

Challenge Paper No. 2

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Unfair Exclusion: The Outcome of Victoria's Disability Services Access Policy

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Background

The Victorian State Disability Plan 2002-2012 (the State Plan) initiated a reorientation of disability services aimed at changing the way the system operates as a whole. In May 2006 the Victorian Parliament passed new disability legislation. It was this legislation, the Disability Act 2006 (the Act), which led to new policy regarding access to disability services and funding. The policy to implement the Act comes from Victoria’s Department of Human Services (DHS).

This Paper analyses the DHS Access Policy (the policy) in the context of the reforms taking place in the provision of disability services. The implications of the policy for the availability of service options and choice are also addressed.

The writer submits that unfair exclusion is the principal outcome and cost-shifting is a consequence of this policy. These adverse outcomes mean that the policy fails to deliver a process that responds positively to the individual needs and choices of persons with a disability, and to the needs and choices of their families. This policy failure is a significant element underpinning the failure of the Victorian Government and DHS to achieve a service system responsive to the people it is meant to support.

1. The Access Policy and Ideology

The history of the development of disability services over the past four to five decades highlights that the driver for change has been an evolving ideology. In its infancy the ideology was characterised by normalisation and the promotion of rights. In more recent times this has evolved into the current ideology of community and social inclusion and market-driven individualism. The State Plan, which set the course for the reorientation of disability services in Victoria, adopted “*a whole-of-government and whole-of-life community approach to disability*”. The Act, which of course was preceded by the State Plan, while embracing participation in the community also emphasises the significant requirements of rights, individual choice, flexibility, responsiveness and respecting the role of the family.

In the context of the Access Policy the relationships between the current ideology, the State Plan and the requirements of the Act cannot be ignored. This paper argues that while the policy is driven by the current ideology of community inclusion and market-driven individualism, it fails to embrace the four guiding principles articulated in the State Plan: Equality – Choice – Diversity – Non-Discrimination. The Paper also argues the policy fails to meet the requirements of the Act in that it is restrictive and seeks to exclude.

While the writer acknowledges the importance of ideology as desirable in guiding a major initiative such as service reorientation, he challenges any circumstance where the ideology becomes the objective. In analysing the Access Policy further below, he exposes the barriers created by what has become the blind crusade promoting community inclusion as the only pathway. In the words of a former Prime Minister E. G. Whitlam, “*All ideological crusades bear the hall-marks of blindness and self-righteousness*”.

Individual rights and choice have been made subservient to the blind and self-serving righteousness that markets generic and informal services as the principal response to meet the needs of persons with a disability. The writer challenges the most ardent ideologically pure who suggest that specialist disability supports can always be best provided by generic providers in generic settings. He also challenges the single-pathway community inclusion advocates to explain how excluding specialist disability supports as a readily available option is not contradictory to the individual’s right to choose.

2. The Access Policy and the Legislative Framework

The Act sets out that access rules are required to be established. Section 8 (2) (d) of the Act requires the department’s Secretary *“to develop and publish criteria to enable priority of access to disability services to be determined in a fair manner”*.

The department argues that the three elements below represent the required criteria enabling priority of access to be determined in a fair manner:

- determining the suitability of the disability service system
- applying priority of access indicators
- applying program specific criteria

While each of these elements is challenged on specific grounds, they are also rejected because they fail to meet the requirements of the Act. They do not represent elements that are measurable and enable access decisions to be made in a fair manner, and in no way can they be considered as representing a set of criteria.

In relation to the first it is contradictory to suggest that even though a person has been assessed as having a disability there is no automatic right of access, but instead it must be first determined whether or not the disability service system is suitable to meet the person’s needs. This first barrier to entry contradicts the person’s right to self-determination or choice as detailed in the State Plan.

The Act requires publication of criteria to ensure fairness. By definition this demands that the criteria be able to determine between one applicant and another in order to assess who has the higher level of priority. The department’s suggestion the three elements actually represent criteria is foolish. Criteria and indicators are not one and the same and it is nonsensical to suggest they are.

If, for example, the concept of indicators as opposed to clear and detailed criteria or rules applied to other legislative requirements such as road rules, education attendance, or access to Centrelink benefits, there would be a public outcry. The criteria determining access to disability services should be equally transparent and rigorous.

The above is brought into even sharper focus when considered in light of the department having recently contracted for the development of a support needs profiling tool. The tool’s development is positive given its intent to provide objective

measures of support needs which will link to a funding level for those who have passed access tests by having gained admission to the Disability Support Register (DSR). However, the department’s acknowledgment of the need to have an objectives measure in allocating funds contrasts sharply with their attitude in denying objective criteria to determine priority of access.

Fairness has two levels. First, the level of ensuring the person being assessed has been assessed against the published criteria. Second, the ability to demonstrate how a decision not to approve access for one person is fair when considered relative to another person who has been granted access. If fairness and transparency are to apply in determining access, then a detailed checklist and rating system must be published and applied.

However, the department has stated, *“There is no planned introduction of a rating system to apply to the decision making process regarding service access”*. Without this system the determination of access will continue to operate as a secret service, with the ever-present potential for the ‘squeaky wheel’ principle to determine priority.

Notwithstanding the above, the notion that one person’s needs and circumstances are of a higher priority than others sends two signals. The first, assessed needs are not about the individual and his or her right to receive a funded service, but are simply used as a basis for a subjective comparative analysis. The second, the system operates as a crisis response. Therefore, given that identified needs are not met at the time they are identified, then the system will always be crisis driven, because needs not met now will become a crisis in the future - unless of course the person dies before this point is reached. This approach to access fails the State Plan test in that it is discriminatory and denies equality.

The word ‘program’ is used in a number of different contexts in various departmental publications, and thus the reference to ‘program criteria’ as one of the three elements conveys a sense of vagueness. For example: What are the programs which are included? Is it possible a particular program in one agency may have different entry rules to the rules of a similar program in another agency? Are the criteria published? Does meeting the program criteria guarantee an automatic right of access to the broader disability service system? Does it guarantee an automatic right of access to the particular program? No answers to any of these critical questions appear anywhere in the Access Policy documents. Without the answers it must be assumed that the requirement of fairness is at best doubtful and at worst ignored.

It is incongruous with the Secretary’s responsibility to develop and publish criteria that disability service providers must make information about specific program related guidelines readily available, as though these represent the Secretary’s criteria.

The Act also makes reference to the provision of assistance with planning by service providers. The requirement of a person having a plan has a direct relationship to the access process, and is discussed further below.

The Disability Act, like any other piece of legislation, imposes on the entity to which it refers certain obligations. As shown above the Access Policy does not adhere to the legislation that gave birth to it and thus is seriously flawed at its base. The department has taken licence with the way it has interpreted the Act’s requirements and in so doing has sought to change not only the letter of the Act but also its intent.

3. The Access Rules and Processes

What are the access rules and processes? The two Access documents, the Policy and its Implementation Guide, in their combined 100 plus pages seek to outline the rules and the process to be followed.

(i) Making a request for disability services

The request for access to the disability service system provides for a formal and informal response. The formal response applies when a person with a disability or a person acting on their behalf requests a service from a provider who provides the service requested. The informal response applies in circumstances where the request for a particular service is not provided by the provider to whom the request is made. The determination on the request must be provided within a maximum of six weeks.

Analysis

The first step of the process identifies two inconsistencies. First, a failure to distinguish between what might be described as the service system, services and service providers, and thus the inconsistency of what access actually means. Does this mean when a person makes an access request to disability services, separate requests must be made to multiple providers if different supports are identified by the person?

The fact the Act allows any disability service provider to perform the role of gatekeeper when a request for access is made to them creates the second inconsistency. The decision of either allowing or disallowing access is therefore spread across each of the department’s eight regions and in excess of 250 registered service providers. The absence of specified objective based criteria, and instead relying on the application of the three elements, means the decision to allow or disallow access becomes a matter of subjective opinion and contravenes the legislative requirement of fairness.

(ii) Determining whether a person has a disability

While some might argue the Act’s definitions of disability in relation to a person are exclusionary, in fact the determination of whether a person has a disability must be considered as the test for access to disability services.

Analysis

Despite the legislative determination, the policy sets rules that seek to exclude persons with a disability from the disability service system on the basis generic service must first be explored. And then explored again and yet again throughout the process.

(iii) Determining priority of access

The Act refers to access as being a priority determination, and thus operating under this requirement the policy sets out the rules for making such a determination.

When determining whether or not a person is a priority for access to services, the disability service provider is required to discuss with the person their goals and needs, and consider their current circumstances. This should include a discussion about the current supports that may be in place for the person through generic services or family and informal networks, and options that could be explored to further develop these informal networks and generic supports.

Through this discussion, a disability service provider may believe, even though a person has a disability, that their needs could best be met with a response from outside the disability service system - in other words, divert them from the specialist system.

The process then follows a three-tiered approach in order to determine if priority of access exists for the person. The first two levels of the assessment process list “*priority of access indicators*” which are verbal descriptors only as opposed to hard-edged objective measures. In addition to the priority indicators, disability service providers are then required to consider any program specific criteria for access to the disability services they provide - either a directly funded service or in response to a person with individual funding - before making a decision whether or not to agree to the request for services. .

Analysis

While the process at a surface level may appear to be rigorous, it is essential to remind ourselves the policy states that the priority indicators “*must be used by all disability service providers in determining who is a priority for access to services.*” While the writer acknowledges the requirements of the Act to develop criteria “*to enable priority of access to disability services*”, he notes the policy’s wording “*determining who is a priority for access*” alters the Act’s obvious intent. In enabling priority of access, the Act conveys an inclusionary intent. Or, in other words, where a clear need is identified, access is a priority and therefore must occur.

The policy’s wording “*determining who is a priority for access*” signals the potential for the determination to simply be one of identifying those who are assessed as a priority to simply access a waiting list. As noted further below, it is reasonable to assume this is the purpose of the DSR.

By stating, *“Given their finite nature, the allocation of resources must be efficient, equitable and maximise options for people with a disability to create independence and promote their participation in the community”*, the policy’s assessment processes are obviously not driven by individual needs and choice, but in the first instance are driven by resource considerations. This statement is of significance also because of its reference to the objective of ensuring equity.

Despite the statement, nowhere in the policy is a definition provided for equity and nowhere in the policy is there an explanation as to how equity is determined.

Equity of course not only means being fair and just, but clearly in the context of its use in the policy it means distributing funds and supports to persons with a disability in such a way so as to ensure no one person receives more than another. Herein lays the challenge. In the absence of a published formula, a set of distribution guidelines or some form of allocation to need ratio, meeting the equity objective is impossible.

Given no such mechanism or tool has been developed to date, it means that the current allocation of resources is therefore based on some sort of subjective pick-a-number approach. While the resource allocation tool which is in the process of being developed will assist in distributing funds to those granted access to the system, this does not address the gross inequity for those who have been left out in the cold. Equity for them does not apply.

If equity and fairness are to apply then DHS must explain how it is fair and equitable that:

- One person may have all his identified needs funded while another has only some needs funded?
- Some people receive funds to meet their needs while others receive none?
- Some people with a disability are granted access to the disability service system and others are not?
- Some people are able to ‘jump the queue’ for supported accommodation, while others who have been waiting for years languish on the DSR?
- Some DHS Regions have a significantly higher ratio of services including respite per head of population, while others have a significantly lower ratio?

These questions require an answer. The State Plan, the Act and DHS through their myriad of policy statements, cannot spout beliefs and intent about equality, equity and fairness unless they can demonstrate how all people with a disability are treated fairly and equitably. Not to do so sends but one message: the principle of non-discrimination is simply used in the State Plan as a feel good statement, and analysed in the context of the Access Policy is like the emperor, it has no clothes.

Given the intent to ensure equity and the Act’s requirement for the access determination to be made in a “*fair manner*” the obvious requirements of the policy must therefore ensure the priority access process is transparent, allows for a measurable comparative analysis of individual needs and circumstances, and is objective.

It is to the shame of the Victorian Government and DHS that the Access Policy has not adopted the same direction as articulated by the Federal Government, when in responding to the House of Representatives Standing Committee on Family, Community, Housing and Youth Report “Who Cares ...”, they signalled their intention of “*ensuring that carers have the support they need and, that the people they care for, have the right mix of services and programs.*”

Victoria’s Access Policy fails to lead in this way. Instead, by restricting access to specialist services to only the chosen few regardless of need, and continuing to rely on families and carers as the principal providers of support, the policy constitutes a ‘back to the future’ type response. It can be only hoped that leadership, initiative and innovation are not seen as residing in the way things are being done in disability in Victoria, particularly in the development of a national framework for service planning and access required by the National Disability Agreement.

The failure of the policy to provide criteria which meet the equity requirement, and therefore enable “*priority of access to disability services to be determined in a fair manner*”, is indisputable.

(iv) Planning and access to funded disability supports

Under the Act all persons with a disability have a right to assistance with planning.

The Act also has a support plan requirement when a person is actually getting a service. This should not be confused with the right to assistance with planning which applies even if a person is not receiving any disability funded services.

The Access Policy requires the provider must be satisfied informal and generic supports have been explored and disability services can only be provided when the identified support required is beyond what is accessible in the wider community.

Disability dollars are now being distributed in two ways. There is the direct allocation of funds to a “*disability service provider*”, which can be a funded agency or a department operated service, and persons with a disability make a request for service directly to the provider. Then there is the allocation of funds to a person. This can be as an Individual Support Package (ISP) via the Disability Support Register and, in this time of re-orientation, there is also allocation of

funds to be ‘individually attached’, such as day program dollars or Futures for Young Adults dollars.

Analysis

An anomaly of the planning process exists when a person with a disability prefers to have planning support provided by family or a nominated support person - no funding is provided. The anomaly occurs because if planning support is sought through the department or an agency, the cost of the planning support is met by the entity.

Despite the Act not requiring a plan to have been completed in order to access disability supports, the policy goes beyond this and only permits access as a result of needs identified through an individualised planning process. However, even where an individual plan exists automatic access does not apply. Even when this requirement has been met, access to disability supports will only be considered if the identified supports required are beyond what is available and accessible in the wider community. If the disability supports are unavailable the person goes onto the DSR or another form of waiting list, where they are parked while still awaiting access to an actual service, or their request for serviced is refused.

Thus, the policy not only adds its own requirements above and beyond those required by law, but even when individual planning occurs and funds granted, access to the system is not guaranteed.

(v) A DSR or waiting list

The DSR and its link to the policy is worthy of comment under its own heading. This so-called register was established as a means of placing those people not yet receiving appropriate disability services, but approved for them, on a list. The interesting thing about the DSR is that a person can only be placed on it once approval to access the service system has been granted.

Analysis

The DSR is a blatant attempt by DHS to avoid having to refer to a Waiting List, where the level of unmet need would be far more readily discernable. The Access Policy also somewhat bewilderingly refers to the DSR as a ‘program’. How can a waiting list, however described, be deemed to be a program? How can it be that when someone has not yet been given access to an actual service, they can be deemed to be in a program? Describing the DSR as a program is fraudulent.

This description is also misleading in that while a person must first gain entry to the system to be placed on the DSR; such entry only provides a waiting list ticket to access a service. The description also promotes false hope because

the DSR does not provide any indication of a person’s position on the register, or how long each person on it has been waiting. In a word the DSR is con.

The DSR rules also exclude people from registering a future need, for example, requiring a residential service in two or three year’s time. Thus a person could have identified such a need in their plan, but DHS’s exclusionary rules fail to accommodate this need.

(vi) Facilitating Understanding

Included in the Act’s principles is the right of persons with a disability to access information in a manner appropriate to their needs. The policy states that *“it provides information for people who have a disability as defined by the Act and who make a request for access to disability services.”* During the Parliamentary Legislation Committee’s consideration of the Secretary’s function to develop and publish criteria to enable priority of access to disability services to be determined in a fair manner, the DHS Director of Disability Services stated *inter alia* that *“the intent of this is to actually put it together in one document that is easily accessible to people so that they can understand across the state how priority of access is determined.”*

Despite this assurance, the Access Policy fails to deliver on providing information appropriate to the needs of all persons with a disability. The 32 pages of its content can not be described as being written in a way that describes a process that is easy to follow and understand. As an example, the two process diagrams detailed in the document rather than add value to understanding actually create confusion.

It is reasonable to conclude that the reason the department found it so difficult to produce a clear policy detailing how persons with a disability can actually access the disability service system, is because the process is essentially about exclusion and diversion to generic services. Given the policy’s principal objective is exclusion, it was obviously necessary, given the title of Access Policy, that the department had to drape the contents in language and diagrammatic representations aimed at diverting attention from the real intent.

4. Funding and Cost Shifting

(i) The diversionary tactic

Two standard approaches have become the catch-cries of governments when challenged about decisions taken or not taken. The first, they will seek to diminish or condemn what the opposition did when they were last in government; this being regardless of how long ago this may have been. The second, to wax lyrical about by how much they have increased the budget for whatever program is being questioned.

The current Victorian government has followed this diversionary approach in relation to service provision and funding for disability services. Despite the claims to record budget increases the fact remains there have been no additional accommodation places since approximately 2002 and the level of unmet and under-met needs remains at crisis point.

In terms of the Access Policy, the interest of this paper however is to expose the game of cost-shifting and the folly of promoting the generic system as a single-track approach at the expense of adequately funding specialist service providers and supports.

(ii) Transition to user-pay

As readers will be well aware, the user-pay system is alive and well in the community where if a particular service is required or a person wants to access supports available from generic service providers, there is cost to the customer. This is despite the government’s investment in community facilities and its funding of ISPs, which are allocated on a restricted and priority basis.

Further, given the strategies of the Access Policy to direct people away from the disability service system and towards the general community sector, the cost of accessing generic supports will be an obvious outcome. Therefore, there should be no doubt: the cost of accessing many of the supports previously funded by the government will now be shifted to the service users and their families.

While community inclusion is the tinsel with which the Access Policy as a by-product of service reorientation is wrapped, hidden in the brown paper wrapping are the realities of cost shifting to persons with a disability and their families, and funding reductions in real terms to the funded sector. How is this fair? Clearly, it is not. Those persons with a disability who are excluded from the disability service system are not only treated unfairly by being excluded, but they then cop another whack by being forced to meet the costs of the generic services and supports they then have to access if their unmet needs are to be met to any degree.

Concluding Comment

By failing to provide detailed criteria the Access Policy avoids scrutiny as to the basis for some individuals with a disability being permitted through the access gates while others are not, and how waiting lists, including the DSR, are managed.

By ignoring rights the policy is discriminatory in that it is selective, where only a lucky few will ever access the disability service system. The policy provides false hope in that even when allowed into the system there is no guarantee the required service will be provided immediately, or in the foreseeable future, or indeed ever.

Diverting people from the specialist system no matter what the circumstances and seeking to fit them to the generic system, regardless of need and preference, smacks of discrimination and exclusion.

This Paper therefore proposes that rather than narrow the available services and supports, they must be expanded. Persons with a disability must be given access to specialist disability supports if this is their identified preference; not barred from them.

The challenge for the Victorian Government and DHS must be to immediately amend the current Access Policy. The amendments must ensure access rather than exclusion. They must get rid of the current discriminatory practice where most persons with a disability are unfairly excluded from access to the disability service system. They must get rid of the discriminatory outcome that requires these same persons having to fund their own services and supports, while those fortunate few who are granted access at least have some of their support needs funded by the Government. Although the Disability Act legislates for fairness for all persons with a disability, the Access Policy unfairly excludes most from the disability service system.

The policy must be amended so that rights, choice and self-direction are genuine outcomes, rather than the illusion as seen through the prism of the ideological crusaders.

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The Challenge Papers

This paper is the second in a series called the Challenge Papers. This series has come about as a result of the many and significant changes and reforms occurring in the disability field in Australia. The consequences of these changes and reforms should not be accepted without question, simply because they are handed down from on-high and claim to represent the future.

The Challenge Papers have three aims:

One, to give voice to those who seek open and transparent development of public policy.

Two, to break down the barrier of fear which stifles challenge and debate.

Three, to uphold the right of persons living with disability and their families, to choose services and supports which meet their needs.

The first of these papers, *Fixing the Broken Disability System* responded to a report of the National Disability Strategy Consultation, *Shut out: the Experience of People with Disabilities and their Families in Australia*. This paper is available on request.