Service told the Committee that:

> we're discharging people to caravan parks, Dower Caravan Park, which is no great accommodation. We are grateful for it, but it's not the sort of place that you'd want to send someone that you were related to or cared about.[769]

Karingal and Gateways maintain that motels and caravans do not provide a safe and secure option for individuals with a disability and/or mental illness and may not provide a safe environment for support staff.[770] FamilyCare told the Committee that due to the lack of accommodation options in rural areas, as well as the lack of options for single mothers with children, organisations are putting people into caravan parks.[771] In addition, the Goulburn Valley Centre Disability Services said that Victorians with a disability and/or mental illness living in caravan parks or motels are vulnerable to intimidation and victimisation.[772] The prevalence of drug abuse in caravan parks is also a concern for people who are vulnerable. Both SNAP and the Homeless Outreach Psychiatric Service argued that caravan parks and motels are inappropriate accommodation options that do not offer support or security to people with a disability and/or mental illness.[773]

In addition, one organisation claimed that people with complex needs are more at risk if living in caravan parks and other unsafe and unstable accommodation. As outlined in earlier chapters, people with complex needs require a clinical treatment model of support rather than a community based support model.

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[769]   *Committee Transcript,* 19.11.08, p.3 (Bendigo Psychiatric Service).

[770]   *Submission* 16, p.7 (Karingal and Gateways).

[771]   *Committee Transcript*, 18.11.08, p.4 (FamilyCare).

[772]   *Committee Transcript*, 18.11.08, p.3 (GV Centre Disability Services).

[773]   *Committee Transcript*, 23.10.08, p.4 (Homeless Outreach Psychiatric Service); *Committee Transcript*, 21.10.08, p.4 (SNAP).

Goulburn Valley Disability Services argued that individuals with complex needs will not have the supervision to ensure medication is managed, nutrition is adequate or finance managed, and unsafe and inadequate living conditions can be detrimental to an individual's health.[774]

With regard to the concepts of quality of life and recovery discussed in earlier chapters, it is important to bear in mind that people with a disability and/or mental illness should have the opportunity like everyone else in the community to choose where they would like to live. As previously mentioned, some individuals might indicate a preference to living in a caravan park environment over an SRS. Provided they have the capacity to make that decision and it does not pose a risk to their safety or wellbeing, such a choice made by a person with a disability and/or mental illness should be respected. Families are particularly fearful of these inappropriate forms of accommodation. Individuals and organisations told the Committee that the system only responds to crisis; it is difficult for families to plan ahead and to obtain accommodation for their child with fellow residents of choice. One carer told the Committee that her son, who has chronic schizophrenia, lived in a 'campervan in a caravan park and at the time was so unwell I was concerned he would commit suicide and where do you get help?'[775]

11.4 Residential settings

For some people with a disability and/or mental illness unable to access the specialist system, their only option is to reside in residential settings that provide support.

These types of settings and facilities include:

- Young people in aged care facilities
- Semi-permanent stays in respite.

11.4.1 Young people in aged care facilities

Some individuals and organisations that provided evidence to the committee expressed concerns regarding people with a disability who have no alternative options but residential aged care (RAC) facilities. In particular, the evidence indicated that people with neurological conditions, acquired brain injuries (ABI) and severe physical disabilities are particularly vulnerable to these arrangements.

Key issues for people who live in these arrangements relate to the lack of social inclusion, opportunity to participate in the community and of specialised support.

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[774] *Committee Transcript*, 18.11.08, p.3 (GV Centre Disability Services).
[775] *Submission* 135, p.1 (L. Douglas).

Overview

The DHS has been extensively involved in exploring alternatives to the situations of people living in residential aged care. This has followed on from Federal initiatives and funding in 2006 to reduce the number of people under 50 years with a disability residing in RAC.

In February 2006, the Council of Australian Governments (COAG) announced a commitment to reduce the number of younger people with disabilities living in residential aged care. The $244 million Commonwealth and State funded five-year program began in July 2006 and targets people aged under 50 living in aged care facilities. The program provides alternative residential care services for some younger people with a disability, improves support services for individuals who remain in residential aged care and assists younger people who are at risk of entering nursing homes.[776]

The Victorian Government initiative *my future, my choice* aims to provide better living options for younger people with a disability who live in, or are at risk of entry to, residential aged care. The initiative aims to develop new accommodation and support options that respond to complex clinical and health care needs, as well as providing social and lifestyle opportunities with which younger people identify. The target group is individuals aged less than 50 years.[777]

While the government has continued to invest in this area, a significant number of young people remain in RAC due to lack of alternatives. The Young People in Nursing Homes Alliance stated that:

> These are the people who predominantly end up in aged-care nursing homes because the disability system as it is at the moment does not have the capacity to respond to their very different needs and expectations.[778]

Inability Possability told the Committee that young people with a severe ABI have unique and changing medical, social and rehabilitation needs. The organisation stated that the only supported accommodation option available for this group is aged care.[779] Inability Possability stated that 'aged care services and facilities are designed for an 'end of life' approach, and are not structured to provide age appropriate accommodation and care for young people who are living life'.[780]

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[776] Council of Australian Governments website. Accessed from <http://www.coag.gov.au/coag_meeting-outcomes/2006-02-10/index.cfm> on 7 September 2009.

[777] Department of Human Services (2008) *My Future My Choice: Better living options for younger people in, or at risk of entry to, residential aged care progress report*. Disability Services Division, DHS, Melbourne.

[778] *Committee Transcript*, 5.11.08, p.2 (Young People in Nursing Homes Alliance).

[779] *Committee Transcript*, 5.11.08, p.2 (Inability Possability).

[780] *Submission* 79, p.2 (Inability Possability).

In July 2009, the Minister for Community Services, the Hon. Lisa Neville, announced a new facility with six new placements as part of its efforts to assist young people residing in aged care to move into appropriate accommodation and receive support. The new facility will be purpose built and designed to enhance the independence of residents.

There are a number of younger (under 65 years of age) adults with a disability living in residential aged care facilities. In 2005, DHS found that around 1550 Victorians with disabilities under 65 years lived in residential aged care settings; of these, just over 200 were under 50.[781] Recommendations from this work included the reduction of inappropriate admission, expansion of alternative accommodation options where appropriate, improvement of RAC where it was the best option, working with the Commonwealth to establish better approaches, and better coordination of support for people with disabilities.

Following on from this work, a five-year Commonwealth initiative targeting this group (in particular people aged under 50) was established in 2006 through COAG.

The COAG initiative, Younger People with Disability in Residential Aged Care (YPIRAC), has three key objectives:

- To move younger people with disability currently in residential aged care into appropriate supported disability accommodation; where supported disability accommodation can be made available and only if the client chooses to move

- To divert future admissions of younger people with disability who are at risk of admission to residential aged care into more appropriate forms of accommodation

- To enhance the delivery of specialist disability services to those younger people with disability who choose to remain in residential aged care, and if residential aged care remains the only available suitable supported accommodation option.

The 2009 National Disability Agreement replaced all previous bilateral agreements under the previous Commonwealth and State/Territory Disability Agreement, however targets under the YPIRAC program have been retained.

In Victoria, this has been implemented through the *my future, my choice* initiative. The Department has announced that the $60.2 million over five years in joint Commonwealth State funding will be used to build group homes providing over

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[781] Department of Human Services (2005) *Creating New Opportunities: Responding to the needs of younger people in Victoria's Residential Aged Care services: Final Report.* Accessed from <http://www.dhs.vic.gov.au/pdpd/downloads/ypirac_final_report.pdf> on 7 September 2009.

100 places for younger Victorians currently living in residential aged care facilities.[782]

11.4.2 Resident profile

In Victoria, approximately 221 people under 50 years live in RAC.[783] Younger people living in RAC have a diverse range of disabilities, support needs, and health issues. The disability types include ABI, multiple sclerosis, Huntington's Disease, cerebral palsy, intellectual disability and other neurological disorders. Many people also have sensory impairments, mental health issues, and secondary health conditions.[784]

11.4.3 Perspectives on young people in RAC

As noted above, some of the evidence received in late 2008 revealed that despite government initiatives to address the issue of young people in RAC, due to the lack of supported accommodation options available to people with high, complex and changing needs, this continues to remain an issue of concern.

Carers Victoria told the Committee that

> The placement of young people in nursing homes leaves them without appropriate peer and other social contact due to the isolating nature of their placement with older residents. They are unable to access educational, training or employment opportunities that are more readily available to their peers who live either in the family home or in specialist disability supported accommodation.[785]

In addition, some organisations stated that aged care nursing staff do not have the required skills and knowledge to provide specialised care for younger people with disabilities, such as an ABI. Inability Possability told the Committee that

> If appropriate care is not given, this group's health status is compromised. This potentially increases the occurrence of acute health episodes, which lead to non-elective admission to hospital. Emergency admissions to hospital often lead to further issues for the young person with severe ABI and are costly.[786]

A key gap identified related to the age cohort between 50 and 64 years, who were not included in the first initiative. The needs of people under 50 are represented in initiatives such as *my future my choice* but individuals between 50

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[782] Department of Human Services (DHS) About *my future, my choice.* DHS website, Accessed from <http://www.dhs.vic.gov.au/disability/supports_for_people/my_future_my_choice /about-my-future-my-choice> on 7 September 2009.

[783] Summer Foundation (2007) *Younger People in Residential Aged Care: Support needs, preferences and future directions.* Victoria, p.1.

[784] Summer Foundation (2007) *Summary: Younger People in Residential Aged Care.* Victoria, p.4.

[785] *Submission* 61, p.8 (Carers Victoria).

[786] *Submission* 79, p.4 (Inability Possablity).

and 64 are not recognised. The coalition Young People in Nursing Homes identified this as a significant issue. They argue that:

> people between 50 and 65, which is the bulk of our clients, just do not have an existence any more. They do not fit, because a system that categorises people on age rather than on need makes that age group, 50 to 65, invisible to the system.[787]

The following table outlines the current status of development for *my future, my choice*.

Table 11.4.3-1: Status of development of *my future, my choice* initiative

Location	Status
Eastern Metropolitan Region	
Balwyn	Opened February 2008
Glen Waverley	Construction
Bayswater	Land secured, in design
Southern Metropolitan Region	
Noble Park	Land secured, design completed
McKinnon	Land secured, design completed
Cranbourne	Land secured, in design
Frankston	Land secured, in design
North & West Metropolitan Region	
Altona	Land secured, design completed
Alphington	Construction
North East	Land search
Northern	Lane search
St Albans	Land secured, in design
Barwon South Western Region	
Belmont	Construction
Grovedale*	Construction
Loddon Mallee Region	
Bendigo	Land secured, in design
Gippsland Region	
Moe*	Land secured
Bairnsdale*	Land secured
Sale*	In design
Grampians Region	
Sebastopol*	Land secured, in design
Horsham*	Land secured, in design
Hume Region	
Shepparton*	Land secured, in design
Wodonga*	Land secured, in design

* Indicates joint Older Carers/my future my choice disability service.

Source: DHS website (2009) Accessed on 26 November 2009 from http://www.dhs.vic.gov.au/disability/supports_for_people/my_future_my_choice.

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[787] *Committee Transcript*, 5.11.08, p.5 (Young People in Nursing Homes).

Recommendations

11.5   That the Victorian Government extends the *my future, my choice* program to 50 to 64 year old age group to provide them with increased opportunities to participate in the community.

11.5   Presentation at and long stays in hospitals

Due to the limited accommodation and support options for Victorians with a disability and/or mental illness, individuals may be taken to hospitals when families or carers are unable to continue to provide the support they need. There are many people with disabilities occupying hospital beds for longer than their medical needs necessitate.[788] A significant cost to the community is incurred by people who are waiting for an appropriate place in a supported accommodation facility occupying hospital beds.[789]

Furthermore, hospitals do not provide adequate support, as the services are internally focused and resources to support community inclusion do not exist. Yooralla argued that in hospitals

> constantly changing rostered staff, a lack of awareness of the specific needs of individuals with disabilities, reduced opportunities to develop new relationships and lack of capacity to assist with external activities or skill development condemns the person with a disability to a life of dependency, boredom and hopelessness.[790]

In its 2006 review of mental health services, the Boston Consulting Group made the point that 'the lack of available inpatient beds in hospitals can result in people with mental illness remaining in Emergency Departments for lengthy periods'.[791]

11.6   Respite

The use of respite as semi-permanent and, at times, permanent accommodation was another issue raised in evidence to the Committee.

A number of organisations said they had anecdotal evidence of people who left a family member in respite due to their inability to cope with their caring responsibilities and the lack of options open to them.

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[788]   Reilly, T. (2009) 'When a hospital bed is the only home there is', *Sunday Age,* Sunday 30 August, p.7.

[789]   *Submission* 100, p.29 (OPA).

[790]   *Submission* 77, p.8 (Yooralla).

[791]   The Boston Consulting Group (2006) *Improving Mental Health Outcomes in Victoria: The Next Wave of Reform.* Department of Premier and Cabinet, Melbourne, July, p.67.

11.6.1 Overview

Respite support enables carers to take short-term or time-limited breaks whilst someone else provides support and care needs to a person with a disability. Respite support includes community participation (day activities), in-home support (support provided in the home), and out-of-home support (facility-based stays, support in family environment, camps/holidays, or other flexible options to meet a person's needs). However, there is no data collected by the DHS with regard to demand for respite services.

11.6.2 Residential profile

Unpaid carers of individuals aged between 6 and 64 who have a disability are eligible for respite. The disabilities include an ABI, intellectual or physical disability, or a degenerative neurological condition. It is important to note, however, that because data is not collected on individuals accessing respite it is not possible to gain an accurate profile of who is using it.

11.6.3 Perspectives on respite as semi-permanent option

During the course of the Inquiry, the Committee heard that people who are awaiting supported accommodation often rely on the availability of respite services. Respite placements are often used as an accommodation option by people who are unable to find a place in a supported accommodation facility or unable to stay at home. The Auditor-General's report states that respite options are often used to meet the accommodation needs of people on the Disability Support Register awaiting supported accommodation.[792] The report suggests that this raises concerns regarding the availability of regular respite for people with a disability and their carers.

The Committee heard that for some people in caring roles, respite is the only form of accommodation support they receive. This includes people in caring relationships who need a break from their full-time caring duties and those who would prefer to have their family member or friend in supported accommodation but are unable to access it due to the shortage of provision. Some individuals and organisations told the Committee that in some extreme situations families have resorted to leaving their child in respite as they are unable to continue their caring role.[793] The evidence indicated that this is often the case with aging carers of adult children who become unwell or become a sole carer after the death of a partner.[794]

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[792] Victorian Auditor-General (2008) *Accommodation for People with a Disability*. Victorian Auditor-General's Office, Melbourne.

[793] *Committee* Transcript, 18.11.08, p.3 (Carers and Parents Support Group); *Submission* 105, p.3 (Wesley Mission); *Submission* 111, p.8 (I. Spicer).

[794] *Submission* 105, p.3 (Wesley Mission).

Access to respite is critical in meeting the needs of individuals with disabilities living at home. While respite is important in sustaining an individual's living situation and supporting their carer's needs, the Committee heard that accessing respite is becoming difficult as a result of places being used to meet the deficiencies in long-term supported accommodation. The loss of respite places, due to bed block, results from the shortcomings in the provision of supported accommodation. As Carers Victoria claimed, 'such practices exacerbate the already desperate situations for some families who are only seeking some short-term respite but cannot do so because of the lack of places'.[795]

The evidence suggests that resorting to respite as a long-term accommodation facility is often an indicator of the desperation of carers when suitable accommodation is not available. As OPA suggests, the use of respite in this context reveals significant systemic issues that are linked with a shortage of accommodation options. This situation can exacerbate existing system problems by contributing to further system blockages and making respite placements harder to get.[796] Long-term residence in respite means that other individuals cannot access the service, increasing the likelihood of a crisis in their households.

Research suggests that there is a heightened risk of health problems with people staying in respite long-term. This can include difficulties in coordinating and establishing continuity of health and medical care and an increase in stress and anxiety, which contributes to new health and psychological conditions.[797] Wilson et al highlight that the care and support of individuals living long-term in respite facilities is also compromised as the capacity to plan for an individual's rehabilitation and support needs are not available. Extended stays in respite are linked to significant negative health impacts on both the resident and the service. Gellibrand Residential Services argued that the skill capacity of individuals is not developed as they are generally 'looked after' rather than being taught to look after themselves and develop new skills.[798] In addition, Interchange Loddon Mallee states that individuals staying in respite for extended periods have very little support to meet their ongoing needs.[799] Wesley Mission told the Committee that ongoing support for people with a disability and/or mental illness cannot be provided by respite services, as staff are not trained to provide the level of support needed. The inconsistency of staff does not enable residents to develop a relationship with their carers in ways that they feel their needs are being met and understood.[800]

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[795] *Submission* 61, p.6 (Carers Victoria).

[796] *Submission* 100, p.28 (OPA).

[797] Wilson, E., Fryffe, C. Fyffe, E. & Heggie, D ((2007) 'Best practice in a resource vacuum: Responding to the accommodation needs of people with high, complex or changing support needs'. *Second Annual Roundtable on Intellectual Disability Policy*, 19 April, p.12.

[798] *Submission* 45, p.5 (Gellibrand Residential Services).

[799] *Committee Transcript*, 19.11.08 p.3 (Interchange Loddon Mallee).

[800] *Submission* 105, p.5 (Wesley Mission).

As the evidence suggests, issues relating to consistency of service and compatibility with other residents are a significant concern for people residing semi-permanently in respite accommodation. One carer pointed out that people with profound disability can be residing in respite facilities with other individuals with a mild or moderate level of disability. Given the diversity of disabilities in respite, an individual's safety is an issue when sharing with people with violent or disruptive behaviours.[801] Mr Ian Spicer told the Committee that the ability to move to another respite facility is limited, leaving little choice for carers but to force the person with a disability to attend the respite facility in fear of loosing access to the service.[802] In addition, Wesley Mission stated that the issue of placing younger women with a disability into respite with men, where there is not an active night shift, is concerning.[803]

Chapter Four provides an overview of respite services and a breakdown of respite places by region. Chapter Ten discusses the implications for families of the lack of respite places.

Table 11.6.3–1: Long stays in respite, June 2009

Region	Families waiting for respite	People using respite beds longer than 4 weeks
Metropolitan		
North & West Metro	N/A*	28
Southern Metro	N/A*	3
Eastern Metro	118	18
Regional		
Loddon Malle	13	3
Grampians	9	0
Hume	0	1
Gippsland	16	0
Barwon South-West	59	9
TOTAL	**215**	**62**

* These regions don't collect data regarding families waiting for respite.

Source: Victorian Parliamentary Debates, *Legislative Assembly*, 11 August 2009, pp.2826-31.

Recommendations

11.6   That the Victorian Government undertakes an inquiry into respite services to determine the use of respite as a semi-permanent option due to the lack of alternatives and the ramifications for families seeking to access respite.

11.7   That the Victorian Government improves data collection in respite to improve measurements of demand for respite, and also length of stay and appropriateness of placement

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[801]   *Submission* 111, p.22 (I. Spicer).

[802]   *Submission* 111, p.22 (I. Spicer).

[803]   *Submission* 105, p.4 (Wesley Mission).

11.7   Living with families unable to provide support

In the evidence provided to the Committee, individuals and organisations commented on circumstances where people with a disability and/or mental illness remained in the family home due to the lack of alternatives. These situations tended to be inadequate to meet the individual needs and aspirations of people with a disability and/or mental illness. Examples included ageing carers with health issues and family carers experiencing high levels of anxiety and stress. In both instances, the view of both carers themselves and support organisations was that the capacity of carers to continue to provide support to the person with a disability and/or mental illness was diminished.

Carers and Parents Support Group stated that the implications for people with a disability not deemed high priority forces them to continue living with ailing parents, who are suffering from increased stress or anxiety. The organisation argued that the lack of knowing what the future is for their family member can lead to severe health problems.[804] One carer said that the system guarantees a crisis response when the parents die whilst caring for a family member who is in his or her 50s or 60s. Mr Anthony Baird suggested that the family member does not have knowledge or experience of how to live in the community, which can be very distressing for the individual.[805]

One carer told the Committee about her experiences of trying to receive support for her family member due to his high and complex needs. Her son has an ISP but this does not adequately cover the costs of his full support needs. She explained that her own health is now suffering as a consequence of providing full-time care.

> After 19 years of providing care and advocacy I have developed a mental illness and have been hospitalised several times. I have had to stop uni, have no social life, no recreation, no sick days (other than hospital days that are classed as respite by Centrelink) and no paid work. I had already stepped out of life by necessity to meet my obligations as a carer and parent even before I became ill.[806]

Gellibrand Residential Services argued that carers experience extreme levels of stress due to the inability to access accommodation and support. From their view, there can be implications for the quality of care provided to family members when carers experience excessively high stress levels.[807]

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[804]   *Committee Transcript*, 18.11.08, p.5 (Carers and Parents Support Group).
[805]   *CommitteeTranscript*, 22.10.08, p.2 (A. Baird).
[806]   *Submission* 55, p.3 (Name Withheld).
[807]   *Submission* 45, p.4 (Gellibrand Residential Services).

11.8   Incarceration

In evidence provided to the Committee, a link was drawn between unmet supported accommodation demand and the high numbers of people with a disability and/or mental illness in the prison population. Forensicare argued that the current management and treatment of people with a mental illness in the criminal justice system is as central to a forensic service as it is in other mental health services.[808] In addition, Forensicare maintained that community accommodation options for forensic patients are very limited. The agency explained that this results in forensic patients remaining in either Thomas Embling Hospital or prison for considerably longer than is required and works against achieving successful community integration, continuity of care and optimal health outcomes. The Peninsula Carer Council suggested that 'we can think of our prisons as being de facto supported accommodation, which is very poor and inappropriate for many people with long-term psychiatric illnesses'.[809] In addition, HACSU argued that many people with a severe mental illness are in prisons waiting for available beds in appropriate treatment facilities.[810]

With regard to disability, research suggests that one of the main reasons that prisoners with an intellectual disability are denied or less likely to receive parole in comparison to non-intellectually disabled prisoners is due to the lack of suitable accommodation in the community.[811] Carers Victoria suggested that by providing enough accommodation and support in the community instead of putting individuals with a disability and/or mental illness in prisons, the current pressure on the justice system will be alleviated and a significant amount of money will be saved.[812]

The Committee's attention was also drawn to the case of Mr Michael Rendina, a 41-year-old man with an intellectual disability who had been in the Melbourne Assessment Prison in 23-hour lock-up. The case was heard by the County Court and it was revealed in media coverage that Mr Rendina was inappropriately incarcerated for 11 months due to a lack of available 'non-custodial accommodation options' and no treatment plan.[813] In the trial, Judge Mark Taft requested that the DHS secure appropriate support and accommodation for Mr Rendina. Within two weeks, on 23 November 2009, DHS advised Judge Taft that a placement had been found for Mr Rendina at Plenty Residential Services in Bundoora with 24 hour care.[814]

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[808]   *Submission* 122, p.9 (Forensicare).

[809]   *Committee Transcript*, 5.11.08, p4 (Peninsula Carer Council).

[810]   *Submission* 121A, p.9 (HACSU).

[811]   Department of Justice (2007) *Intellectual Disability in the Victorian Prison System: Characteristics of prisoners with an intellectual disability released from prison in 2003-2006*. Corrections Research Paper Series, No. 2, September.

[812]   *Committee Transcript*, 22.10.08, p.12 (Carers Victoria).

[813]   Butcher, S. (2009) 'Judge slams man's jailing', *The Age*, 10 November, p.1.

[814]   Lowe, A. (2009) 'Home found for prisoner unfit to plead', *The Age*, 24 November, p.3.

The number of individuals with a disability and/or mental illness in the corrections system is an issue that is outside the scope of this Inquiry. The Committee notes, however, that this issue warrants further investigation.

Recommendation

11.8   That the Victorian Government undertakes an inquiry into shortages of supported accommodation and the implications for people with a disability and/or mental illness in prisons or specialist forensic services.

11.9   No accommodation

The Committee also was told about the experiences of people with a disability and/or mental illness who had no accommodation options and who would be classed as homeless. This included primary, secondary and tertiary homelessness. The options for people with a disability and/or mental illness in these circumstances include living on the streets, and using crisis and transitional services in the Supported Accommodation and Assistance Program.

Research suggests that individuals with a mental illness remain homeless for longer periods than other groups.[815] Factors such as social attitudes towards mental illness, difficulty in meeting labour and housing market demands, and the extent of family support shape the experiences of individuals on the homeless pathway. Evidence provided by organisations and individuals highlighted the outcomes for individuals with a disability and/or mental illness experiencing homelessness.

HomeGround stated that people with a mental illness who experience homelessness often live in tertiary homelessness and experience a high level of violence, abuse and deterioration in their health and wellbeing.[816] Some individuals with a mental illness may experience cycles of homelessness where they move through various forms of tenuous accommodation and periods of living on the streets.[817] Hanover Welfare Services explained that repeated attempts at establishing adequate housing contribute to accumulated trauma, which compounds poor mental health and persistent homelessness.[818]

People with a disability are also at risk of homelessness. Hanover Welfare Services maintained that this could be due to domestic and family violence, which are critical drivers of homelessness, as well as the lack of affordable accommodation and support options.[819] The organisation suggested that the

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[815]   Johnson, G., Gronda, H. & S Coutts, S. (2008) *On The Outside: Pathways In and Out of Homelessness.* Australian Scholarly Publishing, North Melbourne, p.14.

[816]   *Submission* 71, p.5 (HomeGround).

[817]   *Submission* 69, p.2 (Hanover Welfare Services); *Submission* 68, p.2 (C. & G. Paton).

[818]   *Submission* 69, p.2 (Hanover Welfare Services).

[819]   *Submission* 69, p.2 (Hanover Welfare Services).

lack of accommodation and support puts people with a disability at risk of returning to SAAP.

The Committee will further explore the issue of homelessness and appropriate housing in its Inquiry into the Adequacy and Future Directions of Public Housing, due to be tabled on 30 September 2010.

Chapter Twelve:
Alternative supported
accommodation options

Committee findings

- That alternative models of supported accommodation can contribute to an increased range of options for people with a disability and/or mental illness.

- That the key to developing alternative models of supported accommodation is to ensure the greatest level of choice for people with a disability and/or mental illness.

- That participants in the Inquiry drew attention to a range of alternative types of support and accommodation that are used in Victoria, nationally and internationally. **(Sections 12.1—12.3)**

- That while suitable to some population groups, there is no single model of support and accommodation that ought to be promoted over other models. **(Sections 12.1 & 12.2)**

- That there is a continued need for a range of models to suit the diverse needs of people with a disability and/or mental illness. **(Sections 12.1 & 12.2)**

T his chapter explores the range of models of accommodation and support settings that were recommended to the Committee as alternatives to existing models. The Committee heard that there are many models that can potentially meet the diverse needs of people with a disability and/or mental illness. It noted that no one model can meet these diverse needs, but that they can contribute to the broad continuum of possible support and accommodation settings.

The alternative models proposed to the Committee fall into two categories:

- Alternative supported accommodation models
- Alternative approaches to either accommodation (such as housing associations) or support (such as outreach support) for people with a disability and/or mental illness.

The links between accommodation and support are increasingly complex for people with a disability and/or mental illness. This becomes more evident when exploring the alternative options to existing models of supported accommodation.

The Committee heard that a key consideration in the development of alternative models is ensuring the greatest level of choice for people with a disability and/or mental illness. Some models might be seen as cost-effective and others well positioned to achieve policy objectives that promote increased community participation. The underlying message to the Committee, however, was that people with a disability and/or mental illness are diverse in their needs and preferences and should have the same opportunities as others in the community to choose their own living arrangements.

As with other chapters, the alternative options relating to disability and mental illness are discussed separately.

12.1 Alternative options: disability supported accommodation

The Committee heard many suggestions and proposals for alternative approaches to supported accommodation from participants in the Inquiry. These approaches can be broadly grouped into three categories that are based on a 2008 study by the Centre for Developmental Disability Studies (CDDS) into support and accommodation undertaken for the Department of Human Services (DHS). All three options link support and accommodation:

- Village communities
- Cluster housing
- Dispersed accommodation.

12.1.1   Village communities

The village community model provides accommodation for individuals with and without a disability. They were established on strong religious or philosophical foundations and run by non-government organisations, independent of public services. They are typically campus-style arrangements that tend to support more able individuals who have moved from either the family home or residential educational establishments.[820]

Some of the models suggested by participants in the Inquiry included the L'Arche communities, Camphill Village Trust and the Doehaeko Support Network.

L'Arche communities

Some participants referred to the L'Arche communities and recommended that the Committee give consideration to the model. Family carers, Mrs Bernadette Ransom and Mrs Katherine Haggerty, were particularly supportive of the model. Mrs Ransom explained that

> What they were doing in L'Arche communities was living life as a family with adults with intellectual disability in a home environment. When our other children leave home, they would go to their own homes, and that is what I would like for our son.[821]

L'Arche communities were established in France in 1964 by Jean Vanier. L'Arche is a federation of faith-based communities spread throughout 35 countries, where people with and without a disability share their lives in homes, workshops, and day programs. The objective of L'Arche communities is to offer people with a disability a family-style living environment that encourages them to create a home, to develop individual talents, and build relationships with other people in the community.

L'Arche communities work to support people with an intellectual disability to take their rightful place in the community and society. The aim of the communities is to create an environment that welcomes people with an intellectual disability and those who choose to live with them or support them.

Camphill Village Trust

The first Camphill community was founded in 1939 in Scotland by Dr Karl Koenig. Inspired by the works of the philosopher and educator, Rudolf Steiner, Camphill communities were established to work with children with developmental disabilities.

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[820]   Emerson, E. (2004) 'Cluster housing for adults with intellectual disabilities'. *Journal of Intellectual and Developmental Disability,* Vol. 29(3), September, p.188.

[821]   *Committee Transcript*, 19.11.08, p.2 (B. Ransom & K. Haggarty).

Camphill villages aim to offer opportunities for people with learning disabilities and other special needs to live, learn and work with others of all abilities in an atmosphere of mutual care and respect, based on Christian values. The villages include independent residential and day schools, specialist colleges of further education and adult communities. The size of the community varies and communities are located in a range of settings.

One carer told the Committee that the Camphill model was impressive given that both residents and staff were very happy and satisfied in their lives, work, and social activities.[822]

Deohaeko Support Network

Other participants in the Inquiry requested that the Committee explore the Deohaeko model. Interchange Central Gippsland suggested that this model is successful as it has:

> gathered families together and actually built appropriate accommodation according to what they like. But they have also contributed to the families, but so have the Government contributed to it. And it's actually community supported as well, with university students living there with free rent, etcetera, but they support the person with the disability.[823]

The Deohaeko model is an intentional community in which people with a disability live with people of all abilities. The model was established in Toronto, Canada in 1988 by a group of families who did not want a residential service for their children with a disability.

The model has a family-governed, person-centred approach in that Deohaeko supports only a small number of people. Families hire support people specifically for their family member. A coordinator works for their whole group, as well as for each individual and family. The coordinator assists families to deal with times of transition and change.

Family governance model

The concept of a family governance model was suggested by a number of participants in the Inquiry. [824] The detail of this model and its operation was not outlined in detail, but did appear to be based on similar features to the Deohaeko Support Network. Features of the model include families investing in accommodation for their family member, families having their own individual support pages (ISP) and employing their own staff to support their family member with a disability.

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[822] *Submission* 2, p.1 (J. Spiers).

[823] *Committee Transcript*, 21.10.08, p.6 (Interchange Central Gippsland).

[824] *Committee Transcript*, 23.10.08, p.2 (M. Kuchenmeister); *Committee Transcript* 23.10.08, p.14 (Karingal).

Mrs Stephanie Mortimer, from the Concerned Individuals and Parents Advocacy on Intellectual Disability group, provided one example of this model to the Committee. She explained that she has an ISP to provide care for her sister who has a dual disability. Based on a family governance model, Mrs Mortimer has been able to employ staff and use a service provider as an intermediary for a fee.[825] Her staff provide invoices for the work they have done. Mrs Mortimer told the Committee that 'this model is called family governance and has been available through the department for over 10 years but is not promoted. This model allows flexibility, and the money in the package goes about three times the distance'.[826]

Individuals and groups told the Committee that there are parents who would like to contribute to accommodation and support for their children. Ms Leigh, who is a parent carer and a client of Karingal, said that one model is where a group of parents pool their funds and build a home for their family member with a disability. She explained to the Committee that the important part of this arrangement would be the provision of support, which could be through DHS or a NGO service provider.[827] Ms Leigh argued that: 'It is a contribution that I do not think is used widely enough, but I think … there will be a lot of parents who would be willing to contribute financially'.[828]

The Committee heard that the success of the family governance model is dependent on reaching an agreement on issues regarding shared equity, ownership, and partnerships with support organisations.[829]

One organisation that worked with both individuals and organisations to provide flexible accommodation options for individuals with a disability was Singleton Equity Housing Ltd. Established in 1989, Singleton Equity Housing provided accommodation to individuals with a disability, while care and support services required by an individual were provided separately by approved support service providers, funded by DHS. Singleton Equity Housing bought and managed properties that were occupied by individuals with a disability.

This model is based on the shared or mixed equity concept involving a combination of funds from residents, the accommodation provider and the state government and a partnership arrangement with a number of individuals and organisations.[830] The original theory of this model was that residents and/or their families would be shareholders. Some residents might be sponsored

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825   *Committee Transcript*, 22.1.08, p.2 (S. Mortimer).

826   *Committee Transcript*, 22.1.08, p.2 (S. Mortimer).

827   *Committee Transcript*, 23.10.08, p.14 (Karingal).

828   *Committee Transcript*, 23.10.08, p.14 (Karingal).

829   *Committee Transcript*, 23.10.08, p.14 (Karingal).

830   Housing Choices Australia website. Accessed from <http://hcau.org.au> on 2 September 2009.

through an investment from a third party and the residents enjoy occupancy rights as a nominee of the ethical investor.[831]

Singleton Equity Housing Ltd has merged with Housing Choices Australia. Housing Choices Australia is a housing association which provides affordable housing to low and moderate income earners.

Housing Choices Australia explained to the Committee that the mixed equity is a

> program where we contribute to the funds, the Office of Housing contributes to the funds and generally family, but sometimes a person with a disability contributes funds. It is quite a targeted program…
> One of the conditions to get into the program is that they have got to be assessed as needing support to live in the community; and they have got to have that support in place…
> It is a program that is very resource intensive… we would anecdotally say that we would work with 30 families who express an interest before one of them feels that this is the right move for them…[832]

Research into village communities

Comparative research on village communities, residential campuses and dispersed communities suggests that the village community model ranks equal with dispersed community houses across a number of quality indicators.[833] Notably, the research emphasises that the communities identified in the research were not developed as a direct result of institution closure or downsizing. Most models of the community village are based on the desires of families to provide living options for their family member with a disability in an alternative environment to residential care.

Based on this research, the CDDS suggested 'that village communities should remain as an option for people with disability, as long as the person and their family choose the option'. [834] CDDS recommended, however, that:

> Intentional/village communities are not seen as an option for the process of devolving congregate-care facilities. The success of these communities appears as a result of their having evolved from a religious or faith-based foundation.[835]

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[831] Housing Choices Australia website. Accessed from <http://hcau.org.au> on 2 September 2009.

[832] Committee Transcript, 30.4.09, pp.8-9 (Housing Choices Australia).

[833] Emerson, E. (2004) 'Cluster housing for adults with intellectual disabilities'. *Journal of Intellectual and Developmental Disability,* Vol. 29(3), September, p.188.

[834] Centre for Developmental Disability Studies (CDDS) (2008) *Disability Accommodation and Support Framework Report.* Prepared for the Department of Human Services, Victorian Government, p.37.

[835] CDDS, *Disability Accommodation and Support Framework Report*, p.37.

In view of the small number of proposed models and the contradictory research findings, the Committee did not consider it could make any recommendations relating to the village community models as an alternative to existing models.

12.1.2   Cluster models

The Committee heard from a significant number of participants regarding the cluster model of accommodation. There were mixed views regarding cluster models for people with a disability, with some participants supporting an increase in their availability and some expressing reservations arising from particular research that found cluster living imposed constraints on social inclusion.

Cluster models are a type of accommodation located either as part of a campus development (three or more houses with onsite day centre) or in a group of homes for people with intellectual disabilities (for example, a cul-de-sac with three or more houses).[836] Research suggests that in the context of institutional closure, the cluster model has been a favoured model, particularly by families. One example of this model is the Plenty Residential Services (PRS) development in Victoria, outlined by Christine Bigby as a 'cluster housing development for 100 residents, … built … as part of the closure program of the Janefield institution'. [837]

Examples of cluster models some participants supported included Fern River in Western Australia[838] (group of six units staffed by care support workers providing permanent care), Octagon Community Housing[839] (six individual units set out in an octagon-shaped arrangement around a communal kitchen, living area and laundry), and aged care facilities such as Waldreas Lodge.[840]

While many families supported cluster living arrangements, there were also arguments put to the Committee in opposition to the model and to specific examples of this model. For example, Christine Bigby expressed reservations about PRS, suggesting that a 'significant cultural and attitudinal change' is needed to address its 'institutional nature'.[841] In addition, a network of self-advocacy organisations (VALID, Reinforce, STAR and AMIDA) that advocate for people with an intellectual disability believe cluster models of accommodation do not promote community participation or social inclusion and should therefore not be considered by the Committee. They suggest that the debate continues to be

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[836]   Emerson, 'Cluster housing for adults with intellectual disabilities', p.190 [see Footnote 833].

[837]   Bigby, C. (2004) 'But why are these questions being asked?: a commentary on Emerson (2004)'. *Journal of Intellectual and Developmental Disability,* Vol. 29(3), September, p.203.

[838]   *Committee Transcript* 5.11.08, p.7 (Young People in Nursing Homes).

[839]   *Submission* 2, p.2 (J Spiers).

[840]   *Submission* 3, p.3 (S. Mortimer); *Committee Transcript* 22.10.08, p.3 (CIPAID).

[841]   Bigby, 'But why are these questions being asked?', p.203 [see Footnote 837].

about the potential benefits of living in cluster housing particularly for groups labelled as having challenging behaviour or with severe or profound impairments. The driving force behind much of the debate is not so much the advantages of larger scale living, but rather the failure of small group homes to match expectations and deliver community inclusion.[842]

This view is consistent with research undertaken by Eric Emerson in 2004. He states that residents in cluster living arrangements were more likely to be:

- supported by fewer staff

- exposed to greater changes/inconsistencies in living arrangements

- exposed to more restrictive management practices (seclusion, sedation, physical restraint)

- living more sedentary lives and be underweight

- participating in fewer leisure, social and friendship activities.[843]

Furthermore, Emerson's research found that 'assumptions that cluster housing can provide a "connected" community of people with intellectual disabilities were not supported'.[844]

In its report to the DHS, the CDDS took on board these research findings and made the following recommendation:

> That serious consideration should be given to the configuration of supports provided, in cluster housing arrangements, before embarking upon this approach. Existing evidence indicates poorer outcomes for people with a disability living in cluster housing as against dispersed housing.[845]

In view of the mixed findings throughout the Inquiry, the Committee supports the recommendation of CDDS. The Committee considers it is important to have a range of options for people with a disability, but that the development of future cluster living arrangements needs to be pursued in consultation with people with a disability.

12.1.3   Dispersed accommodation

Dispersed accommodation is defined as housing for people with a disability that is located among the community of people of all abilities and without regard to the location of accommodation for other people with a disability.[846] Dispersed accommodation includes apartments and/or houses of the same type and size as

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842   *Submission* 106 p.15 (VALID, STAR, Reinforce, and AMIDA).

843   Emerson, 'Cluster housing for adults with intellectual disabilities', pp.192-95 [see Footnote 833].

844   CDDS, *Disability accommodation and support framework report*, p.39.

845   CDDS, *Disability accommodation and support framework report*, p.40.

846   Burbidge, A. (2002) *Accommodation models discussion paper.* Office of the Public Advocate, Melbourne, p.3, Accessed from <http://publicadvocate.vic.gov.au/file/file/Research /Discussion/ 2002/Accommodation_Models.pdf> on 10 October 2009.

houses that the majority of the population live in, scattered throughout residential neighbourhoods among the rest of the population.

This model evolved in the 1960s and 1970s. Early examples of dispersed accommodation supported people with less severe disabilities, but by the 1970s, examples were beginning to be developed for people with more severe disabilities.[847] From the early 1980s, there was rapid development of dispersed accommodation to replace institutions.

In Victoria, the closure of institutions has led to a significant increase in dispersed accommodation models. The shared supported accommodation (SSA) model, formerly known as Community Residential Units (CRUs), is a form of dispersed accommodation. As highlighted throughout the report, there is significant support for the SSA model for people with a disability. While concerns have been raised about the need for SSA to adapt more effectively to changing support practices, VALID, STAR, Reinforce and AMIDA suggest that 'shared supported accommodation is not a defunct model but one that holds significantly more potential than is currently realised in Victoria'.[848]

A number of individuals and organisations providing evidence also highlighted the 'key ring' model, suggesting that the government needs to further explore the model and to consider adopting it as an additional option within the existing range.[849] The 'key ring' approach to providing accommodation and support was developed in the United Kingdom and has been reported as a successful model. In its *Housing Options Unlocked* guide, DHS advises that Marillac House has licensed the rights to this model in Australia, with 'KeyRing' being the licensed name.

National Disability Services suggested the KeyRing model provides important links and supports to a group of people living independently in the community.[850] HACSU also argues that this model is worthy of consideration for future alternative options:

> This model allows for flexibility in living arrangement (shared/single), caters to the individual needs (twice daily support up to monthly support) and can also accommodate individuals with some high support needs in some circumstances. This model is a useful component of a service system for some people with disability and needs to be considered.[851]

The KeyRing model is based on establishing a number of people with a disability (nine is considered optimal) in accommodation within a defined

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[847]   National Disability Authority website. Accessed from
        <http://www.nda.ie/cntmgmtnew.nsf/0/292BC9700CF60D7C802575BD003C1CD4/$Fil
        e/housing_review_03.htm> on 10 October 2009.

[848]   *Submission* 106 p.17 (VALID, STAR, Reinforce, AMIDA).

[849]   For example, see *Submission* 120 (NDS); *Committee Transcript*, 5.11.08 (HACSU); *Submission*
        111 (I. Spicer); *Submission* 118 (Marillac House).

[850]   *Submission* 120, p.6, (NDS).

[851]   *Submission* 121B, p.17 (HACSU).

neighbourhood area. Ten properties are scattered around a small neighbourhood, making them easily accessible by individuals living in each property. Nine of the properties belong to people with a disability, who have assured tenancies or own their own property. The tenth property is occupied by KeyRing's Care Manager, who supports the members on a flexible basis and who may be a volunteer. This arrangement enables varying levels of support to be built around the network members.

People in the 'ring' receive their individual disability supports as required and have the additional assistance of a worker who lives within the same area and who is able to provide accommodation support and links to other members of the group. KeyRing is generally a low support option for people with a disability. The flexibility of support enables the support worker to provide support when the member needs it. While personal care is not provided, the Care Manager of KeyRing can develop additional support external to the organisation.

The Committee visited KeyRing's licence holder, Marillac House, on 24 September 2008, and also received from it a written submission to the Inquiry, although this did not specifically discuss its views on the key ring model.

Based on the broad support for this model, the Committee considers there is potential for further pursuing the development of this model of dispersed accommodation. In view of its low support nature, however, the Committee considers that the key ring model can be considered as one option within an ideal range of options that can meet the diverse needs of people with a disability.

Recommendation

12.1   That the Victorian Government further develops and expands evaluated variations on the KeyRing model to contribute to a broader range of options of supported accommodation for people with a disability that enhances their opportunities for community participation.

Choice and inclusion

The self-advocacy network suggested to the Committee that the critical point in considering alternative models is to ensure that people with a disability have choice and that there is consultation about the development of new models:

> There is no one housing and support model that can work as a blanket solution for all people with intellectual disabilities. A careful and detailed policy response should be taken to improve existing models and to introduce new ones in a way that is inclusive and effective.

The Committee heard this argument consistently.

Recommendations

12.2   That the Victorian Government pursues and funds alternative models of supported accommodation to increase the range of options available to people with a disability and/or mental illness where evidence shows that people with a disability and/or mental illness will benefit from the model.

12.3   That the Victorian Government identifies and, where possible, removes regulatory barriers in developing alternative models of supported accommodation that are operated externally from government.

12.2 Alternative options: mental health supported accommodation

Options for supported accommodation are significantly different in the mental health sector. Similarly to the disability sector, the participants in the Inquiry proposed a range of alternative models of supported accommodation for individuals with a mental illness.

As discussed in Chapter Eight, participants highlighted to the Committee the benefits of existing programs such as home-based outreach support (HBOS) and the former housing and support program (HASP). While a variation on the HASP continues in the form of nomination rights for HBOS services, the Committee heard several arguments for the expansion of this program.

In considering alternative models, there is value in looking at models in other states, such as the Housing and Support Initiative (HASI) in NSW and Project 300 in Queensland. These are discussed in Chapter Six.

12.2.1 Cluster accommodation

As previously outlined, cluster accommodation is housing in a campus-style setting or group homes. Many individuals and organisations gave evidence suggesting that cluster accommodation would be a suitable alternative housing and support option for individuals with a mental illness. As FamilyCare point out, the cluster housing model has been adopted by the disability sector but the advantages of the group setting or supported accommodation would be beneficial if developed in the mental health sector.[852] FamilyCare told the Committee that this model would enable family units to remain together whilst the individual received treatment.[853]

The Homeless Outreach Psychiatric Service told the Committee that a cluster of units with a common room and kitchen, with staff on site from 9 a.m. to 5 p.m. would be helpful in addressing the gaps between HASP and supported

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[852]   *Committee Transcript* 18.11.08, p.12 (FamilyCare).
[853]   *Committee Transcript* 18.11.08, p.12 (FamilyCare).

residential service (SRS) accommodation. Despite the success of HASP, the Homeless Outreach Psychiatric Service maintain that 'clients of HASP properties do not always receive the level of support required, but are not yet ready for residential support where they become deskilled and dependent'.[854]

The organisation CHUMS proposes a cluster accommodation model in order to address the lack of supported accommodation for people with a mental illness. The aim of the 'lifestyle units' are to create an environment for individuals with a mental illness who are unable to continue living in their home but are capable of living a fulfilling life with the support of care workers.[855] The cluster accommodation approach proposed by CHUMS is based on the octagon model outlined earlier in this chapter.

The issues raised in research on cluster accommodation in the disability sector need also to be considered with regard to the mental health sector. Further research into cluster accommodation as an adequate housing and support option for individuals with a mental illness is necessary.

12.2.2   Supportive housing

Supportive housing was developed in the United States in the early 1990s. It has been effective in ending homelessness for individuals with complex needs. Following the success of overseas programs such as Home First and Pathways to Housing, supportive housing has been introduced in Australia, including the Elizabeth St Common Ground development in Melbourne.

The Elizabeth St Common Ground seeks to reduce the number of chronically homeless by providing a place where services are contained on the one site and support is provided in relation to mental health services, employment assistance and medical referrals.

The Elizabeth St Common Ground is a supportive housing partnership between State and Federal governments, Yarra Community Housing, HomeGround Services, and the developer Grocon. The model will provide accommodation for 131 supported tenants and 30 tenancies to low income earners.

Yarra Community Housing will own the building and manage tenancies while HomeGround will provide all onsite support services in the areas of health, law, education, recreation and wellness, and 24 hour security and concierge services.

The Victorian Government has committed approximately $44 million to the Elizabeth St development as a part of the government's response to the affordable housing shortage and to homelessness and disadvantage. The Federal Government has committed a further $12.5 million to the project under its *A*

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[854]   *Committee Transcript* 23.10.08, p.6 (Homeless Outreach Psychiatric Service).
[855]   *Submission* 88, p.1 (CHUMS).

Place to Call Home initiative.[856] The support services within the building have been allocated $3.1 million over four years by the Victorian Government.[857]

The fundamental factor in supportive housing is the combination of long-term tailored support and long-term quality, affordable housing. Supportive housing allocates accommodation to people with a mental illness with their own apartments and offers intensive and individualised social and clinical support services that address the diverse needs of individuals.[858] It incorporates flexible tenancy management and has an emphasis on community integration and reduction of social isolation. Studies have found that the supportive housing model has reduced the use of other more expensive emergency and crisis services.[859]

HomeGround suggest that the combination of accommodation and support can assist people to stabilise and recover from mental health issues and homelessness. In their submission to the Inquiry, HomeGround told the Committee that supportive housing has 'specifically designed features to offer safe, permanent and affordable housing with access to on site support services to people who would otherwise remain chronically homeless and at serious risk of damage to their health and wellbeing'.[860]

Both research and Inquiry evidence suggests, therefore, that supportive housing is a viable approach to accommodation and support for individuals with a mental illness. The Committee supports the Victorian Government investment in the Elizabeth St supportive housing development.

As noted in Chapter Eleven, the Committee will explore issues relating to housing further in its Inquiry into the Adequacy and Future Directions of Public Housing in Victoria. The Committee will report on its findings to the Parliament of Victoria by 30 September 2010.

12.3   Housing associations

Housing associations were another alternative option suggested in the evidence provided to the Committee. Housing associations provide accommodation to low and moderate income earners. Housing Associations own and manage stand-alone properties, accommodation with onsite support, and medium density accommodation and flats. The associations manage and develop new accommodation opportunities and manage rental housing portfolios.

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[856]   Elizabeth St Common Ground website. Accessed from
         <http://www.elizabethstcgsh.org.au/partners.htm> on 25 September 2009.
[857]   HomeGround Services website. Accessed from <http://www.homeground.org.au/page-77-
         82-ElizabethStreetCommonGround.htm> on 25 September 2009.
[858]   Mental Health Council of Australia (2009) *Home Truths: Mental health, housing and homelessness
         in Australia.* Deakin, p.29.
[859]   HomeGround Services. *Supportive Housing,* Accessed from <http://www.homeground.
         org.au/page-77-99-Evidence.htm> on 25 September 2009.
[860]   *Submission* 71, p.7 (HomeGround Services).

Non-profit housing organisations can register as a housing association in order to develop and manage affordable housing.[861] Housing organisations are obliged to register in order to manage properties owned by the State or to receive State funding. Housing associations also have the ability to leverage capital through partnerships with private and philanthropic organisations and local government.

Housing associations operate tenancies under the *Residential Tenancies Act 1997* and undertake property and tenancy management. The regulation of housing associations was introduced in January 2005 under a new *Part VIII* to the *Housing Act 1983*. The regulation holds organisations accountable for their use of public funds and private investments to develop and provide affordable housing for Victorians.[862]

The accommodation provided is typical of community housing which blends into the wider community. Support is provided by partner agencies, such as those working in the disability, mental health, and aged care sectors. The aim of a housing association will generally be to have a mixed tenant profile where tenants with higher incomes, in effect cross-subsidise tenants on lower incomes.[863] Housing Choices Australia told the Committee that they procure properties through spot purchase, house and land purchases, and the association builds and develops properties themselves.[864]

One housing association, the Disability Housing Trust, recognised that people with a disability should have the same opportunities as other people in the community. The Trust was established to enable people with a disability, their families, and a range of organisations to enter into partnering arrangements with the Trust to develop appropriate and affordable housing.[865] The Victorian Government provided an initial capital investment of $10 million to develop accommodation that would provide suitable independent living arrangements to individuals with a disability.[866] The Trust also aimed to attract capital investment through community and family sources and through commercial and philanthropic sources.[867]

The Trust is now part of Housing Choices Australia, which was created from the merging of the Disability Housing Trust, Melbourne Affordable Housing, Supported Housing Ltd, and Singleton Equity Housing Ltd.

[861] Gilmour, T. (2009) 'Network Power: An International Study of Strengthening Housing Association Capacity' Doctoral Thesis. The University of Sydney, August, p.35.

[862] Housing Registrar (2007) *Our regulatory framework*. DHS, Victorian Government, Melbourne, p.4.

[863] Wright-Howie, D. (2004) *Discussion Paper Responding to the Development of Affordable Housing Associations in Victoria*. Council to Homeless Persons, February, p.4.

[864] *Committee Transcript*, 30.4.09, p.4 (Housing Choices Australia).

[865] Housing Choices Australia website. Accessed from <http://www.hcau.org.au> on 10 September 2009.

[866] Department of Human Services website. Accessed from <http://www.dhs.gov.au/ disability/supports_for_people/accommodation/disability_housing_trust> on 10 September 2009.

[867] Housing Choices Australia website. Accessed from <http://hcau.org.au> on 10 September 2009.

In Victoria, there are approximately 5,000 properties currently owned or leased by registered housing associations in a range of locations.[868]

An example of a housing association project includes the recent HomeGround 'supportive housing' initiative under construction in Elizabeth Street, Melbourne, that will build 161 units to house people who are on low incomes or have been homeless. HomeGround explains that the objective of this model is to provide long-term accommodation that ends homelessness permanently for individuals and families. Supportive housing rents are set at a maximum of 30 per cent of tenant income. According to HomeGround, the accommodation is self-contained, high quality housing with controlled access to keep unwelcome visitors out and provides onsite support services that are accessible, flexible and target accommodation stability. The initiative is inclusive of people with a mental illness, but not exclusive. It will aim to house 50 per cent of people who are homeless and 50 per cent on low incomes.

Housing Choices Australia stated that housing associations work to increase the supply of affordable housing to people on the lowest incomes and work in partnership with partner agencies to deliver care and support.[869] They told the Committee that the choices of people with a disability and/or mental illness are limited due to the design, quality, location and cost of accommodation. Housing Choices Australia claimed:

> In the current housing climate there is a lot of competition for low-priced properties. Particularly those people need a combination of property plus care and support linked to them to make accommodation and living in the community viable. The private market traditionally has not responded well to this group. We are a group that is trying to do something about it.[870]

The Victorian Council of Social Service told the Committee that housing associations can provide a valuable alternative to traditional disability supported accommodation options.[871] The Council emphasised that this option needs to be appropriately developed and aligned with government strategies to grow the affordable housing stock through housing associations.[872] Housing Choices Australia told the Committee that due to the funds provided to housing associations in the last State Budget, housing associations have the capacity to deliver SSA.[873] The organisation claimed:

> It is the first time that has been done, and I think it is a useful breakthrough, because we are going to be building developments. We are going to be taking part in big developments that the big developers do — Metricon et cetera. The

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[868]   Department of Human Services website. Accessed from
        <http://www.housing.vic.gov.au/community-and-housing-partnerships/housing-agencies-
        and-cooperatives> on 10 September 2009.
[869]   *Committee Transcript*, 30.4. 09, p.2 (Housing Choices Australia).
[870]   *Committee Transcript*, 30.4. 09, p.2 (Housing Choices Australia).
[871]   *Submission* 96, p.5 (VCOSS).
[872]   *Submission* 96, p.5 (VCOSS).
[873]   *Committee Transcript*, 30.4.09, p.5 (Housing Choices Australia).

more that all sorts of housing is being fed in through us through those bigger developments, the developments we do now, the more we will build good, intentional, inclusive communities. I am not going to pretend that has not started, but let us keep that push going.[874]

A number of organisations, however, expressed their concerns regarding the target group of housing associations. Community Housing Federation of Victoria argued that housing associations are focused on a band of accommodation that caters for individuals who are unable to access private rental but are able to rent affordably. Community Housing Federation stated that housing associations do not target individuals who need support and are on statutory benefits.[875] Similarly, Neami told the Committee that the upkeep of properties would come from rent being collected.[876] The organisation was concerned about what this might mean for individuals with a disability and/or mental illness whose income would not be sufficient to sustain the Housing Associations. Homeground expressed similar reservations:

> We were concerned from day one that housing associations are fairly new in the environment they are operating within and, for all sorts of risk management reasons, would not be housing people who were on the lowest incomes and had the highest risks particularly around rent payments and behaviours.[877]

Homeground argued that a percentage of the funding allocated to housing associations should be made available to ensure the most vulnerable have access to this accommodation. The organisation explained that there is growth in accommodation provided by housing associations and a portion of this housing should be made available to individuals with a disability and/or mental illness.[878]

The Committee anticipates exploring these issues further in its future Inquiry into the Adequacy and Future Directions of Public Housing.

Recommendations

12.4   That the Victorian Government assigns a minimum quota of places to housing associations to be allocated to individuals with a mental illness and/or disability.

12.5   That the Victorian Government increases alternative accommodation options by developing stronger partnerships between Disability Services Division and the Office of Housing.

12.6   That the Victorian Government promotes innovation by creating new and alternative models when investing in supported accommodation in the future.

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[874]   *Committee Transcript*, 30.4.09, p.5 (Housing Choices Australia).
[875]   *Committee Transcript*, 5.11.08, p.6 (Community Housing Federation of Victoria).
[876]   *Submission* 75, p.4 (Neami).
[877]   *Committee Transcript*, 30.4.09, pp.7-8 (HomeGround Services).
[878]   *Committee Transcript*, 30.4.09, p.8 (HomeGround Services).

Appendix: Mental health & disability policy in other states

Other Jurisdictions: Disability

Key policy document/s

ACT   ACT Disability policy framework 2009-2014:

NSW   Stronger together: a new direction for disability services: 2006-2016

QLD   Growing stronger (2007-2011): A four year program of reform to deliver a better specialist disability service system for Queensland

SA   State Strategic Plan
             Supported Accommodation Strategy

NZ   New Zealand Disability Strategy

UK   In the UK, the introduction of significant reforms to the Disability Discrimination Act in 2005 has influenced the strategic approaches to disability policy.

What does the policy document say about supported accommodation?

ACT   The ACT Government is currently updating its policy framework.

             A consultation process on the priorities took place throughout May and June. The group engaged with people with disability, families and carers, service providers, community organisations and Government agencies through public forums, targeted discussions and meetings and through written submissions.

             The Group developed six strategic priorities for the period 2009-14 that underpin the policy framework. The priorities are:

- 'I want the right support, right time, right place'
- 'I want to contribute to the community'
- 'I want to socialise and engage in the community'
- 'I want to know what I need to know'

▪   'I want to tell my story once', and

▪   'I want a quality service system'.

NSW   Stronger together gives a clear commitment to close large residential centres over time.

Where specialist accommodation is required, a range of different dwellings will be available to meet individual needs, locations and changing circumstances. The support provided will be consistent with contemporary accommodation and care standards and will comply with the *NSW Disability Services Act 1993*.

QLD   A strong focus of the Growing Stronger document is the introduction of a person-centred approach to delivering specialist disability services through tailored service responses informed by assessment outcomes.

The central goal of the policy is to consolidate funding programs. Under this system, services will be offered according to a tailored service response designed to maintain or improve a person's capacity.

Since the development of this document, a single application form to access disability services has been released.[879]

SA   *State Strategic Plan:* one of the SA Government's highest priorities is to increase the supply of community-based accommodation for people with disabilities. Specifically, there are plans to double the number of people with disabilities appropriately housed and supported in community based accommodation by 2014.[880]

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[879]   Accessed from <http://www.disability.qld.gov.au/key-projects/growing-stronger/documents/growing-stronger.pdf> on 25 September 2009.

[880]   Accessed from <http://www.sa.alp.org.au/download/now/disabled_policy.pdf> on 25 September 2009.

[881]   Accessed from <http://www.familiesandcommunities.sa.gov.au/DesktopModules/SAHT_DNN2_Documents/Download/633875888930900128/Supported%20Accommodation%20Strategy.pdf> on 25 September 2009.

Supported Accommodation Strategy: The supported accommodation strategy sits alongside the housing plan for South Australia which is aimed at increasing the supply of housing and accommodation opportunities for people in South Australia, including those with a disability. [881]

The policy aims to improve the management, coordination, assessment and provision of supported accommodation to South Australians with a disability by creating:

- a single waiting list
- a single system of service coordination
- service providers to meet service standards
- service based on people's support needs not diagnosis
- a new accommodation act to better ensure that service providers meet acceptable standards.[882]

NZ One of the objectives of the NZ Disability Strategy is to 'create long-term support services centred on the individual'. The government provides disability support services through the Ministry of Health.

Relevant legislation

ACT *Disability Services Act 1991.*

NSW *Disability Services Act 1993*: provides for the funding and provision of disability services

QLD *Disability Services Act 2006.*

SA *Disability Services Act 1993.*

NZ *New Zealand Public Health and Disability Act 2000.*

UK *Disability Discrimination Act 1995.*

Recent/proposed revisions to legislation?

NSW The *Disability Services Act 1993* is currently under review.

QLD The 2006 Act Replaces *The Disability Services Act 1993*. It has introduced a number of changes which safeguard the rights of Queenslanders with a disability. It also strengthens the service delivery requirements for non-government disability

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882 Accessed from
<http://www.familiesandcommunities.sa.gov.au/DesktopModules/SAHT_DNN2_
Documents/Download/6338758889930900128/Supported%20Accommodation%20Strategy
.pdf> on 25 September 2009.

service providers funded by Disability Services Queensland.

SA   Disability SA provides three types of accommodation services:

- Campus-based residential care services
- Community group homes
- In-home support.

These services are complemented by accommodation services operated by non-government organisations.

Access to services is through referrals from Disability SA Regional Community Services to the Accommodation Placement Panel with priority given to people in most urgent need.[883].

UK   The UK approach builds on the concept of 'active citizenship', which involves:

- establishing and maintaining fundamental rights
- ensuring that people with disabilities are included and have a sense of 'belonging'
- enabling people with disabilities to carry out their responsibilities as citizens alongside having reciprocal rights.

Supported accommodation model

ACT   Disability ACT currently provides supported accommodation in 65 households across the ACT. The service is primarily provided in group-shared arrangements for people who have high and complex needs.[884]

NSW   The Department of Aging Disability and Home Care is responsible for funding and directly providing a range of services for people with disabilities in NSW.

In doing this, the Department makes a significant investment in supported accommodation services. This funds primarily three major models of supported accommodation. These are:

- Group homes
- Large residential centres
- In home support.

A Group home is a dwelling for four to six people who have an intellectual disability. It is staffed by residential support workers.

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[883]   Accessed from <http://www.dfc.sa.gov.au/pub/tabId/264/itemId/676/moduleId/979/Supported-accommodation.aspx> on 25 September 2009.

[884]   Accessed from <http://www.dhcs.act.gov.au/disability_act/services> on 25 September 2009.

QLD   The Disability Service Queensland Accommodation Support Service provides houses and units where adults with an intellectual disability share support services and facilities in a community setting, with the support of paid disability service Queensland staff.

A typical household includes three to five people supported by a group of five or six Residential Care Officers.[885]

NZ   A review in 2001 found that more than two-thirds of adults in New Zealand with a disability who are living in residential facilitates lived in rest homes or homes for older people. A further 25 per cent lived in private hospitals.

Long stay residential units (with 10 or more residents) for people with an intellectual, psychiatric or physical disability or multiple disabilities exist separately.

UK   Multi-tiered model:

- Some provisions for housing associations and councils to provide a proportion of accessible housing for people with disabilities.
- Until recently, the *Supporting People* program provided support to a wide target group including those with disabilities living in a range of settings including sheltered or specialist supported housing.
- Sheltered housing (varying levels of care)
- Care homes.

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[885]   Accessed from <http://www.disability.qld.gov.au/support-services/dsq/als.html> on 25 September 2009.

Other Jurisdictions: Mental Illness

Key policy document/s

ACT   Mental health services plan 2009-2014

NSW   New South Wales: A new direction for mental health (2006-2011)

QLD   Queensland plan for Mental Health (2007-2017)

SA   South Australia's Mental Health and Wellbeing Policy, 2009-14
(currently in draft)

NZ   Te Tāhuhu – Improving Mental health 2005-2015

UK   Mental Health National Service Framework

What does the policy document say about supported accommodation?

ACT   The document was formally released on 3 September 2009. It articulates the strategic directions for the development of the ACT mental health sector to the year 2020. The implementation of the plan will be staged with the initial plan guiding change for the first five years. [886]

NSW   Planned increases in the range of services provided by public mental health services in NSW through a financial boost for the Housing Accommodation and Support Imitative (HASI).

QLD   Under the plan, the Queensland Government commits to expanding the continuum of supported housing and accommodation available to people with a mental illness in the community.

SA   The policy will identify that linkages between psychosocial rehabilitation and support packages and secure and affordable long-term housing options are especially important for people with complex needs.

NZ   One of the objectives of this plan is to provide recovery-focused mental health services that provide choice, promote independence and are effective, efficient, responsive and timely. [887]

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[886]   Mental health services plan 2009-2014.

[887]   Accessed from <http://www.moh.govt.nz/moh.nsf/pagesmh/2182> on 25 September 2009.

UK   In 1999, this 10-year mental health services strategy was launched. A new strategy is currently being developed.

This plan focused on appropriate treatment at home, rather than hospital.

Appropriate support for housing is acknowledged to be an important aspect of this

Relevant legislation

ACT   *Mental Health (Treatment and Care) Act 2004.*

NSW   *Mental Health Act 2007.*

QLD   *Mental Health Act 2000.*

SA   *Mental Health Act 2009.*

NZ   *Mental Health (compulsory assessment and treatment) Act 1992.*

UK   *Mental Health Act 2007.*

Recent/proposed revisions to legislation?

ACT   The Act is currently being reviewed to ensure that it is consistent with changes in mental health policy and service delivery.

NSW   The Act maintains the same principles as the *Mental Health Act 1990.*

The revised Act specifies that care and treatment should be designed to assist people with a mental illness or disorder to live, work and participate in the community. Every effort that is reasonably practicable should be made to involve patients in the development of treatment plans and plans for ongoing care.[888]

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[888]   Accessed from <http://www.health.nsw.gov.au/policies/ib/2007/pdf/IB2007_053.pdf> on 25 September 2009.

QLD   Replaces the *Mental Health Act 1974*. It has been drafted to reflect contemporary clinical practice, international, national and state policy directions and broad community expectations.

Ἅ   The Act contains provisions for initiating involuntary assessment, authorising involuntary treatment, independent review of involuntary treatment and patient rights. It provides processes for admission of mentally ill offenders from court or custody and decisions about criminal responsibility where the person has a mental illness or intellectual disability.[889]

SA   The Mental Health Bill 2009 was assented to as an Act by the Governor in Executive Council on 11 June 2009. The Mental Health Act will be proclaimed on 1 July 2010. The Act provides SA with an improved legislative framework that more explicitly articulates the rights of people with a mental illness and facilitates, to the greatest extent possible, their recovery and participation in community life. The act introduces into SA legislation:[890]

- The concept of recovery
- A definition of 'relative' that accommodates the kinship rules of Aboriginal and Torres Strait Islander people
- Provision to work collaboratively with traditional healers.

NZ   In 2006, the Act was amended to include the requirement of clinical/medical practitioners to consult with family. In 2006, the guidelines for the provision of community treatment orders under Section 29 of the Act were also amended. In 2006 and 2009, the Act was amended to include special provisions relating to electroconvulsive treatment (ECT).

UK   The Mental Health Act received Royal Assent on 19 July 2007. It amends the *Mental Health Act 1983*.[891]

Supported accommodation model

ACT   A small number of non-inpatient facilities, including units in the SECU model and others providing longer-term residential support.

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[889]   Accessed from <http://www.health.qld.gov.au/mha2000/> on 25 September 2009.

[890]   Accessed from <http://www.health.sa.gov.au/mentalhealth/Portals/0/bulletin1-mh-sahealth-090825.pdf> on 25 September 2009.

[891]   Accessed from <http://www.dh.gov.uk/en/Publicationsandstatistics/Legislation/Actsandbills/DH_643> on 25 September 2009.

NSW   HASI is a partnership program funded by the NSW government that ensures stable housing linked to specialist support for people with mental illness. HASI is a partnership between the NSW Department of Housing, NSW Department of Health and Mental Health NGOs.

Different HASI housing is provided for different levels of support ranging from high support to low outreach support.

QLD   Residential Recovery program: The support service assists residents in a boarding out or hostel environment to develop their independent living skills. The target group is adults over 18 years of age who have a moderate to severe mental illness and are about to be discharged from inpatient mental health care to boarding house or hostel accommodation or are being actively case managed while living in boarding house or hostel accommodation. Eligibility criteria include an individual agreement to fully participate in a recovery-based support program toward achieving their goal.[892]

SA   The SA Government is committed to collaborating with the not-for-profit sector to deliver affordable housing opportunities for South Australians experiencing mental health issues. To this end, the Housing and Accommodation Support Partnership (HASP) program is being established by SA Health as a part of the Stepping Up reform of the Mental Health Sector.

The HASP program is a partnership between not-for-profit Housing Providers, not-for-profit mental health support providers, and clinical mental health services, to provide additional supported accommodation in metropolitan Adelaide.[893]

NZ   In New Zealand, mental health services are provided by district health boards.

Approaches to supported accommodation appear to vary across district health boards depending on the population.

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[892]   Accessed from <http://www.disability.qld.gov.au/support-services/mental-health/documents/resident-recovery-program.pdf> on 25 September 2009.

[893]   Accessed from <http://www.health.sa.gov.au/mentalhealth/Default.aspx?tabid=119> on 25 September 2009.

UK   Long stay wards: usually in large NHS hospitals (high and medium staffed hospitals)

Low staffed hostels: mostly the private and voluntary sectors (a very few are run by local authority social services departments)

Staffed care homes: the private and voluntary sectors with some local authority social service departments

Group homes: the voluntary sector and local authority social services departments.

Submissions

1	MC Two Pty Ltd
2	Ms Jane Spiers
3	Ms Stephanie Mortimer
4	Ms Jillian Sokol
5	Ms Judi Hollingsworth
6	Ms Lyzette Chislett
7	Dr Leesa Cornthwaite
8	South West Sports Assembly
9	Mr Les Evans
10	Mulleraterong Centre Inc
11	Carers & Parents Support Group
12	Mrs N.B. McNamara
13	Mrs Lois Brown
14	Mrs Julie Burton
15	Mrs Elaine Williams
16	Karingal Inc
17	Mrs Mavis Cam
18	Confidential
19	Noel and Yvonne Russell
21	Paul and Kathleen Moate
22	Western Region Disability Network
23	Ms Elizabeth Bentley
24	Shirley Swallow & Kevin Smith
25	Name withheld
26	Headway Gippsland Inc
27	Maccro
28	Mrs Margaret Stronach
29	Ms Sharon Kelly
30	Mrs Elaine McCaig Farber
31	Elizabeth & Hartmut Grieb
32	Mrs Lesley O'Loughlin-Schultz
34	Mr Alan G. Field
35	Mrs Una Harrington
36	Southern Way Direct Care Services Inc
37	Confidential
38	Ms Mary Margaret Jeannette Shilton
39	Confidential
40	Frank and Anita Lynch
41	Victorian Disability Advocacy Network (VDAN)
42	Beyond Blue
43	Mrs Sue Hillier
44	Ms Belinda A. Fay
45	Gellibrand Residential Service
46	West Wimmera Health Service

47	Summer Foundation
48	Pam & Steven Dick
49	Mackillop Family Services
50	Beverley & Ron Schultz
51	Ms Lisa Chapell
52	Gippsland Carers Association Inc
53	Heather & Tony Tregale
54	Accommodation & Care Solutions
55	Name withheld
56	Barrier Breakers Inc.
57	Brotherhood of St Laurence
58	Care Connect
60	Laurel and Malcolm Clark
61	Carers Vic
62	Centre for Development Disability Health Vic (CDDHV)
64	Member for Gippsland East, Mr Craig Ingram MLA
65	Eastern Access Community Health (EACH)
66	East Gippsland Shire Council
67	Ms Geraldine Behan
68	Christine & Graham Paton
69	Hanover Welfare Services
70	Name withheld
71	Homeground Services
72	Housing Resource and Support Service Inc (HRSS)
73	Name withheld
74	Victorian Disability Advisory Council (VDAC)
75	Neami Ltd
77	Yooralla
78	Mr Max Jackson
79	Inability Possability
80	Mr Anthony Baird
82	Confidential
83	Pam & Mel George
84	Sane Australia
85	Mr Paul Hammond
86	Sue & Simon Waters
87	Mallee Family Care Murray Mallee Community Mental Health Services
88	Chums
89	Mark & Robyn Tonissen
90	Mark & Luke Modra
91	Association for Children with Disability
92	East Gippsland Specialist School
93	Ms Caroline Storm
94	Confidential
95	The Salvation Army
96	Victorian Council of Social Service (VCOSS)
97	Scope Victoria
98	Mental Illness Fellowship Victoria (MI Fellowship)
99	The Victorian Coalition of Acquired Brain Injury Service Providers (VCASP)

100	Office of the Public Advocate (OPA)
101	Peninsula Carer Council Inc
102	Kew Cottages Coalition
103	Frankston/Peninsula Carers Inc
104	St Laurence
105	Wesley Mission Melbourne
106	Star-VALID-Reinforce-Amida
107	Victorian Deaf Society
108	Mr Cliff Stephens
109	Southern Way Direct Care Services Inc
110	Southern Grampians Disability Support Group Inc
111	Mr Ian Spicer AM
112	Inner South Parents and Friends
113	Inner South (Supported Residential Services) Network
114	Dr Jane Tracy
115	Ms Jean Marinovic
116	Mrs Karen Thomas
117	Kyeema Centre Inc
118	Marillac House Limited
119	NorthWestern Mental Health
120	National Disability Services (NDS) Victoria
121A	Health and Community Services Union (HACSU) – Mental Illness Services
121B	Health and Community Services Union (HACSU) – Disability Services
122	Forensicare
123	Maroondah City Council
124	Melbourne City Mission
125	Mental Health Legal Centre Inc
126	Mind
127	Moonee Valley City Council
128	Ms Morag Campbell
129	Ms Margaret Ryan
130	St Vincent's
131	Cottisfield Supported Accommodation
132	Mr Matthew Potocnik
133	Confidential
134	Rumbalara Aboriginal Cooperative Ltd
135	Ms Lynette Douglas
136	Scope

Witnesses

Public Hearings

The Committee held the following Public Hearings around the State:

Date	Venue
21 October 2008	Traralgon/Morwell
22 October 2008	Melbourne
23 October 2008	Geelong
5 November 2008	Melbourne
6 November 2008	Mildura
18 November 2008	Shepparton/Mooroopna
19 November 2008	Bendigo
20 November 2008	Ballarat
10 December 2008	Melbourne
30 April 2009	Melbourne
25 August 2009	Melbourne

Witnesses

Traralgon – 21st October 2008

Barrier Breakers
Director, Mr Derek Amos
Central Gippsland Aboriginal Cooperative
Social Emotional Wellbeing Coordinator, Ms Nina McDonough-Monahan
Interchange Central Gippsland Inc
Member – Committee of Management and Family Liaison Officer, Ms Helen Johnson
SNAP Gippsland Inc
Chief Executive Officer, Ms Chris McNamara

Morwell – 21st October 2008

Dawn Accommodation, South Gippsland
Ms Heather Canning
Gippsland Carers Association Inc
President, Ms Jean L. Tops
Individuals
Ms Lyn Douglas
Ms Mary Kooloos

Melbourne – 22nd October 2008

Carers Victoria
Program Manager, Policy & Research, Ms Gill Pierce
Policy Advisor, Ms Leigh Hillman
Policy Advisor, Mr Ben Ilsley
CIPAID Inc
Treasurer, Mrs Stephanie Mortimer
Health and Community Services Union (HACSU)
State Secretary, Mr Lloyd Williams
Kew Cottages Parents Association
Executive Officer, Ms Louise Godwin
Vice President, Mr Jim Scully
MC Two Pty Ltd
Mr Joseph Connellan
Yooralla
Deputy Chief Executive Officer, Ms Marsha Sheridan
Eastern Region Manager, Individual Support Services, Ms Michelle Sproule
Individuals
Mr Tony Baird
Mrs Mary Dight
Mrs Nellie McNamara
Mrs Mary Margaret Shilton
Mr Tony Tregale
Mrs Heather Tregale

Geelong – 23rd October 2008

Homeless Outreach Service, Pathways Rehabilitation and Support Services Inc
Clinical Co-ordinator, Ms Karen Spinks
Housing & Support Worker, Ms Raquel Wright
Housing & Support Worker, Homeless Outreach Psychiatric Service,
Mr Neville Braybrook
Barwon disAbility Resource Council
Executive Officer, Ms Carol Okai
Advocate, Ms Glenda Laby
Board Member, Ms Sharron Cropley

Karingal
Chief Executive Officer, Mr Daryl Starkey
Manager, Mental Health Support Branch, Community Living, Ms Jenny Porter
Manager, Assisted Residential Care Support, Ms Jacqui Pierce
Client, Ms Dot Leigh
Gateways Support Services
Chief Executive Officer, Ms Rosemary Malone
Resident, Kate
Mother of Kate, Marianne
Resident, Ms Janeen Blackmore
Mother of Janeen Blackmore, Ms Judy Blackmore
Geelong South Public Tenants Group
Ms Patricia Norman
Ms Janet Lonzarich

Bayview Disability Services (McKillop Family Services)
Program Manager, Mrs Heather Cooney
Direct Care Worker, Disability Services, DHS
Name withheld
Individuals
Ms Alison McArthur
Ms Donna Francis
Mrs Marie Kuchenmeister

Melbourne – 5th November 2008

Community Housing Federation of Victoria (CHFV)
Policy and Projects Officer, Mr Chris Chaplin
Office of the Public Advocate (OPA)
Public Advocate, Ms Colleen Pearce
Policy & Education Manager, Policy & Research, Ms Janine Bush
National Disability Services (NDS)
State Manager, Ms Kerry Presser
Senior Policy Advisor, Ms Sarah Fordyce
Vice Chair, Ms Liz Bishop
Health and Community Services Union (HACSU)
State Secretary, Mr Lloyd Williams
Assistant State Secretary, Ms Denise Guppy
Disability Support Professional, Mr Patrick Nuzum
Mental Health Practitioner, Mr Graeme Doige
Disability Support Professional, Ms Angela Landmann
Young People in Nursing Homes National Alliance
National Director, Dr Bronwyn Morkham
Policy & Community Partnerships Manager, MS Australia, Mr Alan Blackwood
Chief Executive Officer, Huntington's Disease Association, Ms Ruth Hertan
Peninsula Carer Council
Secretary, Ms Aline Burgess
Member, Ms Nyrie Linder
Member, Ms Carmel Jackson
Member, Assoc. Prof. Richard Newton
Inner south Parents & Friends Mental Health Support Group
Co-Chair, Ms Penny Lewisohn
Co-Chair, Ms Judith Rafferty
Individuals
Ms Caroline Storm
Confidential
Confidential
Confidential
Confidential
Mr Matthew Potocnik
Ms Andrea McGuinness
Ms Sue Stevens

Mildura – 6th November 2008

Murray Mallee Community Mental Health Services
Manager, Ms Cath Murphy
Community Support Worker, Mr B. Janson
Team Leader, Home Based Outreach, Ms Deb McManus
Community Service Worker, Ms Laura Parente
Director, Clinical Mental Health, Mr David Kirby
Sunraysia Residential Services
General Manager, Mr George Ramm
Planning & Support Services Manager, Ms Sue Hermans
Mr Peter Herriman
Mallee Accommodation and Support Program
Executive Officer, Mr Doug Tonge
Annecto
Program Manager, Loddon Mallee Region, Mr Jason Minter
Coordinator, Carer & Community Support Services, Ms Annelies Strietman

Shepparton – 18th November 2008

Carers and Parents Support Group Inc
Co-ordinator, Ms Sally Martin
Ms Bev Schultz
Ms Elaine Williams
Shepparton Access
Chief Executive Officer, Ms Wendy Shanks
GV Centre Disability Services
Finance Officer & Acting Chief Executive Officer, Mr John Clements
Residential Manager, Mr Mark O'Brien
Regional Information and Advocacy Council (RIAC)
Advocacy Team Leader, Ms Wendy Mitchell
FamilyCare
Director, Service Development, Ms Angela Armstrong-Wright
Goulburn Valley Area Mental Health Service
Manager, Adult Mental Services, Ms Christine McDougall
Clinical Manager, Ms Annette Stephens
Psychiatric Services Officer, Ms Carmen Trimboli
Confidential (Organisation)
Individuals
Confidential

Bendigo – 19th November 2008

Bendigo Health Care Group
Team Leader Southern Sector – Psychiatric Services, Mr Eugene Meegan
Loddon Mallee Support Services
Support Manager, Mr Peter McLean
Case Manger – Outreach Support Team, Mr Bradley Quinn
Golden City Housing Services
Chief Executive Officer, Mr Ian McLean

Mind, Bendigo
Program Manager, Mr Ray Butler
Consumer, Ms Kylie McDonald
Interchange Loddon Mallee Region
Chief Executive Officer, Ms Joolee Hughes
Program Manager, Mr Steve Mitchell
Individuals
Confidential
Name withheld
Mrs Bernadette Ransom
Mrs Katherine Haggarty

Ballarat – 20th November 2008

APROTCH-Ballarat Community Health Centre
Chief Executive Officer, Ms Robyn Reeves
Mental Health Co-ordinator, Ms Marilyn Gayle
Ballarat Health Services
Manager, Ballarat Adult Community Psychiatric Services, Ms Tamara Irish
Grampians Community Health Centre
Balgartnie, PDRSS Ararat, Ms Marian Corbett
Hillview Lodge
Proprietors: Mr Gerard Leehane & Ms Beverley Leehane
Individuals
Ms Nancy Hotchin
Mr Tony Tregale
Mrs Heather Tregale

Melbourne – 10th December 2008

Department of Human Services
Executive Director, Mental Health Branch and Drug Division, Ms Gill Callister
Executive Director, Disability Services Division, Mr Arthur Rogers

Melbourne – 30th April 2009

Action on Disabilities within Ethnic Communities (ADEC)
Chief Executive Officer, Ms Licia Kokocinski
Advocacy Manager, Ms E. Ignys
Direct Client Services Manager, Ms W. Chau
Spectrum Migrant Resource Centre
Housing Expert, Aged & Disability Team, Ms Nadereh Edwards
Victorian Transcultural Psychiatry Unit
Director, Mr Associate Professor Harry Minas
Manager, Mr D. Oehm
Victorian Aboriginal Community Controlled Health Organisation (VACCHO)
Senior Policy Officer, Mr Timothy Moore
Spiritual & Emotional Wellbeing Coordinator, Ms N. Cassar
Victorian Mental Illness Awareness Council (VMIAC)
Director, Ms Isabell Collins

Housing Choices Australia
Business Development Manager, Mr Chris Glennen
Board Member, Mr Brian Howe
VICSERV Psychiatric Disability Services of Victoria
Chief Executive Officer, Homeground Services, Mr Stephen Nash

Melbourne – 25th August 2009

Office of the Disability Services Commissioner
Disability Services Commissioner, Mr Laurie Harkin

Site Visits

As part of this Inquiry the Committee visiting the following facilities:

Site	Location
Prevention and Recovery Care Unit (PARC)	South Yarra
Milford Hall, Supported Residential Services (SRS)	Armadale
Canterbury Community Care Units (CCU)	Canterbury
Edith Pardy House, Residential Rehabilitation	Albert Park
Austin Hospital, Secure and Extended Care Units (SECU)	Heidelberg
Marillac Accommodation Services, Group Home	East Brighton
Sandhurst Centre, Congregate Care	Bendigo
Gateways Support Services	Geelong East

MINORITY REPORT

Inquiry into Supported Accommodation for Victorians with a Disability and/or Mental Illness

The Coalition initiated this inquiry in the Legislative Council based on the importance of appropriate accommodation for people with a disability and/or mental illness and the clear and evident failure of the Brumby Government to adequately address the issue. While we support the extensive recommendations made by the Committee, we have a number of concerns relating to the lack of urgency to solve the issues in the report, especially in the Executive Summary and also the Government's overall lack of responsiveness to this inquiry.

Summary of Recommendations

The Coalition supports the evidence received regarding the failure of this Government to ensure appropriate provision of supported accommodation and supports the range of recommendations provided throughout the report to address those failures.

The committee has recommended additional supported accommodation beds for people with a disability and/or mental illness, more respite care, additional individual support packages and the need for reform and long term planning to better support carers and the people they care for in the future.

Report Lacks Urgency

This report however fails to convey the real sense of urgency that is needed to address the failings in the Victorian Government's supported accommodation system.

Most evident in the submissions and hearings was the desperation that is felt by so many of the families and carers who care for loved ones as well as the frustration of disability and mental health organisations who participated in the Inquiry.

Family members painted a bleak picture of people with a mental illness and/or disability languishing on waiting lists with no hope in sight. Submissions highlighted the desperation of parents and families who have dedicated most of their lives caring for their child and battling an "uncaring" DHS bureaucracy.

Ageing parent carers told of being unable to plan for the future and of being too afraid to die for fear of not knowing what would happen to their adult son or daughter with a disability. Managers told of the heartbreak of families who are forced to abandon their children to the system as there are no other options and they just cannot go on.

The consistent messages of crisis and hopelessness that were expressed by the families, carers, community groups and service providers during the inquiry demand immediate action from the Government.

Voices of Families

Much of the deep, raw emotion shown by families, carers and managers throughout the hearings has been excluded from the report. While the report cannot show the tears in their eyes and detail their wavering voices and sense of despair, their words can be reproduced to capture a family's reality:

Parents say that they are forced to:
> *Remain a prisoner of their own homes and live apart from the normality of the rest of the community.*[894]

And many are stuck in what has been described as a *'perpetual nightmare'.*[895]

This experience was also reinforced by a number of key community sector organisations. A representative from Yooralla said that:
> *The criterion for placement in an accommodation service right now is generally homelessness.*[896]

And from Carers Victoria:
> *…I think it is important to state that at June 2008 the disability support register had recorded 1358 people waiting for disability support accommodations options…**we are actually dealing with a crisis"***[897]

This sense of crisis is exacerbated by a lack of adequate support for carers and people with a disability or mental illness while they wait to access supported accommodation. Families are under even more pressure with inadequate and inflexible respite which fails to meet growing levels of demand to sustain carers in their role.
> *We're talking about having to go with begging bowls to the table of the government to ask for in-home support, out-of-home support, respite support, any other kind of support that you can think of.*[898]

The anxiety and sense of crisis that plagues so many Victorian families and people with a mental illness or disability was not fully articulated in the report and certainly not conveyed in the Executive Summary.

Lack of respect and appreciation of carers

The feelings of desperation are perpetuated due to the exclusion of families in the planning and decision making concerning the person they care for and their dissatisfaction with the culture and approach of the Victorian Government.

Many parents and carers have reported being excluded from the assessment, planning and treatment phases and say they lack the information they need to allow them to perform their caring role.
> *Regrettably the culture in DHS is one of paternalism…the attitude of DHS is to exclude families.*[899]

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[894] Alan G Field OAM Submission
[895] Mark & Luke Modra Submission
[896] Yooralla Hearing, 22 October 2008
[897] Carers Victoria Hearing 22 October 2008
[898] Gippsland Carers Association Hearing, 21 October 2008
[899] Cliff Stephens Submission

A representative from Carers Victoria also highlighted similar concerns, including:

> *Families are often shut out of decision making around the needs of their sons and daughters. Families often feel excluded from participating in decision making around the care and management of their son or daughter, even when they are in a residential facility.*[900]

While the lack of engagement with families in the treatment and support of their family member are addressed in the later stages of the report, the importance of the issue was overlooked by its omission from the Executive Summary.

Inquiry Process

The Committee's ability to complete the report was hindered by the lack of responsiveness from the Department of Human Services. Data requests took many months and many reminder letters and phone calls to be provided. The July 2008 data request was received in December 2008 and was incomplete. In July 2009 another request was made to update the data for the new financial year and fill in gaps in information. A proportion of this information was provided by the Department on 11th November 2009 and as late as December information was still being clarified.

The Minister for Community Services, Lisa Neville, despite platitudes about the importance of the Committee's work also failed to genuinely assist in the inquiry. The Minister:
- repeatedly declined invitations to appear before the Committee
- declined to allow the Chief Psychiatrist and the Senior Practitioner to appear at a public hearing
- failed to ensure any timeliness in the Department's response to Committee requests and herself responded on the 6th December to an October 2008 request for a public hearing with Departmental officials scheduled for the 10th December; and
- refused to allow the important DHS data provided to the Committee to be treated as a submission and used as evidence in the inquiry.

It is understandable that many families and carers who contributed to this inquiry are incredibly frustrated about having had to wait more than 22 months to see the outcomes and recommendations.

Despite the challenges faced by the Committee in undertaking the inquiry, there are many important recommendations which we encourage the Government to take up with urgency.
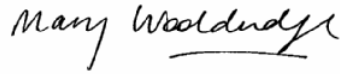
Finally, we would like to thank the many individuals, families and organisations who invested many hours and much emotion to contribute to this inquiry. All people with a disability and/or mental illness deserve the stability and security of appropriate accommodation and their families and carers deserve the peace of mind that would bring.

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[900] Carers Victoria, Hearing, 22 October 2008

The greatest respect the Victorian Government could show to affected individuals and families is to urgently and comprehensively act on these findings.

Jeanette Powell MLA
Deputy Chair

Mary Wooldridge MLA
Committee Member

Bernie Finn MLC
Committee Member

Extract from the Minutes of Committee Proceedings

FAMILY & COMMUNITY DEVELOPMENT COMMITTEE
FIFTY–SIXTH PARLIAMENT
Extract from the Minutes of Committee Meeting No. 65/09

Motion made — That the **Executive Summary** stand part of the report, subject to minor amendments

Moved: Mr Johan Scheffer, MLC
Seconded: Mr Wade Noonan, MLA

The motion was put and the Committee divided:

Ayes: Mr Jude Perera, MLA; Mr Wade Noonan, MLA; Mr Johan Scheffer, MLC.

Noes: Mrs Jeanette Powell, MLA; Mr Bernie Finn, MLC; Ms Mary Wooldridge, MLA.

The ayes and noes being even, the Chair exercised a casting vote. The Chair made a casting vote for the ayes.

The motion was carried with four ayes and three noes.