



# LIVING LIFE MY WAY

## **Putting people with a disability at the centre of decision making**

Outcomes of statewide consultations

August - October 2011

# Executive Summary

The New South Wales (NSW) Government is committed to improving the lives of people with a disability, their families and carers. People with a disability, their families and carers have expressed the need for greater choice and control over state-based disability funding and resources, and the supports and services they access in their daily lives. To ensure that these people are at the centre of decision making about the services they need, the NSW Government will implement person centred approaches by the end of 2014.

The NSW Government is conducting state wide consultations to seek the views of people with a disability, their families and carers, and service providers on person centred approaches and the outcomes people would like to see within the NSW disability service system.

The consultations commenced with the *Living Life My Way* summit on 7 and 8 July 2011, which was hosted by the NSW Minister for Disability Services, the Hon. Andrew Constance MP.

A total of 153 consultation sessions have been held with people with a disability, families and carers and service providers across metropolitan and regional areas of NSW. In addition, the NSW Government commissioned targeted consultations to engage with people from Aboriginal communities, people from culturally and linguistically diverse backgrounds and people with intellectual disability. This report includes the findings of the consultations conducted in languages other than English. The consultations with Aboriginal communities and people with intellectual disability are continuing and will be reported separately.

The consultation sessions explored people's views, in detail, on a person centred approach and its key elements:

- 1 person centred planning;
- 2 personalised funding arrangements; and
- 3 person centred service delivery.

This report provides a summary of the key themes, views and suggested directions arising as a result of the consultations and the written submissions received to date.

During the consultations there was overwhelming support for person centred practice. Person centred practice is seen as an attitude or culture that translates into a way of operating that supports people with a disability to live the life they wish. In a person centred service, a person with a disability is listened to, heard, respected and encouraged to exercise choice and control to the greatest extent possible.

A number of people with a disability, families and carers and service providers shared accounts of how services have become more person centred in recent times. There were a number of positive stories of person centred practice, including direct accounts from people with a disability who had changed their lives significantly as a result.

Carers and family members strongly supported the capacity of person centred approaches to determine the 'right' mix of supports and services at key life stages. Person centred approaches could also contribute to the well being and sustainability of the family unit and continuity of care and support arrangements when family members are no longer around to take part in decision making.

Personalised planning is seen as the way to truly understand and respond to a person's service and support needs. Planning would usefully occur around a person's life stage, needs, circumstances, goals, preferences and aspirations. Families, unpaid carers and friends would frequently play an important part in the planning process, as might paid carers and other support people. All participants agreed on the need for a mechanism to change or adjust a plan as circumstances change and the need for an in-built review mechanism.

A number of service providers already undertake one-on-one planning with the people who access their services but recognise the potential for personalised planning to go much further in responding to their clients' needs.

Personalised funding is seen as critical in terms of providing people with a disability direct control over the supports and services they access. The mechanics of how it might work in practice is the subject of rigorous debate and will require a great deal of thought given the range and complexity of needs and expectations that exist within the community.

A transition to personalised funding has significant implications for the service sector and there is a need to plan for the transition and to develop tools and supports to assist providers to make the change.

Personalised service delivery is seen as a way of thinking and behaving more than anything but there are also significant practical implications in terms of the day-to-day operation of a disability service.

The issues, questions, ideas and views raised during the consultations are summarised below, and will be used to develop a potential model for implementing person centred approaches for disability supports and services within NSW. The model will be developed over the next few months and presented to the community in a second round of consultations in the first half of 2012.

We would like to thank all the participants in the consultation sessions who gave so generously of their time, experience and energy.

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# 1 Introduction

In the last 20 years, there has been a major shift in attitudes to recognise the rights of people with a disability. The *United Nations Convention on the Rights of Persons with Disabilities 2007*, which Australia signed in 2008, recognises the rights of people with a disability to determine their own lives and to participate in communities to the fullest extent possible.

Internationally and within Australia, governments recognise that there are significant implications for disability planning, funding and service delivery. In Australia, the National Disability Reform Agenda and Strategy commits all jurisdictions to work together to build a sustainable and person centred disability support system.

The Productivity Commission Inquiry into a National Disability Insurance Scheme found that the current system is not delivering the kind of care and support for people with a disability that Australians expect. The final report of the Productivity Commission, which was released in July 2011, makes recommendations for substantial reforms to provide certainty around funding, increase access to supports and services and make services and supports more person centred.

The Australian Government is considering the recommendations of the report, and has commenced work with States and Territories in key areas, including:

- develop common assessment tools to determine eligibility for support;
- develop national service and quality standards;
- develop a national pricing structure;
- build the capacity of the disability sector; and
- build workforce capacity.

These national reform directions have the potential to fundamentally change disability service provision within Australia including the potential to address the unmet demand that currently exists. The NSW Government has strongly supported the implementation of a National Disability Insurance Scheme and has identified an opportunity to put in place changes to the current system that are consistent with these reform directions.

The NSW Government is committed to making individualised funding available to service users by 2014. *NSW 2021* includes targets to increase the percentage of disability service users who are using personalised funding arrangements to 10 per cent by 1 July 2014. By 1 July 2019, 100 per cent of disability service users will be able to access individualised funding arrangements (should they wish to take up the option).

In NSW, people with a disability, their families and carers have expressed the need for greater choice and control over state-based disability funding and resources and the supports and services they access in their daily lives.

The NSW Government is conducting statewide consultations to seek the views of people with a disability, their families and carers and service providers on person centred approaches and the outcomes people would like to see within the NSW disability service system.

The consultations commenced with the *Living Life My Way* summit on 7 and 8 July 2011, which was hosted by the NSW Minister for Disability Services, the Hon. Andrew Constance MP. Between 1 August and 19 September 2011, 153 consultations were held across NSW with people with a disability, families, carers, service providers and other stakeholders. There were also 18 consultation sessions with people from culturally and linguistically diverse backgrounds held 10 – 20 October 2011. This report summarises the main themes and perspectives raised in these consultations.

The feedback received from consultation participants was overwhelmingly supportive about the implementation of person centred approaches. For many people with a disability, their families and carers, enthusiasm for person centred approaches emerged from the difficulties they have experienced with the current disability service system.

The difficulties they highlighted included:

- Inability to access existing services and supports due to eligibility requirements;
- Status of previous or current assessments under the new arrangements;
- Concerns that current eligibility criteria disadvantages those people with lower needs or those without an intellectual disability;
- Concerns about the lack of funding in the sector;
- Lack of access to a sufficient quantity and quality of services;
- Waiting times for services, particularly in outside the Sydney metropolitan area;
- Lack of choice of service provider;
- Lack of available services and supports;
- Red tape in the existing system; and
- Lack of information sharing which means individuals and families having to re-tell their story or provide personal details to different services or government agencies on different forms.

Participants in the consultation sessions expect major change will result from these consultations.

## 1.1 What is a person centred system?

A person centred system places the person with a disability at the centre of decision making for the supports and services they use.

In a person centred system, the rights of individuals and their families and carers to direct their lives are respected. In practice, this means that a person with a disability and their families and carers are supported to exercise choice and control over the supports and services they use.

There are three essential elements, or building blocks, in a person centred system:

- 1 **Person centred planning:** planning that is personalised and directed by the individual with appropriate levels of support if needed due to the nature of their disability;
- 2 **Personalised funding:** resources that are allocated to individuals to provide supports based on needs and preferences identified through the planning process; and
- 3 **Person centred service delivery:** tailored service coordination and delivery which may involve a combination of formal and informal, public and privately provided services and supports, to deliver outcomes and meet goals for an individual.

## 1.2 State wide consultations

Between August and September 2011, consultations were facilitated across NSW on behalf of the NSW Government.

The NSW Government also undertook targeted consultations to engage with people from Aboriginal communities, people from culturally and linguistically diverse backgrounds and people with intellectual disability.

Targeted consultations in languages other than English were completed in October 2011 and included 17 sessions with people with a disability, their families and carers and one service provider workshop. The feedback from these sessions is included in this report. These consultations targeted the top ten language groups in NSW other than English (Arabic, Cantonese, Greek, Hindi, Italian, Korean, Mandarin, Spanish, Tagalog and Vietnamese), and there were seven sessions for new and emerging communities (conducted in Bengali, Dinka, Nepali, Polish, Russian, Shona and Tamil). The sessions were conducted by independent bilingual facilitators.

Consultations with people from Aboriginal communities and people with intellectual disability continued until mid December 2011 and will be reported separately.



In total, 2,724 people participated in 174 consultation sessions. This included:

- people with a disability, families and carers (including consultations in languages other than English) – 133 consultations (76.5 per cent of total consultations) involving 56.6 per cent of total participants (1,541 out of 2,724);
- service providers and other stakeholders – 38 consultations (21.8 per cent of total consultations) involving 40.2 per cent of total participants (1,095 out of 2,724); and
- families and stakeholders of large residential centres – 3 consultations (1.7 per cent of total consultations) involving 3.2 per cent of total participants (88 out of 2,724).

Consultation sessions were conducted across metropolitan and regional areas of NSW (82 consultations in metropolitan areas and 92 in regional areas). A full list of consultations is provided in **Appendices A and B**.

Consultation sessions explored people's views, in detail, on a person centred approach and its key elements:

- Person centred planning, flexibility, choice and control;
- Personalised funding arrangements; and
- Person centred service delivery.

### 1.3 This report

This report summarises the key findings and outcomes of the statewide consultations held between August and October 2011. It provides analysis and discussion of the range of views expressed by people with a disability, their families and carers and service providers on a vision for a person centred disability system in NSW and how it might operate in practice. It incorporates feedback and comments obtained from consultation sessions conducted in languages other than English as well as the written and verbal submissions received to date (a total of 91 written submissions and 10 verbal submissions).

## 2 Person centred planning

### 2.1 Introduction

Person centred planning can be used to assist people with a disability to access supports and services. Whilst not all people with a disability may want or need a personal plan, a person centred planning process can assist an individual to match supports and services to their needs.

A person centred planning process is ongoing, collaborative and open. The individual drives decisions around what goes into their plan, recognising that planning may include input from a number of people who have a role in that person's life. The plan would need to evolve and change over time to reflect a person's changing needs, circumstances and goals, particularly at key transition points during life. For example, a plan for a young child would be different to a plan at school entry age or post-school.

Participants in the consultation sessions strongly supported person centred planning in principle. Participants in sessions conducted in languages other than English were supportive as they felt it would provide opportunities to address cultural and linguistic needs in the provision of supports and services. These participants also supported person centred planning as a way of encouraging people with a disability to express their needs and preferences directly.

*“Person centred planning acknowledges the fact that disability does not mean inability because it gives the person power and control over their lives.”*

Family member of a person with a disability

There was recognition among all participants that people have different needs and circumstances and acknowledgement that families, unpaid carers, friends and advocates would frequently play an important part in the planning process as might paid carers and other support people.

Some families and carers expressed a view that a person centred planning process which spanned key life stages would be of great assistance in guiding and determining the 'right' mix of supports and services at any given time. This was seen as particularly important in the early years of a person's life as parents and carers navigate the range of potential service and support options that might assist their circumstances.

As well as providing a means of configuring essential supports and services, from a practical perspective participants supported the notion that planning was a way of setting out and realising a person's broader preferences, goals and aspirations for life. Participants discussed the need for planning to cover essential supports and services and to facilitate a person's aspirations, dreams, interests, likes and dislikes.

*“A plan should identify needs and strengths, and set goals...it should be realistic but not limit dreaming.”*

Family member of a person with a disability

A number of participants, particularly service providers, stated that planning should be carried out at the local level so that it is relevant and appropriate to the context and community in which the person lives.

Some people with a physical disability expressed the view that having a ‘life plan’ should not be a prerequisite for accessing services. For example, people questioned the need for a person with a physical disability to prepare a plan in order to receive funding for essential supports. For this group, targeted service planning may be more appropriate to address particular support needs. The range of views expressed in the consultation sessions reinforced the importance of a flexible approach to planning that meets the needs of the person. Flexibility extends to the scope and extent of a plan, the range of things that might be able to be included and the need to change a plan in response to changing circumstances.

Families and carers also believed that a person centred plan could be greatly beneficial in reducing the number of times they need to tell their ‘story’ to service providers and government staff, a process which causes a great deal of frustration.

*“We’re very tired from having to tell our story again and again. My son is autistic and being asked yearly by Centrelink whether my son still has a disability is frustrating and unbelievable.”*

Parent of a person with a disability

There is also a view that a person centred plan could be a means of ensuring continuity of care and support arrangements when family members are no longer around to take part in decision making. For example, if plans were provided with some kind of legal recognition and longer term standing.

It was also seen as important to ensure that people are able to change a plan in response to changing personal circumstances as well as lessons learned or trial and error either through the planning process itself, preparing and/or updating a plan or in trying different support configurations out in practice. In other words, if something does not work for a person it must be able to be changed and adjusted.

*“In a (person centred) planning process I would be listened to rather than be told what was going to happen to me and be told what to do with my life.”*

Person with a disability

## 2.2 Components of a person centred plan

In the consultations, people with a disability, their families, carers and service providers supported structuring a plan around a person's life stage, needs, circumstances, goals, preferences and aspirations.

The range of potential components to a person centred plan suggested by participants included:

- the person's story and circumstances that can be used to inform relevant government personnel, service providers, medical staff and others;
- the cultural background of the person; and
- the person's needs;
- the person's goals and aspirations (both short term and long term) and steps to achieve them;
- planning for the future, particularly if and when carers are no longer able to offer the existing level or type of care and support, which is a major concern for ageing carers; and
- the domains of a person's life, including health, lifestyle, community engagement and participation, transport, employment and education.

Whilst the components will vary from person to person, in essence the planning process should assist in mapping out the supports and services that will enable a person to live the life they want to live.

A number of participants expressed support for an approach to planning that recognises and builds on the strengths and abilities of people with a disability, seeing it as a way of building the confidence and capacity of individuals and families to seek out and take control of supports and services.

*“It would be good to have clear articulation of the person's abilities so that the person is encouraged to do what they are able to do regardless of their disability.”*

Parent of a person with a disability

All participants agreed on the need for a mechanism to change or adjust a plan as circumstances change and the need for an inbuilt review mechanism.

*“Flexibility is key. There needs to be an ability to change plans, respond to changing circumstances and have the dignity of risk – the ability to make a mistake and change direction.”*

Parent of a person with a disability

It was also agreed, particularly by families and carers, that a person should be made responsible for implementing the plan and act as a central point-of-contact for people with a disability and families and carers to follow up on the plan.

Families and carers from culturally and linguistically diverse backgrounds suggested that there should be capacity for contingency or “back-up planning” for families and carers who may not be coping with the caring role.

### 2.3 Essential components of a person centred plan

There was no consensus among participants as to whether there should be ‘essential’ or ‘mandatory’ components to a person centred plan. One view was that there should be essential components based on the nature of a person’s disability and their life stage. For example, a number of family members and carers expressed support for early intervention and therapy services being an essential component of a person centred plan for a young child with a disability. This was seen as important to give a child the best possible start in life and to maximise developmental opportunities. This was regarded as particularly important where family members themselves were trying to work out the ‘right’ mix of supports and services and would welcome more structured guidance.

Other participants, including some service providers, held a view that there should be no essential components to a person centred plan as each plan will be different. Some participants stated that the concept of ‘essential’ components is contrary to a truly person centred planning process.

### 2.4 Who should planning include?

The majority of participants believed that the person with a disability should drive the planning process, although a number of family members and carers identified that this may not be possible if the person has a severe intellectual disability and is not able to participate in decision making. In these cases, planning would need to be led and/or influenced by the person’s family, representative, trustee, guardian, advocate or an appropriate combination.

*“Planning should involve people who have the person’s best interests at heart.”*

Family member of a person with a disability

There was a broad consensus among participants that planning should include anyone that a person with a disability chooses to involve in the process. Enabling this choice is seen as fundamental to a person centred approach.

The majority of participants commented that planning would generally involve family members, because parents and siblings so often play a central role in providing care and support. Some people indicated that they would like to include extended family members in the process. There was certainly a strong recognition that the well being and sustainability of the family unit is important and should be taken into account in planning disability supports and services. However, participants also recognised that not all people with a disability want their family to be involved in planning.

A number of families and carers and service providers said that planning should involve professionals (e.g. medical professionals) who are able to give an expert opinion on the person's disability and the type of services and supports that would be of assistance. A number of participants in the consultations conducted in languages other than English said that they would feel more confident if professionals were involved. Service providers who know and work closely with a person would also play a potential role in articulating a person's needs, goals, likes and dislikes.

*“Planning should ensure that all the organisations, therapists, doctors that are involved in the care of your child are all on the same page, and have a shared understanding...”*

Parent of a person with a disability

## 2.5 Value of planners

A theme of the consultations was the need for help and assistance in exploring needs and aspirations and understanding, navigating and choosing support and service options. A 'planner' is a potential source of information, advice and assistance.

A common idea was that a person with a disability should have the right to choose whether a personal planner would be involved in their planning process. There are divergent views on whether the role of planner needs to be undertaken independently from the government and/or service providers.

Some families and carers had concerns that creating a role for independent planners may create another layer of bureaucracy in the service system and unnecessarily waste money that could be used on supports and services. One parent stated that the service system should not force individuals to use a personal planner. Those who supported independent planners valued having a skilled, independent professional provide objective advice for the purposes of designing a personalised plan.

*“A planner should be someone who the family trusts, who they feel comfortable with, [who is] known to the family.”*

Service provider

The central value of a 'planner' for families and carers is in providing a source of information and advice on the range of services and supports that are available and assistance in matching supports and services to the specific circumstances of the person with a disability.

Service providers expressed the view that planners should have knowledge of the service system but also possess other skills and competencies such as disability awareness, cultural training and 'soft' skills enabling them to communicate sensitively and effectively with the person with a disability, their families and carers.

Some families, carers and service providers suggested that there could be different types of planners to work with people with different disabilities. It was also recognised that people from culturally and linguistically diverse backgrounds may need a planner who speaks their language and understands their culture.

Some families and carers regarded a planner as similar in role and responsibilities to a case manager while a small number of families and carers likened a planner to a broker. Other families and carers wished to leave the role and responsibilities of a personal planner open and able to be tailored to an individual or family's needs.

*“By having a planner, we would know the direction to take and the services to obtain. With the planner’s knowledge of services and supports that exist, we can control the waiting time problem.”*

Parent of a person with a disability

There were varying opinions on the accountabilities that should exist for a planner with a number of families and carers believing that a personal planner should be responsible for “making the plan happen”.

Regardless of the specific duties, responsibilities and accountabilities of a personal planner, it was broadly agreed that the level of involvement of a planner should be left open to choice by a person with a disability. The spectrum of options raised during the consultations ranges from an individual driving and managing their own personal plan, to varying levels of family and carer involvement, to an independent planner designing a plan, coordinating services and support and potentially oversee implementing the plan on a person or family's behalf.

## 2.6 Support to participate in planning

The most valuable support nominated by people with a disability and families and carers to assist their participation in the planning process was access to credible and accurate information.

*“How can we have a vision of what the future might look like if we don’t know what the possibilities are?”*

Parent of a teenager with a disability

Participants suggested that information on services and support options, and service providers should be centrally located (e.g. an electronic directory) in easy-to-read, accessible formats. This information also needs to be easily available in languages other than English. Some families and carers proposed that this type of directory could be used to rate service providers – either through a star rating system or a green or amber light system to indicate standard and outstanding service providers. This was perceived as important to help people differentiate between service providers.

During the consultations, families and carers expressed the view that financial information, such as a service price index, would be helpful in order to choose from service and support options with confidence that a person is receiving value for money. Some families and carers believe that the maximum level of funding available to people should be known from the outset before a plan is developed.

Many families and carers supported the establishment of mechanisms to share knowledge in relation to what did or did not work for them. For example, web based testimonials for supports and services and culturally specific peer support groups. Some participants from sessions conducted in languages other than English said that sharing success stories would empower individuals, educate the wider community to be more inclusive and also reduce the stigma that is associated with disability in some communities.

*“If we are more open about our lives and our successes, this could be educational for others in the community and hence reduce stigma.”*

Parent of a person with a disability

A significant number of families and carers said that they would like advocacy training or access to advocacy for the person with a disability and the family. They believed that this would facilitate the planning process and better enable people with a disability, families and carers to express their desires, preferences and decisions.

Some families and carers also expressed a frustration with the current level of paperwork they face, and proposed that a person such as a personal planner (similar to a tax agent) could assist them with completing and filing paperwork. Suggestions were made that people with a disability, their families and carers should receive training to assist with planning, for example computer literacy training.

## **2.7 How should planning be resourced?**

Families and carers were concerned that planning could absorb a significant amount of funding which would be better spent on supports. There was a concern that funding may be consumed by brokerage or administrative fees. It was proposed by families and carers that the costs of the planning process and any use of a personal planner be contained and funded by government separately.



## 2.8 Summary of views on person centred planning

There was strong support for person centred planning amongst all participants in the consultation process. Planning would usefully occur around a person's life stage, needs, circumstances, goals, preferences and aspirations. Families, unpaid carers and friends would frequently play an important part in the planning process, as might paid carers and other support people. All participants agreed on the need for a mechanism to change or adjust a plan as circumstances change and the need for an in-built review mechanism.

There was no consensus among participants regarding whether there ought to be 'essential' or 'mandatory' components to a person centred plan. One view was that there should be essential components based on the nature of a person's disability and their life stage. Other participants, including some service providers, held a view that there should be no essential components to a person centred plan as each plan will be different. Some family members stated that the concept of 'essential' plan components is contrary to a truly person centred planning process.

A theme of the consultations was the need for help and assistance in exploring needs and aspirations and understanding, navigating and choosing service and support options. The most valuable support that was nominated by people with a disability and their families and carers to assist their participation in the planning process was access to credible and accurate information.

A potential source of information, advice and assistance is a 'planner'. Many participants thought that a person with a disability should have the right to choose whether a personal planner would be involved in their planning process. There is a range of views on whether this role needs to be undertaken independently from the government and service providers.

Families and carers were concerned that planning could absorb a significant amount of funding which would be better spent on supports. In particular, there was a concern that funding may become consumed by brokerage or administrative fees. It was proposed by families and carers that the costs of the planning process, and any use of a personal planner, be contained and funded by government separately.

## 3 Personalised funding arrangements

### 3.1 Introduction

Personalised funding means each eligible person with a disability has an individual package of funding that is 'attached' to them and control over how the package is used.

Personalised funding is an essential component of a person centred model, and provides people with a disability control and purchasing power over the types of supports and services they use and the design of those supports and services including when and how they use them, and from whom they are purchased.

*“Personalised funding promotes flexibility in how the money can be used and this enables prioritisation of needs given available funding at any given time.”*

Parent of a person with a disability

There are different types of personalised funding, ranging from individually attached and portable allocations paid to service providers through to providing funding directly to the person with a disability or to someone on their behalf.

The NSW Government has made a commitment to making individualised funding available to service users by 2014. NSW 2021 includes targets to increase the percentage of disability service users who are using personalised funding arrangements to 10 per cent by 1 July 2014. By 1 July 2019, 100 per cent of disability service users will be able to access individualised funding arrangements (should they wish to take up the option). This timeframe provides a realistic trajectory for adjustment and transition to the new funding arrangements. The experience in other jurisdictions is that the voluntary uptake of self-managed, direct payments (one option under a spectrum of personalised funding arrangements) is slow and steady as individuals gain the confidence to try it.

During the consultations, there was broad support for the concept of personalised funding from people with a disability and their families and carers. Service providers had divergent views with a number recognising the opportunity that personalised funding provides for people with a disability and for their organisation while others were concerned about the impact that personalised funding might have on their ongoing financial viability.

An outline of the main themes from the consultations with people with a disability, their families and carers and service providers on various aspects of personalised funding follows.

### 3.2 Suitability of personalised funding arrangements for people with a disability

There was broad support for the concept of personalised funding arrangements from people with a disability as well as the families and carers who participated.

People with a disability stated that personalised funding arrangements would be a means for them to have more control over the supports they used which would enable them to have more control over their own lives.

*“We need more freedom to live our lives the way we want to. If we want to study, work, or if we can’t do either, we should be encouraged with financial and physical support to lead lives as fulfilling as possible. Just surviving day to day is hard for some of us. We need reliable support to have reasons to survive for; a future to strive for.”*

Person with a disability

*“The current set up wastes funding...at the moment staff are employed to do many things I could do myself if given the right tools. For example if I have a doctor’s appointment I call a coordinator who organises staff to take me. Instead give me a taxi allowance to go myself.”*

Person with a disability

Participants in the sessions conducted in languages other than English said that their needs could be addressed more quickly if the money were directly available to the person with a disability.

Families and carers were supportive, in principle, though the discussions highlighted a number of issues and questions. One of the main concerns was the capacity of some people with a severe disability to manage funding and direct how funding is used. This was particularly raised by families and carers of people with intellectual disability (who formed the majority of the participants in a number of sessions).

While families and carers recognised that the funding package would be for the person with intellectual disability, there was a predominant view that families and carers would need to influence if not direct decisions around how funding is used. At times, this view was challenged by people with intellectual disability who participated in the consultations and by other family members and carer participants.

Understandably, there were questions around the ‘mechanics’ of personalised funding and the level of control that people would have over the funds. For example, whether funding would be provided in cash or in a lump sum for people to manage as well as whether the person would need to pay invoices or be required to fulfil additional tax and insurance requirements where they directly employed support workers. Some families and carers were excited by the prospect of ‘full control’, others were concerned about the additional time and effort required in addition to their caring role.

*“I want to manage my daughter’s funding and I don’t want someone telling me what to do. There needs to be an easy way to spend the funding without a lot of approvals.”*

Parent of a person with a disability

There were few situations identified where personalised funding packages would not be appropriate. The predominant view among people with a disability and families and carers was that an individual funding package is appropriate for everyone, although the degree of control or influence and the support received to manage a package would vary. A spectrum was suggested ranging from an individual or family/carer having full control over the package (where they could demonstrate capacity to manage the package) through to a third party managing a package on a person’s behalf.

Families and carers were clear that it is important that people with a disability, their families and carers are able to choose to have a third party manage their funding package on their behalf – for those who are not interested in having that responsibility or those who would find it burdensome.

A number of participants noted that there are some people with a disability with very complex needs where a third party would be best placed to manage their package. Some people may not have family members or carers who can assist them to manage a package for whom third party management would also be appropriate.

*“It’s a lot of money and I would be more comfortable if someone else could manage it, with me having control over what it can be used for.”*

Person with a disability

Some service providers raised a concern that people with a disability and/or families and carers could make ‘wrong’ or inappropriate decisions about how they would use their funding or would not have the capacity to manage a funding package. Some participants in sessions conducted in languages other than English said that people and families who are struggling financially may be tempted to divert some funds to other family essentials.

While some service providers saw this as a reason why a funding package would not be appropriate for some people, others indicated that it was about the management and support of the package and not the individualised nature of the package.

### **3.3 Support to manage personalised funding arrangements**

All participants recognised that there would be a range of needs for support to manage a funding package. Participants recognised that the need for support would depend on an individual’s (and/or their family’s or carer’s) willingness to accept responsibility for managing funds, their capacity to manage a package, the complexity of their circumstances (the type and extent of disability, their

family situation, the support networks available etc) and the kind of support they need. Further, participants thought that people with a disability and/or their family or carer should be able to choose the nature and level of support they receive and whether someone else managed their package on their behalf. Participants with a disability identified that while they may need support to manage their package initially, over time they wanted to develop the skills and capacity to manage their package themselves.

*“Personalised funding can provide opportunities for recipients to learn about financial management.”*

Person with a disability

Many participants agreed that anyone who wishes to manage a package themselves would need to be able to demonstrate the capacity to manage their package and to be able to access training or support to build their financial management skills. A number of participants thought that it would be beneficial if the day-to-day administration of managing a package (such as paying invoices or completing paperwork) could be done by someone else, even where people choose to manage a package themselves.

There were concerns about the cost of assistance to undertake financial management – particularly by families and carers – and whether this cost would be met by an individual’s package. There was a view that those who needed support to manage their package could be unfairly disadvantaged if they had to pay for this support. One suggestion was for the cost of managing a package to be met from outside an individual’s package.

*“There may be an unintended consequence creating inequality if people have to pay for the cost of assistance to manage their funds... people would not want to use external assistance to manage their funds even though this may be the best thing for them.”*

Family member of a person with a disability

Some service providers had a similar concern about the cost of supporting people to manage a package and about whether and how they would be funded for this function. They also recognised that there would be varying levels of support required (and thus varying levels of cost to individuals), and that this support cannot necessarily be separated from ‘planning’ supports or coordination of supports.

### 3.4 Funding package design

Participants agreed that there needs to be a fair and transparent way to determine who gets a funding package, how the level of funding is determined and whether there should be any restricted or quarantined components of a funding package.

Participants did not have a consistent view on how the amount of funds in an individual's package should be determined. All agreed that the allocation of funding should be based on a fair and robust needs assessment process.

*“Funding needs to be at a realistic level to meet a person's needs – there should be enough to buy what a person needs.”*

Service provider

Some participants – families, carers and service providers – thought that the amount in a funding package should be based on a person's plan and how much it would cost to implement the plan. Others thought that a fairer way would be for the amount to be determined up-front and the plan based on this amount – mainly to avoid people developing unrealistic plans and to avoid “people with the best plans getting the most money”.

Participants in sessions conducted in languages other than English were concerned that they would miss out or be disadvantaged by not being able to communicate their funding needs. It was suggested that transparent eligibility criteria for funding packages would be beneficial.

*“Many others like me would need to know how to apply for funding packages... if we can help each other, then no one will miss out.”*

Parent of a person with a disability

There were differing views on how a funding package should be structured and whether parts of a funding package should be restricted or ‘quarantined’ for specific purposes (for example, for accommodation support or for transition to work). Families and carers saw the benefit, from their perspective, of having as few restrictions as possible although a number of service providers stressed the value of potentially quarantining some funding for specific purposes to ensure that people used the funding to achieve the best outcome for them in the longer-term.

A number of families and carers were concerned that the existing supports they and the person they care for receive may be at risk and that they would need to go through another intensive process to ensure that they maintain the level of support they have now. They stressed the importance of rolling over whatever people receive now into a funding package so that no one would be worse off. Many families articulated that they wanted the funding to follow the individual throughout their life so they do not have to continually tell their story and start afresh every time they use a service.

*“The new system needs to flow on, so if you change service provider you don't lose or have to reapply for funding.”*

Person with a disability

### 3.5 Services and supports that can be purchased with funding packages

The majority of people with a disability and families and carers thought that any support or service that meets a person's needs or helps achieve their goals should be able to be purchased from a funding package. This included the more 'traditional' types of supports that are available currently as well as other types of supports that might not be available. Examples included a variety of recreation activities, carers to accompany people and families on holidays and different types of goods or equipment. Families and carers said that support for them in their caring role is important, in particular respite care should be readily available as well as counselling services.

*“It is important to think about consumables – like nappies – which are often overlooked by bigger expense items. Not much funding is required for smaller items, but this can go a long way to help people.”*

Family member of a person with a disability

Regardless of the 'types' of supports and services that could be purchased, participants thought that supports and services should be flexible and individuals and families should have input into the way they are provided. There was broad agreement that funding packages should not be able to be used for everyday living expenses or for things such as alcohol or gambling.

The views of service providers were more mixed. Some service providers saw opportunity in a transition to personalised funding arrangements to redesign services and supports. Many identified the need to “change the way they do things” and recognised that what their service delivers now may not be what people with a disability actually want in the future. A number of service providers were concerned about the risks associated with people being able to use their funding package for a range of different supports. Potential risks include people receiving poor quality or inappropriate supports or engaging private organisations or individuals who are not qualified or competent to provide disability supports and services.

An area of contention among families and carers and service providers was whether funding for accommodation support should be included in funding packages. A number of families and carers thought accommodation should be included and that it was no different from any other type of support.

*“Accommodation is such a key stepping stone for a person to start living an independent life.”*

Parent of a person with a disability

There is a view that including accommodation in a package could promote more creative uses of accommodation support funding, such as pooling resources to purchase property as alternatives to the traditional group home model. Others recognised that the dollars involved are substantial and there may be additional risks involved with including accommodation support in a package (including the potential that some people could use their accommodation support funding for other supports). There were suggestions that the amount allocated for accommodation support might need to be separated or quarantined. Families and carers noted that access to accommodation support is very difficult currently and it would be difficult to ensure that accommodation support funding is spread equitably.

*“We have so many problems with our son’s accommodation... currently he lives in a home with old people. That is no way for a young person to live their life. He should be surrounded by people of his own age.”*

Parent of a person with a disability

Families of people with a severe disability living in larger residential centres expressed concerns about applying personalised funding to this form of accommodation and support. Service providers also highlighted the high infrastructure costs associated with providing 24-hour accommodation support and the need to ensure that funding for accommodation support took this into account. Some service providers also highlighted the risk that, without certainty of funding for 24-hour accommodation support, they could end up carrying the cost of vacancies. That is, they would bear costs associated with operating a group home or other accommodation facility although potentially receiving revenue only for the places that are filled.

*“The intensity and specialised nature of 24-hour accommodation support means it is best funded through block grants, which is a more reliable and stable form of funding. We need to ensure that the quality of the service is maintained.”*

Family member of a resident of a large residential facility



### 3.6 Pricing services and supports

People with a disability, their families and carers identified the importance of receiving value for money and paying a 'fair price' for services. This might mean setting maximum prices for different support types. Participants also recognised that supports would not always come from a set 'menu' and that individualised tailoring of supports may impact on price. Some people with a disability and families – mainly in metropolitan areas – thought that personalised funding would create competition in the sector, which could exercise some control on prices. This was not a widespread view and not shared by people living in regional and rural areas who wanted more price restrictions.

*“If prices are not fair, then government funding is wasted.”*

Family member of a person with a disability

There was no consistency in the views of service providers on who should set prices. A number were concerned about government setting prices on their behalf and about bearing the costs of providing more flexible supports without adequate revenue. On the other hand, some service providers were concerned that if they were left to set prices themselves the ensuing competition may lead to some providers being 'priced out' of the market.

Price and cost differences between metropolitan, rural and regional areas were raised consistently – by people with a disability, their families and carers and by service providers. Families and carers in regional areas also raised the issue that transport is challenging and the cost of transport is higher in regional, rural and remote areas. Participants in regional consultations suggested that transport costs needed to be taken into account in determining the packages for individuals who live in these areas so that they are not disadvantaged.

*“Transport is vital to us. Right now we depend on a school bus for transport, which means that access to services and supports is non-existent on weekends and during school holidays.”*

Parent of a person with a disability

Service providers raised a similar issue, stating that the cost of providing services is higher in regional, rural and remote areas and this needs to be reflected in prices for services and the size of packages allocated to individuals needs to take account of these higher prices.

There was concern expressed about administration charges being passed on to people with a disability and that this would detract from the funding in their package. There was mixed support among service providers for the idea of a limit being set for administration charges that can be both charged and passed on to the person with a disability.

### 3.7 Accountabilities for personalised funding

Accountability for funding was a topic of significant discussion during the consultations and all participants supported the need for clear and transparent accountability and reporting mechanisms that ensured funds were spent appropriately.

However, among people with a disability, their families and carers there was no consistent view on what accountability and reporting requirements should be put in place or who would be responsible for reporting. There were a variety of opinions regarding the tension between accountability and flexibility. Many wanted to ensure strict accountability to maintain integrity in the system whilst at the same time creating a system that does not require onerous reporting or auditing processes. Many stressed the need for simple and clear rules and guidelines.

Clearly, there are divergent views on the need for rules and the requisite accountabilities to be placed on individuals and families who opt to take up self-management.

*“People will misuse funds if there aren’t rules to check and prevent it.”*

*“There should be minimal rules on what services and supports people can use their funds for in order to be a truly person centred system.”*

Family members of a person with a disability

Many participants expressed a view that financial accountability would be ensured through adherence to the plan if those responsible for developing and delivering particular outcomes were identified in the plan and held accountable for implementation.

One common theme among people with a disability, their families and carers was that people managing the package should be accountable for the use of public funds and delivering the outcomes specified in a person’s plan. People’s views differed on the level of detail required, with some participants stating that people should be accountable and report on every dollar spent whereas others view accountability and reporting as something carried out at a higher level. This could involve a dollar threshold below which expenditure on items are not reported or certain expenditure items not requiring to be reported (e.g. continence aids) or people reporting on the general proportions of expenditure across categories of expenditure rather than reporting each cost item. Most participants agreed on the need to avoid burdensome accountability and reporting requirements.

*“We should be sensible about accounting for and reporting use of funds. Most people will want to spend their funding packages appropriately, and this should be the starting assumption for accountability and reporting requirements.”*

Family member of a person with a disability

A number of participants with a disability, their families and carers stated that service providers should be accountable to them for the delivery of supports but government may also have a role in ensuring that providers deliver quality services.

### 3.8 Impact of personalised funding arrangements on the sector

Many service providers were concerned about their ongoing financial viability under personalised funding particularly the uncertainty and variability of future funding and the possibility that they would receive less funding than they do currently. Service providers raised issues relating to their workforce and certainty of employment for their staff and difficulties in managing a permanent workforce when demand for their services and the revenue they receive may fluctuate.

Some service providers identified the possibility that funding uncertainty may make the disability sector a less attractive place in which to work adding to the recruitment challenges service providers already face.

*“It will inhibit our ability to be innovative to develop new, sustainable models of support.”*

Service provider

Service providers also noted that revenue uncertainty may impact on their long term planning and investment decisions. A number of service providers thought that some services would have to close, though recognised that others may thrive and grow under personalised funding arrangements.

Some service providers were also concerned with the costs and time associated with individual service contracts and debtor management (and following up on payments for the supports and services they provided – from government or from a number of individuals).

However, other service providers saw the opportunity that personalised funding arrangements could have on the design of services, freeing them from restrictive contractual obligations and narrow service type definitions. Providers also saw opportunities to assist people with a disability in the planning stages as well as the management of a funding package and coordination of supports.

*“My organisation has already started speaking to clients and what we are hearing tells us that there are opportunities. Clients will need guidance and advice on the range of different services and supports and how they can be delivered, and we could be there to help.”*

Service provider

Overall, service provider participants identified a need for 'core' funding to support their ongoing operations. This funding could be provided as a block grant to enable them to maintain a minimum level of capacity and support investment in infrastructure and workforce development. Service providers then identified a need for transitional funding so that they could move from block funding to personalised funding and make the required changes to systems, processes and service delivery models.

### 3.9 Summary of views on personalised funding

There was broad support for the concept of personalised funding arrangements from people with a disability as a means for them to have more control over the supports they receive and their own lives.

Families and carers were also supportive though they raised some concerns. One of the main concerns related to the capacity of some people with a severe disability to manage funding and direct how funding is used. This was particularly an issue raised by families and carers of people with intellectual disability.

Some families and carers were excited by the prospect and that they could be in 'full control'; others were concerned about the additional time and effort required to manage a package. There was generally support for the ability to choose to have a third party manage a funding package on a person's behalf. There were views that the costs of this should be met from outside an individual's package.

There were concerns raised by service providers around the impact of personalised funding arrangements on revenue and revenue certainty and thus ongoing service viability. Service providers were concerned that reduced funding certainty would impact on their ability to be innovative and to develop new, sustainable models of support. Some service providers were also concerned with the costs and time associated with individual service contracts and debtor management.

All participants agreed that the allocation of funding should be based on a fair and robust needs assessment process. Some participants thought that the amount in a funding package should be based on a person's plan. Others thought that a fairer way would be for the amount to be determined up-front and the plan based on this.

There were differing views on how a funding package should be structured and whether parts of a funding package should be restricted or 'quarantined' for specific purposes. Families and carers saw the benefit of having as few restrictions as possible.

People with a disability and families and carers identified the importance of receiving value for money for their funding package and paying a 'fair price' for services. This might mean setting maximum prices for different support types. There was concern that prices may be higher in rural and regional areas and they should make an allowance for the costs of transport to use supports.

All participants recognised that people managing the package should be accountable for the use of public funds and delivering the outcomes specified in a person's plan. People differed on the level of detail required with some participants stating that people should be accountable for, and report on, every dollar spent, whereas others view accountability and reporting as something carried out at a higher level.

## 4 Personalised service delivery

### 4.1 Introduction

Stakeholders at the consultations were asked to think about and discuss person centred services and a person centred service system.

People with a disability, families and carers were asked to consider and provide their views about:

- what a person centred service looks like
- the kinds of services they would like
- how the service system would need to change to be responsive to their life and to better serve them.

Service providers were asked to consider the impact of moving to a person centred approach for both their own service and the sector as a whole.

In particular, they were asked for their views about:

- what a person centred service looks like
- how a move to a person centred service delivery approach would impact on the sector
- the challenges for the workforce in being more flexible
- the assistance that service providers may need to manage the transition.

### 4.2 Support for person centred services

During the consultations there was overwhelming support for person centred practice. Person centred practice is seen as an attitude or culture that translates into a way of operating that supports people with a disability to live the life they wish. In a person centred service, a person with a disability is listened to, heard, respected and encouraged to exercise choice and control to the greatest extent possible.

A number of people with a disability, families and carers and service providers shared accounts of how services have become more person centred in recent times. There were a number of positive stories of person centred practice, including direct accounts from people with a disability who had changed their lives significantly as a result.

*“My son’s current [individualised] early intervention service...is a fantastic model. It is so reassuring to have an organisation that I know I can turn to if I have any problems, where I feel my concerns matter.”*

Parent of a person with a disability

Some families and carers expressed the view that the services their family member used were already person centred and there was no need to change a service that “wasn’t broken”. Parents whose children were in supported accommodation (group homes or residential care) frequently expressed a view that they had “fought” to get access to the service in the first place and they were concerned about the impact of change. In particular, there are concerns about the impact on individuals and families of moving people into independent living in the community without adequate support. Parents and family members were concerned about whether their loved one would eat well, look after themselves and be safe living alone in the community.

Some participants in sessions conducted in languages other than English said that the apparent lack of cultural awareness on the part of service providers means that a lot of clients from culturally and linguistically diverse backgrounds think accessing services is a waste of time. It was stated that service providers need to assure prospective clients that they will be protected from stigma and discrimination.

Service providers generally support the concept of a person centred system. However, understanding what that means in practice varies. Some service providers already view themselves as operating in a person centred way. Some service providers desire further change to enable their service to become more flexible and responsive and are eager to see this approach throughout the entire system. Other service providers were supportive of a person centred approach but grapple with the many challenges and solutions required to reorientate their service and the system as a whole. The need for flexibility in terms of service offerings and the real and practical implications for managing the workforce were seen as the greatest challenge.

### 4.3 What does a person centred service and system look like?

There was a broad consensus across all stakeholder groups about what person centred services 'look and feel' like. In summary, a person centred service:

- listens to a person with a disability, their family and carers and respects their opinions and views
- provides an opportunity to discuss people's expectations as well as language and cultural requirements in the provision of services and supports
- empowers and supports people with a disability to plan for and achieve their goals and aspirations
- enables and encourages people with a disability and their family to exercise choice in supports and providers
- empowers people with a disability and their family to participate in designing and controlling their own supports (e.g. through planning and funding packages)
- responds to a person with a disability and their family's needs and circumstances quickly and in a flexible way
- provides services of a high quality
- engages passionate, well trained and qualified staff.

*"The system should give us a say in the flexibility of services in terms of times of availability, frequency, how and where the services can be provided."*

Family member of a person with a disability

*"Service providers need to take us seriously – to listen to us."*

Family member of a person with a disability

Some participants provided examples of services and supports that they currently use and consider person centred. For example:

- a) **Individual plans.** Many people with a disability, their families and carers spoke of the use of individual plans as enabling existing services to work in a more person centred way. Individual plans were said to enable a person's likes/dislikes, goals and aspirations to be identified and known by service providers so that supports could be put in place to assist the individual to work towards them. This was evidenced as putting a person with a disability at the centre of service delivery.
- b) **Community Participation.** This existing ADHC program was referred to by many as enabling services to work in a person centred way. The services involved in the program were cited as thinking outside traditional disability services and supports in order to provide person centred supports with numerous benefits for individuals, families and the community. Two examples are provided below.



*“Through the personalised planning process in the Community Participation program I was able to change existing disability supports to focus on equestrian sports and support my aspiration to become skilled in dressage. I am now ranked in the top five riders in Australia in my division.”*

Person with a disability

*“My son is supported by a service provider to pursue his passion for fishing. He has joined a community fishing group and it gives him something to look forward to each week.”*

Parent of a person with a disability

- c) Examples of support being provided to people with a disability, their families and carers in more innovative, self directed ways. One example is provided below.

*“I take care of my grandson who has a disability but I was having difficulty with day-to-day tasks of caring for him. Getting to the washing line was painful, and I told this to ADHC. Rather than giving me a home care service (which I would have disliked), they built me a new path to my washing line. Now I can do the washing and take care of my grandson.”*

Grandparent of a person with a disability

Despite these real life examples, person centred approaches are not mainstream practice yet. Participants representing all stakeholder groups recognised that there are constraints within the current system that work against person centred practice. Prescriptive funding and service agreements, workforce and workplace regulation were identified as presenting real challenges to person centred practice.

Many services equated the adoption of personalised planning with being a person centred service. While the move to person centred planning with individuals was welcomed by many people with a disability and their families and carers, there is a desire for deeper change.

*“We need a whole-of-system change. Personal planning is great, but we need the right services and supports, the right attitudes and the right resources.”*

Family member of a person with a disability

Some participants talked about the need for a personal plan to support access to multiple services whether disability specific or other services. For example, a number of parents with children of school age suggested that a plan for their child should link with existing education plans in the school system. Similar views were expressed about linking plans with the health system. This kind of cross service linkage does not currently exist and is a source of frustration for many families.

## 4.4 Who can deliver services?

There were mixed views across and within stakeholder groups about who can provide services in a person centred system beyond traditional disability service providers.

### Mainstream services

The majority of people with a disability, their families and carers supported the use of funding to purchase mainstream supports and services, i.e. things that sit outside disability specific services. Gym memberships, mainstream community leisure activities and TAFE classes were given as examples because these services provide support to an individual with the advantage of promoting independence and participation in the broader community. Another idea was for funding to train identified people from a specific cultural or language community to either deliver disability services or better tailor their service to people with a disability.

The views of service providers were mixed. Some recognised that mainstream services can provide different types of support to an individual. Mainstream services may meet the needs of the individual, family and carer in a more flexible and tailored way and provide benefits from a social inclusion and community development perspective.

*“Mainstream services have been out of reach but my daughter would love to have art lessons. Art therapy, music therapy... there are proven benefits from using these types of mainstream services.”*

Parent of a person with a disability

Participants in consultations conducted in languages other than English also wanted greater access to mainstream services.

Whilst there is support for choice in terms of a person's access to services, some participants raised concerns regarding the use of mainstream services. For example, a mainstream service may not have the necessary equipment or comply with the quality and safety standards to which disability services and their staff adhere. There is a concern that people will not know whether a service is good or how to choose between mainstream service options. Some participants suggested there is a need for some form of regulation or accreditation of disability service providers. Also, feedback was received from sessions conducted in languages other than English that mainstream services need to consider cultural competency training including the use of interpreters so they can provide more culturally appropriate services.

## Family members and friends

A key issue in terms of person centred practice is the importance of the relationship between the person with a disability and the person providing care or support. Many participants talked about the impact of this relationship on their lives and the difference it makes when the person providing support is someone who they trust, like and respect. Freedom to choose the person who provides support is a key part of person centred practice. However, the potential extension of choice to employing/paying family members or friends to provide services and supports is complex and raised mixed views amongst and within stakeholder groups.

Amongst people with a disability, there were differing views. Some welcomed the opportunity to employ family members or friends. They said it involved them in their lives and formally recognised the support that they already provide. Others expressed the view that they would like to keep some elements of their care and support separate from their family and friendship networks. Similar views were held by families. Parents with young children tended to support the idea, whereas parents of older children, siblings or partners of a person with a disability expressed a preference for external service providers, rather than family members or friends.

*“Families need time off from caring for their child or sibling with a disability. But they may turn to extended relatives who know and care for the person, and understand the situation.”*

Parent of a person with a disability

Participants in consultations conducted in languages other than English highlighted that there needs to be a shift in the way that families from culturally and linguistically diverse backgrounds perceive disability and families are reluctant to seek external support as a result.

*“Embarrassment is very important and to ask for help may mean ‘losing face’...help-seeking can be considered unacceptable.”*

Family member of a person with a disability

Whilst there is consensus around the importance of choice, there is also recognition that employing family members and friends changes the relationship and the dynamic between an individual and the broader family and social network. Some saw potential for this to extend their purchasing power and to get greater value out of a package. Examples were given about the cost of formal respite services versus employing a friend or family member on an hourly rate.

The inherent risks of hiring family members and friends were discussed in many sessions. Participants acknowledged the changes in family and social dynamics that can occur as a result of introducing an employer/employee relationship. Participants cited instances where the wishes of a person with a disability are in conflict with that of the family or carer as a challenge for this model. Additionally, there was concern that some people with a disability, despite the best intentions, may not get the entirety of their needs met, may not receive high quality or safe services and supports or may even be at risk of being exploited or isolated as a result of separation from a disability service provider.

*“We need to know that people won’t be exploited. The trouble is it will be difficult to prove unless something bad happens.”*

Service provider

### Employing staff

Many people with a disability and family members who participated in the consultations expressed an interest in employing their own staff to provide supports. This triggered a great deal of discussion around the real and practical challenges posed by industrial agreements, occupational health and safety, insurance, quality assurance, income tax and other business and administrative matters related to workforce and workplace relations.

Service providers expressed mixed views. Some saw the extension of choice in terms of who provides support as a step forward in providing tailored and flexible support options. Some providers also moved to discuss how they might assist people with a disability, their families and carers with the practicalities of the employer/employee relationship by acting as a kind of broker/advisory service.

Service providers were able to discuss the complexity of the administrative, regulatory and industrial context under which this arrangement would fall. Concerns were raised regarding the nature of the employment relationship, whether people would be employed as casuals, permanent staff or engaged as subcontractors and the effect of this on the rest of the sector.

*“I am worried that a casualisation of the workplace will occur. Attracting and retaining staff is vital to us and clients.”*

Service provider

Award wages and conditions and security in employment were raised as real concerns. Also raised was the potential undermining of the professionalism of the disability sector’s workforce by the introduction of casual workers who are not necessarily skilled, trained or qualified in the provision of disability services and supports or who are employed in working arrangements which do not comply with occupational health and safety laws, minimum wage or workplace award conditions.

Service providers expressed concerns about the ability of people with a disability, their families and their employees to negotiate and comply with the variety of industrial, occupational health and safety, quality standards and other regulations. There was discussion about the need to assist people with a disability, families and carers to negotiate this system and a view that this assistance could come from service providers or ADHC.

## 4.5 Choice and competition

Choice is a key feature of a person centred system. In the consultation sessions held to date, there was consensus across stakeholders that people with a disability, their families and carers want to be able to choose the types of services and supports that best suit their needs, aspirations and circumstances and influence the way they are provided.

People with a disability, families and carers consistently raised concerns about their inability to exercise choice within the existing system and the lack of services from which to choose. Lack of choice in terms of service providers and service options was raised by people with a disability, families and carers across metropolitan and non-metropolitan areas, although it was felt more keenly in non-metropolitan areas.

The introduction of portability in terms of a person's funding was viewed by all as a real driver and incentive for new organisations to enter the market or for existing providers to diversify their service offerings.

*“Because individual funding is brought into the open market...competition between services should improve the level of service offered.”*

Written submission – community organisation

During the discussions, the positives of stimulating competition to promote greater choice were weighed against the challenges and potential pitfalls. Whilst there was consensus that a more competitive system could offer more choice, there is also a risk that it could undermine quality and increase costs if it is not regulated appropriately. For example, new services could ‘spring up’ on a for-profit basis, purporting to offer cheaper services but doing so at the expense of quality. This could produce a ‘race to the bottom’ in terms of cost and quality.

Service providers recognised that they would need to potentially re-think the way that services operate, are priced and resourced. Some providers felt that a more competitive system would mean that they would need to advertise their services better, which would involve allocating time and funds away from service delivery.

*“In the short-term, service providers who market themselves better will attract the clients and it will take time and courage for clients to try other places.”*

Service provider

Other service providers were confident that the quality of their service and existing client base would mean that no significant change would be required. They were confident in the quality, price and sustainability of their service. In fact, they saw the opposite problem – turning too many people away from their service due to increased demand for their service. There was a similarly divergent view about whether competition would support or inhibit the growth and survival of smaller niche services.

Collaboration was identified by service providers as a key means of overcoming some of the challenges of a transition to a more competitive environment. This could include working together to promote service offerings, developing and implementing an enhanced referral system, expanding and diversifying service offerings to meet the changing needs of people with a disability and, in some cases, joining with other providers to offer a broader suite of services. Collaboration, as a result of competition, was seen as a positive outcome.

## 4.6 Quality of services

Ensuring the quality of services and supports was a clear theme in the consultations. The need to ensure quality and safety is universally recognised but there is a diversity of views about how best to do that and the need for regulation, for example, against quality standards.

In the discussions held to date, a number of providers talked about the importance of quality and safety standards and expressed concerns that new service providers, including family/friend employees or mainstream services, would not have or be able to reach the same standards. They saw this tension as being detrimental to the support and care of people with a disability and unfair in the context of a more competitive environment.

Many people with a disability, families and service providers, therefore, supported a requirement that funding could only be used for service providers that had obtained accreditation against quality standards.

There is also a strongly held view amongst people with a disability, their families and carers that they need information about the quality of the services that exist, what they provide and to whom, in what area and to what standard. Some participants raised the idea of a quality rating system as a credible and reliable way of comparing services in order to choose between them.

## 4.7 Workforce

People with a disability, families and carers identified workforce issues as important to a person centred service. Skilled, trained, qualified, passionate, respectful, flexible and innovative workers were seen as the lifeblood of the system. There was recognition that these workers are in high demand.

*“Our worker is terrific and we would love for everyone to have the same level of service as us. But currently with poor quality staff around, it only makes us worried that she will either take in more families and give us less time, or disappear from being fed up with the system.”*

Family member of a person with a disability

People with a disability spoke of the need to have a connection with workers. Workers are an integral part of their daily life and they would like a relationship that is appropriate to their age, gender, needs and circumstances. For people from culturally and linguistically diverse backgrounds, this extends to culture and language which underscores the importance of bilingual workers and interpreters. People with a disability also spoke of the importance of continuity and the time it takes to build trust and rapport. Family members and carers spoke of the need to have flexible, ‘can-do’, reliable, trustworthy, committed and long term staff working in their home or with their family member. Some parents of children with autism, particularly, noted the importance of a mid-long term timeframe (years rather than months) in terms of staffing due to the difficulty a change in patterns and relationships can cause.

It was noted by both stakeholder groups that it is difficult to attract and retain quality and passionate staff to the sector. Generally low wages and conditions were cited as a disincentive for workers to stay in the one job or sector for a long time.

Services also noted the difficulty of attracting and retaining skilled, trained and qualified staff with the right ‘fit’. Wages, conditions and permanency were said to be challenges. In this context, a move to more flexible practice raises real challenges. A person centred system that is responsive to people with a disability means getting out of the 9am to 3pm service paradigm.

The expectation and demand for services and supports to fit around a person most likely being offered at different times of day, perhaps even on a 24-7 basis, raises real workforce issues. Low wages and restrictive award conditions present a real barrier and disincentive to flexible operation and could place additional stresses on a system in which it is already difficult to attract and retain people.

*“There is potential for burn out of staff who work outside normal hours. Taking time in lieu of working additional time can place a strain on remaining service team and service capacity.”*

Service provider

There is a strong view that wages and conditions need to be maintained or improved. However, this is contradicted by the view that there would be economic benefits in being able to employ family members or friends at a lower rate than formal service providers.

## 4.8 Other issues for consideration in implementation

### Cultural change

Cultural change is viewed as necessary at a sector, service and individual level to make the system person centred. People with a disability, families and carers spoke of the need for a deep and lasting culture change, including the way individual staff interact with people. At its heart, placing the person at the centre of a service requires listening to people with a disability, their families and carers, respecting their views and taking action to support those views.

*“The way that staff interact with people needs to change, not necessarily the actual services offered.”*

Person with a disability

*“The disabled community are now consumers and providers need to provide a quality service that attracts business.”*

Service provider

### Sharing information

People with a disability, their families and carers consistently raised the need for services, ADHC and other government departments and agencies to share information about their needs and circumstances. Many examples were given of having to ‘re-tell’ one’s story repeatedly to a service provider, ADHC or other government departments and agencies. This was said to be frustrating, time consuming and stressful for people with a disability and their families and carers. Furthermore, it can be traumatic to have to re-detail the specific injuries causing a disability, circumstances or personal history in order to use a service.

Participants spoke of having to state and repeatedly confirm that their disability has not changed. Personal accounts were given of people with permanent spinal cord damage having to confirm that they ‘still’ used a wheelchair.

Centrelink, State Government departments, hospitals, general practitioners, other health providers, disability service providers and ADHC were identified as agencies that could work together better to collect and share a person’s ‘story’ in order to alleviate stress and save time and resources.

*“The state and federal governments need to talk to each other so we don’t have to tell our story over and over again.”*

Person with a disability



Duplication could also be reduced at a service level by services keeping a consolidated record and using this record when they are required to update ADHC. People with a disability, their families and carers acknowledged that many of these constraints arise as a result of privacy laws designed to protect the confidentiality of their information. However, there was a suggestion that people should be able to choose to opt-in, to have their information shared across agencies if they wished. Service providers raised concerns with privacy but generally were more supportive of the concept of the consent-based opt-in model.

#### Identification of service providers

Service providers acknowledged that 'cherry picking' is a recognised issue. Some families may find it difficult to identify service providers from whom they can access the necessary supports for the person with a disability. This can be a particular issue in circumstances where there are challenging behaviours which could place staff or property at risk.

*“There will be clients that will be more profitable than others, and if service providers cherry pick it will have impact for the rest of the sector.”*

Service provider

#### Reporting and administration

Services identified that the existing system can present onerous reporting and administration requirements. There were concerns about how this would change under a new approach. It was felt that personalised funding would introduce individualised reporting and accountability to the individual as well as to government as the funder. There was a general concern that reporting and administration will increase under this type of approach absorbing a disproportionate amount of resources and detracting from the core business of service delivery.

## 4.9 Support for services

Service providers identified a need for support from Government to move to a person centred approach. In particular, assistance was requested to support:

- service design and re-orientation;
- marketing of services;
- transitional funding to ensure viability of services;
- funding to cover core operating costs;
- specific funding for small and/or niche services to ensure viability and the continuation of specific services to meet specific needs – particularly in rural and regional areas;
- governance;
- collaboration and sharing of information about clients;
- management of workforce issues; and
- promotion of ‘good practice’ case studies and examples.

## 4.10 Summary of views on person centred services

There was overwhelming support from people with a disability for person centred practice. Person centred practice is seen as an attitude or culture that ensures a person with a disability is listened to, heard, respected and encouraged to exercise choice and control to the greatest extent possible.

Some families and carers expressed the view that they thought the services their family member used were already person centred and there was no need to change a service that ‘wasn’t broken’. Family members of people living in supported accommodation (group homes or residential care) frequently expressed a view that they had ‘fought’ to get access to the service in the first place and they were concerned about the impact of change, in particular, moving people into independent living in the community without adequate support.

There were mixed views about who should provide services. The majority of people with a disability, families and carers supported the use of funding to purchase mainstream supports and services, i.e. things that sit outside the disability specific services. Some also welcomed the opportunity to employ family members or friends. Others expressed the view that they would like to keep some elements of their care and support separate from their family and friendship networks.

Many people with a disability and family members who participated in the consultations expressed an interest in employing their own staff to provide supports. This triggered a great deal of discussion around the real and practical challenges posed by industrial agreements, occupational health and safety, insurance, quality assurance, income tax and other business and administrative matters related to workforce and workplace relations.

There was consensus that a more competitive system could offer more choice, However, some participants believed that there is also a risk that it could undermine quality and increase costs if it is not regulated appropriately. For example, new services could 'spring up' on a for-profit basis, purporting to offer cheaper services but doing so at the expense of quality. Many people with a disability, families and service providers, therefore, supported a requirement that funding could only be used for service providers which had obtained accreditation against quality standards.

People with a disability, families and carers identified workforce issues as important to a person centred service. Skilled, trained, qualified, passionate, respectful, flexible and innovative workers were seen as the lifeblood of the system. It was noted by both stakeholder groups that it is difficult to attract and retain quality and passionate staff to the sector. Generally low wages and conditions were cited as a disincentive for workers to stay in the one job or sector for a long time. The additional demands of providing a flexible service, such as outside business hours, were seen as a further challenge for workforce retention.

## 5 Next steps

The consultations generated robust discussion and numerous ideas for improvements to the current system. The ideas, issues and outcomes identified in the consultations and summit will be used to develop a person centred model for supporting people with a disability in NSW.

The development of a person centred model will be further discussed in an additional round of consultations across NSW to be held in the first half of 2012.

## 6 Appendices

### A Location and dates of generalist consultations

Location	Date – 2011
Albury	10 & 11 August
Armidale	29 & 30 August
Ashfield	9 & 11 August
Bathurst	18 & 19 August
Baulkham Hills	10 & 17 August
Blacktown	19 August
Blue Mountains	18 & 19 August
Broken Hill	15 & 16 August
Burwood	8 & 10 August
Campbelltown	4 & 9 August & 13 September
Central Coast (for Hunter Residences)	20 October
Coffs Harbour	1 & 2 September
Dee Why	14 September
Dubbo	15 & 16 August
Fairfield	5 & 10 August
Gosford	22 & 23 August
Goulburn	17 & 18 August
GyMEA	3 & 8 August
Hornsby	18 & 19 August and 12 September
Kogarah	1 & 2 August
Lismore	25 & 26 August
Maitland	22 August
Moruya	31 August
Kingsford	15 September
Newcastle	23 & 24 August
Nowra	10 & 11 August
Orange	16 & 17 August
Parramatta	15 & 16 August
Penrith	16 & 17 August
Port Macquarie	29 & 30 August

<b>Location</b>	<b>Date – 2011</b>
Port Stephens	25 & 26 August
Queanbeyan	15 & 16 August
Rydalmere ADHC Residence	10 September
Stockton Centre (for Hunter Residences)	26 October
Tamworth	31 August & 1 September
Tweed heads	18 & 19 August
Wagga Wagga	8 & 9 August
West Ryde	11 & 12 August & 14 September
Wollongong	8 & 9 August
Wyong	31 August & 1 September

## B Languages and dates of consultations conducted in languages other than English

<b>Location</b>	<b>Date – 2011</b>
Mandarin	10 October
Polish	10 October
Tamil	11 October
Vietnamese	11 October
Bengali	12 October
Nepali	13 October
Korean	13 October
Hindi	13 October
Russian	14 October
Tagalog	14 October
Dinka	14 October
Shona	17 October
Cantonese	17 October
Arabic	17 October
Spanish	18 October
Italian	19 October
Greek	20 October
English (service providers)	18 October