



PEOPLE WITH DISABILITIES (WA) INC. (PWdWA)

**SUBMISSION to the WA Parliament Community Development and
Justice Standing Committee's Inquiry into Accommodation and
Intensive Family Support Funding for People with Disabilities.**

January 2014

Contact Details:

Andrew Jefferson, Executive Director

People with Disabilities (WA) Inc.

Oasis Lotteries House, 1/37 Hampden Rd,
Nedlands, WA 6009

Email: andrew@pwdwa.org

Tel: (08) 9485 8900 TTY: (08) 9386 6451

Fax: (08) 9386 1011

Country Callers: 1800 193 331

Website: <http://www.pwdwa.org>

People with Disabilities (WA) Inc.

President: Greg Madson

Executive Director: Andrew Jefferson

Contents

1. People with Disabilities WA Inc (PWdWA).....	3
2. Context.....	4
2.1. National Disability Insurance Scheme, and the NIIS.....	4
2.2. <i>My Way</i> Initiative.....	5
2.3. Transition.....	5
3. Addressing the Inquiry’s Terms of Reference.....	7
3.1. Adequacy of current processes to determine funding.....	7
3.2. The level of unmet need.....	9
3.3. The nature and extent of planning required to meet increasing demand.....	11

1. People with Disabilities Western Australia Inc (PWdWA)

People with Disabilities (WA) Inc. (PWdWA) welcomes the Committee's Inquiry and was pleased to have our Executive Director, Andrew Jefferson provide evidence to the Committee 4 December 2013. PWdWA appreciates the opportunity to provide a submission after further research, consultation, and consideration.

People with Disabilities (WA) Inc. (PWdWA) is the peak disability consumer organisation representing the rights, needs and equity of all Western Australians with a disability via individual and systemic advocacy. PWdWA is a not-for-profit, non-government organisation and provides clients with a non-legal, fee-free service. The organisation is run BY and FOR people with disabilities and, as such, strives to be the voice for all people with disabilities in WA.

Our vision is:

A community where all people have a full and valued life with the freedom to make their own choices.

Our mission is:

Empowering the voices of people with disabilities in WA.

Our values are:

- ***We embrace diversity and participation to ensure inclusion for all.***
- ***We believe respect is fundamental to all positive relationships.***
- ***We seek to enhance opportunity and remove barriers to ensure real choice.***
- ***We are committed to every citizen's right to equality.***

2. Context

PWdWA recognises the importance of the Inquiry, as people who do not have access to necessary supports, or whose level of support received is inadequate to meet their needs, remain at significant disadvantage. In the changing disability service context it is particularly important to assess the adequacy, effectiveness and fairness of the processes available to people with disabilities to access rationed support funding from the Disability Services Commission. The Inquiry should seek to recognise and resolve the immediate need for resources to address the unnecessary hardships that people with disabilities are experiencing and the impact this deficit has in compromising their potential. It should also consider how the failure to adequately address unmet need within the disability services system creates blockages within other service systems under the jurisdiction of the WA Government, and of the Commonwealth Government (such as health and aged care). The adverse economic effects upon these systems as well as the adverse social costs for those people with disabilities affected needs to be accounted for and considered when decisions are made about future funding priorities. The number of people with disabilities who identify as having unmet needs and the deficits they are experiencing needs to be measured independent of the Combined Application Process.

2.1. National Disability Insurance Scheme, and the NIIS

In the past seven years people with disability in Australia have witnessed a profound change in the way that their issues are understood and acted upon. Following the Australian Government signing the United Nations Convention on the Rights of Persons with Disabilities, the most significant process of disability service reform, the National Disability Insurance Scheme (NDIS), was commenced, and initial trials began in July 2013. This is a universal entitlement scheme, which promises to address the needs of all people with disability equitably, regardless of where they live in Australia, and a level of intense, individualised support to people with severe and profound disabilities to enable them to participate in the life that they choose. The new scheme was made possible by a unique combination of popular support and organised engagement, which raised the profile of people with disability across the general community. PWdWA was very active in WA and nationally in ensuring that people with disability were given the opportunity to voice their opinions during the establishment of the new scheme

The NDIS, fully implemented, is just one element of a broader National Disability Strategy (NDS), which has as its aim the improvement of conditions generally of people with disability in Australia, so that each can participate in the community, contribute to the wealth and wellbeing of the country, and enjoy the benefits that currently accrue to those living without disability. The NDS has goals of improving access to education and employment for people with disabilities, recognising that having paid work is the best way to avoid poverty in Australia. Issues of income

support, in particular eligibility for the Disability Support Pension (DSP) have been prominent over the past five years, and recipients are often the target of media and popular criticisms about not deserving these benefits and being work avoiders. Comparisons with other OECD¹ countries, however, indicate that Australians with disabilities are amongst the most vulnerable to poverty, and our country has the worst rate, against twenty seven countries, of employment of people with disability. The implementation of the NDIS will, therefore, only go so far to enabling people with disability to participate, and our role, and that of our colleagues across the country, is to continue to push for other structural and policy changes to be made to address inequality and disadvantage.

Another important initiative which was discussed in the Productivity Commission's Report was the development of a National Injury Insurance Scheme, to ensure that people who experienced traumatic injuries which resulted in disability had access to no fault insurance benefits to cover the costs associated with the ongoing support they would need, regardless of where they were in Australia. Currently these schemes exist in different forms in three States, with South Australia recently having passed legislation. No clear timetable for the delivery of a NIIS has been announced by the WA Government

2.2. My Way Initiative

Another important aspect of the NDIS is the gradual nature of its implementation across the country. It operates very partially currently in four States, and this will increase incrementally until full operation in 2019. In WA it will commence in a trial form in July 2014, alongside the WA *My Way* initiative. PWdWA is supportive of the introduction of the *My Way* trials in Perth from 2014, and looks forward to the evaluation of both these and the NDIS operations in WA.

2.3. Transition

Whilst PWdWA welcomes these new initiatives, both for the additional resources they bring, and the innovative ways in which they will operate, the next few years (at least until the NDIS is fully implemented in 2019) will be characterised by significant overlaps of responsibility between State and Commonwealth departments, which in turn may be confusing for people with disabilities, and could lead to inequities of access and service quality in the interim. The trial sites will focus on every person with a severe and profound disability and their family carers in an agreed geographical area. Everyone else from everywhere else in WA will continue to rely on a resource limited, crisis lead response approach. Currently in WA the bulk of disability services remain under the administration of the Disability Services Commission. Like its State counterparts that department is moving to reform its own practices and those of the services it funds, to meet the expectations of people with

¹ Pricewaterhouse Coopers (2011). Disability expectations: Investing in a better life, a stronger Australia, available [online]: <http://www.pwc.com.au/industry/government/assets/disability-in-australia.pdf>

disabilities and their families. In addition to the WA Government's procurement reforms changes are being made to the administration of disability services in preparation for the National scheme. It has been indicated that these may result in greater efficiencies and free up resources but there is no indication that these savings will be directed to those people with disabilities and their families who are enduring the distressing consequences of unmet need now. In fact, PWdWA is deeply concerned that the WA Government procurement reforms, welcomed as providing more flexibility and reducing 'red tape', is being implemented in the disability sector in a way that will be to the detriment of people with disabilities who currently have funding, particularly those with severe and profound disability. PWdWA believes that it is inevitable that the new funding arrangements will lead to dozens of new applications for additional funding to counter the reductions in service they will experience. These applications will serve to swell the list of people applying for rationed funding through the Combined Application Process that already runs to hundreds in number.

In providing context it also needs to be noted that 30 people with disabilities (60% of the population that have been receiving services from the Disability Services Commission directly) have been identified to transition to approved service providers in the non-Government Sector. This decision has triggered some negative reactions within the disability community, with unions representing the government workers and some families opposing the move.

The Disability Services Commission is attempting to manage an extraordinarily complex series of agendas and reforms while it is experiencing significant cuts in its own personnel and resources.

3. Addressing the Inquiry's Terms of Reference

PWdWA understands that the Inquiry will examine:

1. The adequacy of current processes for determining funding support for people with disabilities who live with their families;
2. The level of unmet need; and
3. The nature and extent of planning required to meet increasing demand for these support services in WA in the future.

Many of these issues are so interrelated that it is hard to deal with them separately. In particular, the relationship between rationed funding and the levels of unmet need, current resource allocation processes, and the planning that identifies and prioritises need. As far as possible the issues have been kept separate in the sections below, but issues of funding adequacy feature across all three areas.

3.1. Adequacy of current processes to determine funding

Andrew Jefferson in his evidence to this inquiry highlighted some of the many challenges that exist in the current processes. PWdWA believes that it is generally accepted across the Disability Sector in WA, including amongst senior staff at the Disability Services Commission, that the Combined Application Process (CAP) needs reform.

PWdWA is concerned that only small incremental changes to the CAP process are likely to be considered at this time in light of the imminent introduction of the NDIS trials. PWdWA is concerned that any changes are likely to favour those parties with the most effective lobbyists. One particular danger is that the demand from some Service Providers for the funding pool available for CAP to be split. This call for a specific allocation for 'changed need' appears to best serve the interests of Service Providers and their clients and will severely disadvantage people with disabilities who currently live at home with family Carers who want to access long term funding along with the people trying to vacate health service facilities.

PWdWA is clear that committing time and resources to reforming the current processes is secondary to the urgent need for greater resourcing. PWdWA considers that the provision of significantly greater funding levels is the only meaningful way to address the crisis in unmet need.

Failure to address unmet need

PWdWA has been supportive of the Barnett Government's initiative to boost services to people with disabilities in WA through the addition of \$600 million indicated in the May 2011 budget. This was promoted at the time as a significant injection of new funds to address unmet need amongst the population of people with disabilities in the State, with the West Australian reporting on 19 May 2011, "Hundreds of

thousands of West Australians with a disability will benefit from an unprecedented commitment to welfare services in today's State Budget, with the Barnett Government to reveal a \$600 million boost to social services”.

Procurement Reforms impact on funds available for individualised supports

The pool of funding that is used by the DSC to resource individual funding is stable, apart from an occasional top up from the Government, and relies on natural attrition (usually when someone who is in receipt of funds dies) for funds to be available for CAP applicants. The recent Government-led procurement reforms have permitted each Disability Service Provider to charge for the ‘actual’ cost of their services. It appears that new hourly rates negotiated with the DSC are higher than previous. These agreements were reached without the involvement of people with disabilities or their representatives. These agreements will adversely affect people with disabilities.

PWdWA considers that the clear good intent of the WA Government towards people with disabilities has been misplaced as it appears that it is only the organisations and agencies who claim to serve interests of people with disabilities that have benefitted. PWdWA has only become aware of the significance of the changes. Advocates were shocked by the information received from a Service Provider recently. PWdWA considers it likely that there will be similar negative impacts for people, especially those with most limited capacities, across the sector. PWdWA has been informed that under the new arrangement this particular Service Provider will charge the person with person with a disability considerably more for the support service delivered. As there will not be any equal increase in an individual's personal funding the service provided will decrease in quantity to the level that can be afforded.

For example Billy has individualised funding of \$100,000 per annum. Under the old arrangement the service provider previously charged him an ‘admin’ fee of 15%. This \$15,000 was used by the service provider to meet various costs associated with provisions other than direct support staff such as management structures, insurances, Human Resources functions, quality assurance and training etc. Under the previous arrangement Billy had \$85,000 remaining to meet the costs of the support staff that helped him to look after his health, shower, have meals, and go out for social events – things which directly addressed both his needs and his aspirations to participate on his terms in his local community. Under the new system the Service Provider will now charge Billy the equivalent of a 25% fee. The Provider will therefore receive \$25,000 before spending on support staff. Billy will now have only \$75,000 remaining to meet the cost of support staff. This is \$10,000 per year less than he had under the old arrangement. As the staff will not be costing any less Billy will now have to endure a reduction in staff available to him. The support provider gains a 40% increase in their administration fee and Billy loses 7.5% of his staff. This will mean that Billy will have less support to look after his health, take showers, have meals or socialise, which will often result in compromising on those

activities which enable him to interact with the local community, and to have an increasingly productive impact on it. If Billy lives in a group home (which is common for people with the most limited capacities) with 5 other people, the total funding available for staff in his home will reduce by \$60,000 per year. As support workers earn as little as \$20 per hour this equates to the permanent loss of more than one full time worker. It equates to a reduction in support and care of over 46 hours per week.

Recommendation 1: That an urgent review of the impact that the new funding agreements will have on the numbers of people that will be able to be assisted in the next Cap funding round, and that the CAP fund be increased to (at minimum) to compensate for the reduction in service hours that will be afforded from the fund as a result of the higher rates being charged by Service Providers.

3.2. The level of unmet need

The level of unmet need for disability supports in WA remains high, and is having a detrimental impact upon people with disabilities and families. Traditionally it has been hard to quantify what these levels are, but the impacts of low and no support to people in need across Australia, including WA, have been catalogued in publications such as *Shut Out* (2009)² and in the everyday stories we hear of people with disabilities and families in crisis. Unmet need also manifests itself in the inappropriate placement of people in congregate settings, where their access to choice and control is limited. The reforms of the NDIS and *My Way* set out to address these issues by better targeting individual need and addressing it with reference to each person's cultural and lifestyle preferences. But access to these systems fully operational will not be for some years yet, and there is a need to commit resources to addressing unmet need now.

Quantifying the problem

Information about unmet need is difficult for people with disabilities and their families to source. One of the failings of previous systems approaches to meeting disability needs has been the problem of accurately identifying the extent and the nature of needs broadly across the community. However, the Disability Services Commission *Count Me In – Disability Future Directions* document indicates that approximately one third of the people who would be eligible currently receive funded services³.

² Australian Government. (2009). *Shut Out: The experience of people with disability and their families in Australia*. National Disability Strategy Consultation Report. Prepared by the National People with Disabilities and Carer Council.

³ Details of where the report can be accessed DSC Website

PWdWA considers that the Disability Services Commission has a good understanding of the level of fully met, partially met, and unmet need of people with disabilities in WA and clear indicators as to the needs of family carers including ageing parents in a caring capacity. For example, it has been indicated that in the NDIS launch site in Perth Hills and the *My Way* sites the number of people with disabilities and their broad circumstances are known to the WA and Commonwealth Governments, and that this will permit effective planning. By contrast the Disability Support Funding Bulletin (a brief report of the outcomes of each Combined Application Process funding round) appears to serve only to confuse and concern. It is not helpful in understanding the extent of the unmet need across the State or in identifying any demographic hotspots of priority need, or systemic failings.

PWdWA is familiar with the data that is available through the National Minimum Data Set (NMDS), and the Australian Bureau of Statistics' *Disability, Ageing and Carers, Australia* survey, last conducted in 2012. Whilst these are publically available, neither provides any useful quantitative information about levels of unmet need for services. This would suggest that the data available to the DSC comes from other sources, which are not publicly available

Recommendation 2: That the WA Disability Services Commission make publically available, in accessible formats, the data and their analyses relating to levels and types of unmet need, to better inform public debate and allow people with disabilities and their families, and the organisations that represent their interests, to make a positive and constructive contribution to the challenge of addressing unmet need.

3.3. Understanding and Planning for Unmet Need

Impact - Wasted individual potential

People with disabilities living at home and their family Carers without adequate information and support often fail to achieve their potential as productive members of the community. They are often damaged by the strain, isolation and sense of hopelessness. The risk of physical and mental ill health is very real. The personal and financial costs associated with this can be considerable. The need for crisis interventions is common. The lack of investment in this critical area serves no individual or community well.

Impact – cost to related services

No matter what the process of applying for funding is the lack of available funding between now and the full rollout of the NDIS in 2019 is a most serious and pressing problem. The impact of the huge waiting list for support funding does not only affect individuals and their families. The impact on the efficacy of other agencies that

serve people with disabilities as part of their wider consumer base is considerable and expensive. The effect on health services treating people who became disabled as a result of catastrophic injury is a clear example. These people required access to a series of timely medical treatments and processes. The systems that have been developed to manage the complex treatment and rehabilitation processes are staged. The person's experience may be very lengthy and they will be served by medical and health professionals from many fields in Intensive Care, medical, trauma services, psychological and physical rehabilitation. This investment to catastrophically injured patients contributes to her or his survival, and ultimately serves to return that person to a community life that permits maximum independence. PWdWA is aware of many people who have worked through long, painful recovery and rehabilitation processes only to become stuck inappropriately and unnecessarily in an expensive medical/rehabilitation resource due to the inability of other people, assessed as ready to leave a rehabilitation facility, being unable to achieve funding through the CAP process. These people often describe their situations as hopeless and say that they have resigned themselves to permanently residing with groups of other similarly affected people in health funded institutionalised care.

There are other groups who are also living in inappropriate settings. There are people with disabilities who also have psychosocial disabilities living isolated existences in private hostels similar to boarding houses. There are young people residing in Nursing homes designed for the care of an elderly frail population.

Inadequate, inappropriate and lack of services has a compound effect, therefore, because of the expensive nature of crisis responses, the blockages caused in services where people are inappropriately placed, but, most importantly because of the damage caused to the individual which will need to be rectified in future years, often with increased amounts and duration of personal supports.

3.3. The nature and extent of planning required to meet increasing demand

Future planning should aim not only to identify accurately the level of need that exists, but also how best to address that need for each and every individual. This requires a planning system which actively seeks to understand the needs of people with a disability who require support, and commits to matching funding to meeting those needs. The system also need to maximise the value of funds allocated for support purposes, by ensuring supports are delivered with reference to an individual's aspirations and needs, and meet stated outcomes, and the maximum value possible of each dollar is expended on the direct support for those individuals.

Recommendation 3: That an urgent review to identify people with disabilities who are residing unnecessarily in health and or aged care services as they cannot access funding from DSC to facilitate a move to a more appropriate setting, and that the DSC and the Department of Health work quickly to resolve this situation.

Addressing the needs of people whose disability has resulted from traumatic injury

Currently the system nationally to address the ongoing support needs of people who experience traumatic injury is diverse and inequitable, with systems in NSW and Victoria (and to some extent Tasmania, and recently South Australia) delivering no fault insurance schemes which enable people to live at home. This is not available to people in WA, and the current differential resource arrangements for people with similar levels of disability add to the crisis of unmet need which falls to the Government to address.

PWdWA supports the development of a single national approach to meeting the needs of people who have experienced traumatic injuries, whether these result from car accidents or any other event, in line with the recommendations for the establishment of a National Injury Insurance Scheme (NIIS). The resources available to the States Government in WA should be made available to establish a scheme as soon as possible.

Recommendation 4: That the State Government addresses the unfair treatment of all people in WA by swiftly implementing fully funded no fault motor vehicle accident scheme, and timetable the full integration into a NIIS.

A Shared Responsibility

Disability Consumer peaks, Advocacy organisations, Carers organisations, unfunded special interest groups, peer support networks and many individuals with disabilities and family members work cooperatively with government departments and other stakeholders to achieve better outcomes for people with disabilities. PWdWA Committee of Management, staff and members make huge commitments to these processes. People do this because they believe that the development of well-considered policy and practice will achieve better outcomes for people with disability and be most cost effective and sustainable.

PWdWA does not believe that campaigning for more money necessarily serves the disability community well, but in relation to the subject of this inquiry there appears to be little choice. There is a desperate need to stop families disintegrating under the pressure, help people who are hurting themselves, unblock beds in healthcare

services and let people complete their rehabilitation journey, and allow people with a disability and their families to live more productive lives.

Western Australians are very generous both in terms of giving of their time in volunteering and in supporting deserving causes. PWdWA believes that the WA community would be deeply concerned that their generosity, a well-supported lottery, and the considerable funding provided by both State and Commonwealth Governments is failing to reach so many people with disabilities and their family carers. PWdWA considers that it is important that it is made clear to everyone, especially to people with disabilities, where the money has goes.

A quick review of the Annual financial statements of a few approved Disability Service Providers provides evidence of regular financial surpluses, and reserves running into the tens of millions of dollars. These organisations' funds and assets were achieved through a combination of funding to deliver services to people with disabilities, and through fund raising from charitable giving. .

PWdWA believes that there needs to be far greater accountability on the part of these organisations to the DSC, as the WA Government department which has primary responsibility for the wellbeing of people with disabilities, with regard to how their organisational resources and reserves are spent. Freeing up some of this money, through a requirement to invest in supports which address areas such as unmet need, could make a significant difference, not just because of the actual resources that would be expended, but in the goodwill that this would generate.

Recommendation 5: That the DSC take a leadership role in challenging their approved Disability Service Providers to direct some of their resources to addressing the unmet need crisis.

Planning for unmet need must consider the wider service sector and the community.

Supports to people with disability that are delivered effectively will enable people to interact with their community. Conversely, as has been discussed above, unmet need impacts on many areas of service delivery within the wider community. When planning to address unmet need for the future, issues such as the delivery of primary and preventative healthcare, and the availability of suitable housing, must be included.