
PEOPLE WITH DISABILITIES (WA) INC (PWdWA)
SUBMISSION TO THE PRODUCTIVITY COMMISSION'S
INQUIRY INTO DISABILITY CARE AND SUPPORT
(POST DRAFT REPORT)
MAY 2011

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ORGANISATION PROFILE

PWdWA is a Peak Disability Organisation providing advocacy and information services across Western Australia. Our main services involve Individual and Systemic Advocacy. PWdWA's Disability First Stop is a service that provides assistance to adults with a newly diagnosed disability who need to navigate their way through the disability sector. We encourage self-advocacy wherever possible.

PWdWA is run by and for people with disabilities. PWdWA is committed to its mission:

“Empowering the voices of people with disabilities in Western Australia”

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METHODOLOGY

This submission is based on a collation of information from the following sources:

1. Feedback from public forums on the 'Inquiry into Disability Care and Support' PWdWA staff attended across Western Australia; in Broome (Kimberly region), Claremont (central) and Mandurah (south west).
2. Feedback from our members and associates.
3. Issue raised by PWdWA clients through individual, systemic and self advocacy.
4. Reports, transcripts and submissions published on the Productivity Commission's website.
5. Publically available media releases and speeches.

DISCLAIMER

In accordance with the Privacy Act 1988 and National Disability Service Standard 4, the names of PWdWA clients have not been disclosed in this submission. Note that PWdWA is not responsible for the names or content disclosed by external websites, publications or media releases that have been referred to in this document.

We have tried our best to reflect the views of the Western Australian public in this submission. We recognise that not every Western Australian will agree with all the points made in this document, and welcome public comment on our submission.

INTRODUCTION

PWdWA welcomes the Draft Report and acknowledges the Productivity Commission's efforts to reflect on the content of the submissions and the contributions made at the public hearings. It has been helpful for many to have the difficulties they have experienced through an unfair and underfunded system validated. The Report has given many people with disabilities, and their families and carers, hope of more fulfilling lives. This submission focuses on the National Disability Insurance Scheme (NDIS), though we acknowledge that some points addressed in this document may be relevant to both the NDIS and the National Injury Insurance Scheme (NIIS).

MAIN COMMENTS AND CONCERNS

This submission is divided into five sections. Section 1 considers the Governance of the proposed scheme in empowering the voices of people with disabilities across Australia. Section 2 provides a rationale for independent advocacy to be separately funded under the scheme. Section 3 provides information supporting a national system, as proposed in the Productivity Commission's Draft Report. Section 4 considers the role of the (local) case managers, as named in the Draft Report. Lastly, Section 5 lists our concerns regarding the

Eligibility Criteria for the NDIS and proposed excess charge for some people using the scheme.

1. GOVERNANCE

RECOMMENDATIONS

- 1.1. People with disabilities are consulted at every stage of the development of the scheme, and represented at all levels of governance.
- 1.2. Each State and Territory should be proportionally represented in the governance of the scheme and involved at all stages in developing the scheme, including the first full-scale roll-out of the scheme.

PWdWA supports the establishment of an "independent advisory council comprising of people with disabilities, carers, suppliers of equipment and services, and state and territory service providers and administrators" (Ch. 7, p. 1). We would like to stress that people with disabilities, and people from different state and territories should be represented at every level of governance of the scheme, and involved in the development and monitoring of the scheme. We know from the experiences of our staff and members that gaining access to conferences and meetings in different states can be problematic. We know that attending meetings via the internet is an option but not everyone can easily access the internet. We are aware that these details of the scheme that may be considered at a later date, though we suggest that potential issues and costs involved in governing the scheme should be considered at the early stages.

In the Key Features section of the Draft Report, it is suggested that "The NDIS would begin a full-scale roll-out in one region of Australia in 2014. It would extend to all Australia in 2015 covering those most in need, and then progressively expand coverage to all significant disabilities by 2018" (p. 4). PWdWA recommends that all States and Territories are given the opportunity to be involved in the first roll-out of the scheme. We are also aware from the feedback we have received from people living in rural and remote areas that their experiences of the disability service system differ greatly from the experiences of people

living in metropolitan areas, especially in terms of access to facilities and equipment, and choice of services.

PWdWA strongly supports the Draft Report in placing the 'individual' at the centre of the scheme. We believe that the proposed scheme has the potential to reflect the key principles outlined in the National Disability Strategy 2010-2020, that forms its basis on the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).

We have listed below some key points from the National Disability Strategy (NDS) relating to the governance of the scheme.

National Disability Strategy 2010-2020

Involvement of people with disability (p. 23)

The views of people with disability are central to the design, funding, delivery and evaluation of policies, programs and services which impact on them, with appropriate support and adjustment for participation.

Roles and Responsibilities (p. 24)

People with disability have lived experience of disability and must play a central role in shaping and implementing policies, programs and services that affect them. Governments have a responsibility to ensure inclusion, accessibility and connection across levels of government in all matters affecting the interests of people with disability.

PWdWA recommends that the Final Report makes clear references to the UNCRPD and NDS. We acknowledge that the NDS was only endorsed by the Council of Australian Governments in February 2011 and understand that there was little opportunity for the Productivity Commission to refer to the NDS in the Draft Report.

The next section of this submission will address the role of independent advocacy under the NDIS.

2. INDEPENDENT ADVOCACY

RECOMMENDATIONS

- 2.1. The role of 'independent advocacy' is clearly recognised in the Final Report.
- 2.2. Independent Disability Advocacy Agencies (IDAAs)* are viewed as independent of Services Providers and Disability Support Organisations (DSOs).
- 2.3. Independent disability advocacy is funded separately under the scheme and freely available to participants in the scheme.

* Term used for the purpose of this submission.

We have noticed that the term 'advocacy' is used throughout the Draft Report with no clear indication of whether the report is referring to independent advocacy or advocacy in the general use of the term. We would like to assist the Productivity Commission in helping to clarify the role of 'independent advocacy' in relation to the proposed scheme.

Importantly, the National Disability Strategy 2010-2020, supports "independent advocacy to protect the rights of people with disability" as one of its 12 key areas for future action. Independent advocacy has been mentioned in several submissions made to the productivity commission (e.g., Sub363, Sub490, Sub524 & Sub570), and referred to in the Draft Report Public Hearings in Hobart, Melbourne, Brisbane, Adelaide and Perth. Below, we refer to quotes from two documents that we encourage the Productivity Commission to read in full prior to submitting the Final Report: the National Disability Advocacy Program and the Proposal for a New Administrative and Leadership Framework for Disability Advocacy.

National Disability Advocacy Program

The Department of Families, Housing, Community Services and Indigenous Affairs, FaHCSIA

"In broad terms, advocacy for people with disability can be defined as speaking, acting or writing with minimal conflict of interest on behalf of the interests of a person or group, in order to promote, protect and defend the welfare of and justice for either the person or

group by: 1) being on their side and no one else's; 2) being primarily concerned with their fundamental needs; and 3) remaining loyal and accountable to them in a way which is empathic and vigorous."

Proposal for a New Administrative and Leadership Framework for Disability Advocacy

Disability Advocacy Network Australia (DANA)

"Advocacy support for people with disabilities comes from many sources: family, friends, government officials, service providers and independent advocacy organisations. All possible sources of advocacy support will from time to time have interests that differ from those of the people with disabilities being supported. Many will have limited capacity, knowledge or resources to devote to the task.

Independent advocacy organisations are vital additions to the advocacy support available because they focus on minimising any potential conflicts of interest and on developing their advocacy skills and expertise to achieve the outcomes desired by people with disabilities. They are not beholden to another set of service or government imperatives and so are able to focus wholly on serving the goals and interests of people with disabilities.

The delivery of advocacy support to people with disabilities must be provided by agencies that are able to demonstrate independence from all actual, potential or perceived conflicting interests... To establish independence, an agency needs to have advocacy as its core business and not to be a provider of any of the following services: employment, accommodation support, personal care support, independent living support, respite, vocational training, brokerage, mediation or case management." (p.14)

PWdWA supports the rationale and principles for independent advocacy as outlined in DANA's Proposal. Based on our own knowledge and experience in providing independent advocacy support for people with disabilities, we predict that participants in the scheme may seek independent advocacy for a range of issues, including those relating to -

- NDIA assessment procedures and outcomes;

- NDIA case managers (local coordinators)
- Disability Support Organisations;
- Formal and Informal Support Workers;
- Other Service Providers; and
- Systemic Issues.

NDIA = National Disability Insurance Authority

PWdWA recommends that independent advocacy, provided by not-for-profit organisations, is made freely available to participants in the scheme. PWdWA believes that it would be unfair to expect a person to pay for independent advocacy out of their individual budget, especially when their concerns relate to the scheme itself and the services provided through the scheme. PWdWA suggests that independent disability advocacy should be separately funded under the scheme, where the allocation of funds should take into account the costs of training and workplace development, raising public awareness and the provision of independent advocacy. We have found that often non-legal independent advocates can assist people in addressing issues without the need for legal intervention; which is likely to save considerable time, anxiety and expense. We believe that raising awareness of the availability of independent advocacy will help individuals and organisations to become more accountable for their actions, while providing a safety net for the people participating in the scheme.

As indicated at the Perth Public Hearing, 20 April 2011, PWdWA are not convinced that advocacy services should be performed by DSOs. In our discussion with the Commissioners, it was revealed that there were some inconsistencies in the report regarding the distinct role of DSOs and Service Providers. As a reminder to the Commissioners who will be writing the Final Report, we have cited below the contradicting statements.

Draft Report, Overview (p. 31)

The functions of disability support organisations and service providers could overlap, but should not be exactly the same. Service providers could *act* as disability support organisations for the services from (b) to (f), but could not undertake (a).

Draft Report, Chapter 7 (p. 15)

To avoid conflicts of interest, there would need to be some constraints on the extent to which a DSO could also provide services. In particular, it would not be appropriate for a DSO to act as a service provider. But in other areas — such as assisting with the administrative burdens of self-directed funding — it could also be a provider.

The next section responds to the following key questions we have heard across WA:

“Is the Western Australian disability service system broken?”

“Is a nationally governed system preferable to a state system?”

3. NATIONAL or STATE SYSTEM?

RECOMMENDATION

3.1. PWdWA believes that the national scheme, as set out in the draft report is preferable to the current state disability service system.

There is some debate as to whether or not the current system in Western Australia is broken. PWdWA would like to stress that opinions from the authorities who ‘run the system’ may not necessarily reflect the experiences of the people who ‘use the system’.

In their post Draft Report submission, the WA Government declared that “Western Australia disputes the general assumption that the disability service system is broken... Western Australia’s continued position is that any changes to the disability system should... Ensure state control of funding and administration of any proposed scheme.” (Subdr0683, p. 1). Unfortunately, the WA Government’s submission provides no clear methodology or referencing detailing where they sourced this information from, with no clear evidence that their submission represents the views of the Western Australian people or the non-Government disability sector.

We would also like to note that in both their pre and post Draft Report submissions (Sub0533 and Subdr0683), the WA Government refer to themselves as 'Western Australia', rather than the 'Western Australian Government'. Consequently, we fear that the WA Government's submissions may have given readers an inaccurate account of the views of the Western Australian people.

According to the issues raised by the people with disabilities and their families we consult with on a daily basis, there still exist some significant inconsistencies and gaps within the WA State Government's disability service system.

The main issues raised by PWdWA clients and members include -

- Inconsistencies in funding and assessment outcomes.
- Inconsistencies in service provision.
- Funding cut-off points at crucial stages of transition.
- Lengthy assessment processes.
- Lack of choice and empowerment.
- Uncertainty about the future.

Under the current system in WA, we are aware that people may wait several years to acquire the services they need. In the Perth Public Hearing, 20 April 2011, Karen Miller, representing the Council of Regional Disability Services (CORDS), stated that "There's a belief in WA that the current service system is not broken, yet we have people waiting between one and nine years for funding in the combined applications process, 35 per cent of people more than three years and between 86 and 90 per cent of applicants are rejected at each funding round".

PWdWA has heard from many concerned people with disabilities and their families who are worried that they will lose the services they currently have, that they have often fought hard to get. We understand that the NDIS is based on choice of service provision and has been

designed so that people will not lose the supports they wish to keep, though we suggest that this is made clearer in the Final Report.

We are grateful to the Productivity Commission for producing a Draft Report that incorporates extensive research and consultation, reviews of hundreds of submissions, and feedback from public hearings across Australia, including Western Australia. According to our own research and consultations, and the knowledge we have gained by reading documents published on the Productivity Commission's website, PWdWA supports the following declarations:

"The current disability support system is underfunded, unfair, fragmented, and inefficient, and gives people with a disability little choice and no certainty of access to appropriate supports." (Draft Report Overview, p. 2)

"Families are facing an uncertain future because they can't be confident funding will be there when they need it. There are failures to intervene early, there is lack of clear responsibilities. There is no real choice or power. The system is unsustainable... It's inefficient; it's a maze and has a poor evidence base." (Commissioner Patricia Scott, National Disability and Carer Congress, Melbourne, May 2011)

PWdWA supports a national system which promotes consistency across states and territories. We support the portability of the scheme which we believe would be difficult to implement under state control of funding and administration. We believe that a national scheme has the ability to promote disability awareness across Australia in a way that cannot be matched under state control. We support a national scheme that places Australia in line with other countries who have already successfully implemented schemes focused on self-directed funding and choice for people with disabilities and their families.

The next section of this submission refers to the role of the proposed NDIA Local Case Managers.

4. LOCAL AREA COORDINATION or CASE MANAGEMENT?

RECOMMENDATION

4.1. PWdWA recommends that a local area coordination model is preferable to a case management model.

The Draft Report proposes that "the model of a 'local area coordinator', as used in Western Australia, may be the best form of case management" (Draft Report Ch. 8, p. 14). We would like to clarify that it is our opinion that local area coordinators are not case managers, where case management may be defined as "a collaborative process of assessment, planning, facilitation and advocacy for options and services to meet an individual's health needs through communication and available resources to promote quality cost effective outcomes" (Case Management Society of Australia). Evidently, case management is viewed here as including services that should remain independent under the proposed scheme (e.g., assessments and advocacy). Accordingly, we support People with Disabilities Australia's response to the Draft Report in clarifying that "People with disability are not 'cases', the new system is not about 'management' of a suite of disconnected services – so the term is inappropriate" (PWD E-Bulletin, 11 April 2011, p. 5).

In the Perth Public Hearing, 20 April 2011, we expressed our support for a "local area coordination model as preferable to case management". We would like to clarify that we support the concept of local area coordination, but believe that there is scope for service delivery improvements. With reference to the proposed scheme, we view local area coordination as a system where people with disabilities can choose to have a qualified person assist them in putting together their individual support package in their local area. We know from the feedback we have received that this is particularly important for people living in rural and remote areas.

The next section of this submission comments on the eligibility criteria for the National Disability Insurance Scheme.

5. ELIGIBILITY CRITERIA

RECOMMENDATIONS

PWdWA recommends that:

- 5.1. Any person with a disability is eligible to participate in the NDIS.
- 5.2. The scheme is flexible enough to allow for people to have joint arrangements and pool their funds to provide services or equipment that will benefit more than one person.
- 5.3. The proposed 'excess fee' arrangement is removed from the scheme.

In this section of the submission we refer to the following statement on page 22 of the Overview of the Draft Report:

“Ultimately, there must be boundaries to the NDIS — it cannot take over responsibility for all services and supports that people with a disability use, or it would be too unwieldy and governments would be unlikely to implement it. The main complementary services are education, employment, health, housing, income support and public transport.”

We understand that it would be difficult for a scheme to include all services for all persons with disabilities in its early stages; though we hope there is an opportunity to expand the scope of the NDIS in the future, thus, creating a more person-centred and cohesive disability service system. PWdWA considers that any person with a disability could benefit from the NDIS and the opportunity for empowerment through choice and the option to self-direct their funding. Based on the feedback we have received from people with disabilities and their families, we are aware that many people are still falling through the gaps in accessing services and funds, and hope that these gaps can be addressed by the NDIS. PWdWA believes that the NDIS should include people with chronic conditions, people with psychosocial needs and people with non-acute mental health needs, associated with their disabilities that are not met by other services.

We are aware that often it is the people with low support needs who fall through the gaps in the system. For example, under the WA Disability Services Commission's eligibility policy, people with low support needs such as specific learning difficulties and speech and language disorders are not eligible for funded disability professional services and equipment. Furthermore, in contrast to the Disability Discrimination Act 1992, the WA Disability Services Act 1993 does not account for people who may have a non-permanent disability. Notably, it is the Disability Services Act and not the Disability Discrimination Act that governs the WA Disability Services Commission's eligibility policies.

Some groups of people with disabilities have also been ineligible for funding for equipment or assistive technology depending on the setting they may wish to use the equipment in. The WA Independent Living Centre, for example, currently states that "Grants will not be provided for equipment for use in educational settings... Applications must specify the functional need that will be met through the provision of the equipment requested" (ILC Disability Equipment Grant: Information Package, p. 2). If the education provider is also unwilling to supply the equipment, the person with the disability is left with their needs unmet. In accordance with a person-centred, rather than a service centred approach, we believe that the NDIS could make it easier for the person with a disability to cost-effectively purchase equipment to use in a range of settings (e.g., at home, school and work).

At the Hobart Public Hearing (4 April 2011), Rebecca Astell, representing Speak Out Association of Tasmania, commented on joint arrangements, as outlined below: "My husband and I both have a disability. Currently, I receive nine hours a week from a service provider for support, but it doesn't currently suit our situation. With my hours, I can use them for myself. If I'm there, my husband can use them as well. But if I'm away, he can't use those hours. If he puts in for his own, it won't suit because he works and he only needs them very occasionally. So it would suit us better if we could have a program where we could join it together and share the hours so it's more flexible".

PWdWA supports a flexible scheme that allows for people to have joint arrangements and to pool their funds to provide services or equipment that may be used by more than one person. Several PWdWA clients and members could benefit from such a system, including families and groups of friends where more than one person has a disability. Joint funding arrangements may, for example, enable a group to enjoy an activity that they would not be able to afford from their individual budgets.

Page 20 of the Overview of the Draft Report refers to an excess fee arrangement: “As in the Medicare safety net and most insurance products, there would *sometimes* be a requirement to pay a fixed upfront contribution (of say \$500 per annum) to the NDIS, with free access to services after that point — so-called ‘excesses’. These increase the likelihood that people would only make reasonable claims. However, there would be a waiver of any excess for families assessed as already contributing significantly towards the costs of their support through unpaid care. (In effect, they already ‘pay’ an excess in the form of unpaid support.)”

PWdWA recommends that the proposed excess arrangement is removed from the scheme as it risks introducing unfairness into the scheme. We feel that the excess distracts from the broad aims of the scheme, where the small financial benefit to the scheme does not justify the impact the payment could have to the individual. Based on feedback from the forums we have attended, there is a public opinion that most people would be eligible for the waiver, as most families do contribute significantly towards the costs of their support through unpaid care. We believe that people who are not fortunate enough to have supportive friends and family members who can provide unpaid care should not be required to pay the excess, and that the proposed excess arrangement should not be included in the Final Report.

CONCLUSION

We would like to thank the Productivity Commission for the opportunity to comment on the Draft Report. We acknowledge that we have only focused on a small number of key areas in a much wider scheme. PWdWA supports the broad aims of the scheme as described in the Draft Report. We recognise that there is much more detail to be developed and that this will take time. We look forward to reading the Final Report from the Productivity Commission and look forward to a brighter future for people with disabilities across Australia.

Mary-Anne Bath, PWdWA President

Andrew Jefferson, Executive Director

Dr Amber Arazi, Systemic Advocate

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