Women With Disabilities South Australia

Submission to the Productivity Commission's National Disability Strategy

May 2011

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RESPONSE TO THE AUSTRALIAN GOVERNMENTS PRODUCTIVITY COMMISSION DISABILITY CARE & SUPPORT

Background

Women With Disabilities South Australia held its inaugural meeting on October 16th 2010. Establishing an organisation for Women With Disabilities within South Australia was thought necessary for two key reasons. The first was in direct response to the lack of opportunity to respond directly to State Government in particular to the needs of South Australian women with disabilities. Secondly, it is fair to say whenever Government has consulted the disability sector; it does so in the generic sense. Meaning that any information which is gathered about disability is generally without a gender lens, which often fails to acknowledge the gender differences between men and women with disabilities as well as the implications this has on being a woman living with disability.

With this in mind, WWDSA makes this submission to the Productivity Commission on the National Disability Strategy on behalf of our growing membership. We believe that as a new organisation it is important to be a part of this process for the future benefit of all women with disabilities.

Feedback Required by the Commission

Should the Carer Payment, Carer Supplement, Carer Allowance, Mobility Allowance, and the Child Disability Assistance Payment fall within the scope of the NDIS?

> WWDSA is of the opinion that should such payments fall within the scope of the NDIS, that it go directly to the person and not the parent or carer, and that it be clearly earmark as that particular payment, and that it remain as the intended payment.

The Commission considers that the NDIS should fund artificial limbs and seeks feedback on the desirability and practicality of this option. What items should be included if in the NDIS?

> WWDSA considers that while the National Injury Insurance Scheme would assist people who become disabled in later life, there would be individuals with lifelong disabilities who would require new limbs especially during years spanning from childhood-adolescence and from adolescence-young adulthood. WWDSA recommends that the funding of artificial limbs become a part of an individual’s package as required.

Should higher electricity costs that are unavoidable be accounted for some people with disabilities?

> WWDSA is aware that there are disabilities which require individuals to maintain a stable body temperature, year-round; and so would recommend that this would be given consideration for those who need this to maintain their wellbeing. WWDSA advocates that this would need to be made evident within

the assessment process and may include statement by the individuals' general practitioner.

Discussion from Members

WWDSA welcomes the flexibility that the NDIS will offer people. As research and anecdotal evidence suggests, when people are given the responsibility of getting what is right for them, more often than not, they prove that such freedom can bring savings. We are also pleased that once individuals are assessed and provided with their individual packages that the package will be transferrable between jurisdictions – thus at last not restricting individuals to that particular State.

Already Working

Currently within South Australia there is a person support organisation that is governed by the people who use the service. This agency encourages those who use it to be self-directive. This means that those who have the ability take control over how the personal support is managed. Individuals are given the autonomy to hire and fire their own support workers, are self-directing in the times that they receive their service - thus giving the individual control over their personal support hours. Having such flexibility gives individuals the opportunity to 'bank' unused hours; such flexibility assists in times when the individuals need extra support for other reason such as illness or sudden emergency. In recent times this agency has become a broker for a few individuals where are trailing self-managed funds.

The 'Brokerage' Service

WWDSA members felt that while the 'brokerage' service sounded like something that many would use, members were also mindful that the service would need to demonstrate their clear commitment and ability to meet specific and individual needs of all who use the service. It is important that when using a brokered service that women can feel assured that the service they use, can respond to their need in situations of diversity. Here we are referring to women with disabilities who have communication difficulties; they may have little, no, or difficult to understand speech; women who come from NESB, or those who face cultural oppression; those living with either intellectual disability or mental illness (here we refer to women with disabilities who also live with mental illness).

There is an assumption in society that parents/partners or siblings who take on the role of "carer" do have the individual's best wishes at heart. However the reality is that not everyone with a disability has or even *wants* to be looked after by their family. Therefore WWDSA advocates for an education program giving young girls and women with disabilities, education into how to become confident in knowing their needs are and how to become empowered to have those needs met. While the NDIS is not responsible for education, WWDSA believes that for women with disabilities to get the full benefits from this new scheme there ought to be some encouragement for young girls and women in this area.

While WWDSA does not represent a specific disability type, it is reasonable to suggest that the majority of our members would fall into the second tier under the NDIS. And while the next few discussion points would generally also come under this category, it was important to our members that these points be included in our submission. Even though WWDSA as an organisation is new, many of us have been a part of and have experienced the South Australian disability sector for many years. Many of us have also been hardened to the long waiting lists, the exclusion of not fitting into a specific category (i.e., too old, too young, wrong type of disability, too needy, not needy enough, etc.); or simply hearing “there’s no money”.

At ‘Crisis’ Point

However, when WWDSA invited members to discuss the draft for the Productivity Commission a number of concerns were raised. Of deep concern to WWDSA is the fact that many women with disability continually having to wait until they hit crisis point before they can get services and/or support. While there are instance where anyone with any type of disability may have occasion to either under or over represent their disabilities, it is a common experience for women with mild or hidden disabilities.

> *After undergoing heart by-pass surgery in 2003 a woman living alone, with low vision was assessed and granted minimal support from her Local Council – the support included minimal cleaning, gardening and gutter cleaning. These services are offered in most Council areas of Adelaide, to people with disabilities and the elderly, and generally can be accessed once a year.*
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> *In trying to access these services again in the last few years - after having surgery on both hands and then her eye; the women was denied this minimal support. Upon asking why this was, she was told by the Home Assist Coordinator that such services were reserved for people who were over 65. The woman’s frustration was compounded when she considered that not only does she “shy [away] from over using services” she is very aware that the demographics of people who reside in this Council are professional retirees.*
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> *Unable to approach the affluent Council area and get anywhere on her own, the woman turned to the advocacy services of the Manager of Sensory Directions Program at Guide Dogs SA. Only through this person was the woman able to negotiate to gain cleaning assistance for only three times a year. This gain came after the advocate being told that his client had already received assistance from this service at least three times and that the issues from the Councils perspective was that this was going to be an “ongoing problem”.*

WWDSA assumes that this issue has been heard over and over again during the NDIS Consultations. However, our concern is that in the spirit of not wanting more than we are entitled to, women with disabilities are constantly putting others needs ahead of our own. AS women we feel the urge to – use only what help we need; or not have a piece of equipment because we can get by without it. Women with disabilities tend to forego minor needs because of the misguided belief that someone else will get what they desperately need of a waiting list which can be 2 or 3 years long.

Women with Disabilities As Parents or Carers

Women with disabilities are *not* recognised as having responsibilities in the same way as women without disabilities. For instance women with disabilities are seldom recognised as being mothers or carers to other family members. Because women with disabilities are often perceived as needing to be 'cared for', as opposed to being the primary 'carer' for someone else, it is not until they hit crisis point, that they can get support. The result of this is that the issues associated with the role of being a carer are not addressed. When asking for support in general, many of our members spoke about having to either talk up, or talk down about their disability depending on what they need to achieve in relation to gaining services.

In 2009 Women With Disabilities Australia (WWDA) found that mothers with disabilities reported that even when they themselves received personal care and domestic support, that this support did not extend to support in caring for their babies or young children. One of the findings within this paper suggests that parents with disabilities often incur higher costs associated with parenting their children than their peers who do not have children or their able bodied counterparts (WWDA, Parenting Issues for Women with Disabilities in Australia, 2009: 13). Although we all incur costs throughout our lives, parents with disabilities have extra expenses which can range from gaining support to assist them to give their children an ordinary and happy childhood (WWDA, 2009).

WWWDSA urges the Commission to take the extra needs of women with disabilities who take on the "caring" responsibilities for others. It is conceivable that support needs for a mother with disability would decrease as her children grow older; however if the women is caring for a parent or a sibling, her support needs could increase. Therefore the frequency of assessments would need to be in response to the changing requirements for women with disabilities who are responsible and caring for others.

Mental Illness and Women with Disabilities

WWDSA is concerned that all too often the diagnosis of Mental Illness for women with disabilities can go unrecognised. It is reasonable to suggest that women, especially in individuals with life-long disabilities, fall victim to mental illness for a variety of reasons. These reasons are as many as they are varied, and include negative life circumstances, experiences of violence – sexual, physical and emotional, as well as mental illnesses that can be acerbated by a disability. WWDSA strongly advocates that the account of mental illness and disability – especially for women, be recognised and accounted for by the NDIS. Again this could be evidence by a letter from the treating general practitioner, psychologist of psychiatrist.

> *A woman with Cerebral Palsy reported that her symptoms of depression were not treated. The woman went on to suggest that the reason for the delay in treatment was that the physicians treating her were unsure of how to treat her because of her Cerebral Palsy. It was only when the woman physically lashed out, that steps were taken to try and treat her. The woman goes on to say,*
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> > *They didn't understand that my disability was separate from my mental health issues. Lashing out was the final resort…I didn't know what else to do.*
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> *Despite not wanting to place the woman on any medication that would have negative impact on her disability, this is exactly what occurred. The woman reported that she was put on medicated which had a sedative affect. This meant that her walking, speech and general ability to perform ordinary tasks were severely affected. These drugs not only skewed her perception of reality, she also began to rely on these drugs to get through her day. Therefore the woman is unable to recall any positive steps that were made for her ability to regain a sense of normality.*
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> *Following her six week stay in the public hospital and subsequent outpatient visits; and despite her protests that the treatment was not helping, the woman was subjected to eight more months of ineffective and inappropriate treatment for her mental illness. Frustrated at be unable to become well in herself the woman sought out other avenues of support to regain control over her life. One of these outcomes was seeing a new Psychiatrist who began assisting her by finding a more appropriate treatment option. This meant a change in medication and ongoing appointments which not only gave a name to the illness which the woman was suffering, but allowed the woman to take back the control to resume her life.*

What is evident from this account in that women with disabilities can develop mental illness and that while mental illness is not a disability per se, mental illness can be a result either directly or indirectly of disability. Therefore, WWDSA recommends that funding be made available for extra expense associated with women with disabilities who also live with a mental illness.

Supported Residential Facilities, Violence & Feeling Safe

WWDSA notes the that is very little mention in the Draft report concerning issues for people with intellectual disabilities who are currently living in institution type settings such as Supported Residential Facilities – or SRF's as commonly referred as, or group homes. Our concern is that many women with Intellectual disabilities are ending up in these facilities without being given the choice of where they live, and more importantly who they live with.

SRF's were originally established to provide housing and support for the most vulnerable in society. The supports offered by these facilities include, assistance with personal care, managing and distributing medication, physical assistance with mobility problems and other practical advisory support. Many of the buildings are old and not very accessible for people with mobility issues. The residents who call these facilities home, can number between 4 and 64, with most housing 27 residents (Shelter SA, Snapshot 2004). However because many of these houses are old, and limited in space it is not uncommon for bedrooms to sleep a number of individuals and that bedrooms may be divided with partitions – giving the illusion of privacy. It is our position that paying a substantial amount of money for a low level of privacy and dignity is unacceptable.

One of the highest priorities for women with disabilities needs to be where they live, are they safe, and do they have choice. As just mentioned, many women who live in Supported Residential Facilities or in group homes have very little or no control over who they live with or who they share a bedroom with. Living in situations where one has little or no control of who shares their living space can leave women-who are already vulnerable, at risk of violence and feeling that their personal safety is at risk.

WWDSA is aware that there are some individuals who still live in the few institutional environments which still exist in South Australia. Of concern is the notion that individuals living in these situations are not able to gather funding that they need to live in the community if they wished to. As mentioned above, many people living in such situations are led to believe that it would cost too much to support them in the community, and that there is not enough funding to support them.

We strongly urge the Productivity Commission take account of people who live in such situations and develop a package of support which would give these people more choice and freedom in their lives.

Choice of Equipment, Equipment Provider, and Servicing Company

Just like purchasing a car is an individual choice, WWDSA firmly believe that the purchasing of equipment and who maintains it; should be up to the person using that piece of equipment. While the Draft Overview does allude to giving individuals more control over where they seek their services, we seek assurance that such control will extend to the purchasing of essential equipment.

Our concern with seeking this clarification is based on the historical nature of the South Australian equipment schemes. The scheme was managed by Domiciliary Care, which catered for the equipment needs for both the disability and the aged sectors. During the 1990's these schemes were separated to meet the needs of both sectors more effectively. The managing and administration for equipment for the disability sector went to what was known as the Independent Living Equipment Program (ILEP). Under LEP people were prescribed equipment which was more suitable for their needs. However, in a bid to cull the waiting lists both schemes were once again consolidated. Not only this not reduced the waiting lists, it has severely reduced choice in equipment type and has the on flow effect to business closures due to the limiting of what equipment can be purchase.

WWDSA has many concerns about the restructuring of the South Australian equipment program has gone through over the past few years. Our first concern is that many women with disabilities are receiving second hand equipment (in some instances this is older then what they currently use). While they have the option of refusing to accept a second hand piece of equipment they are often perceive as trouble makers and are relegated to the back of the queue and made to wait until they are at the top of the list again.

WWDSA recognises that certain pieces of equipment may be recycled and reallocated we believe that this is not appropriate for devices that need to be tailored to individuals need – such as wheelchairs. It is often the case that wheelchairs need to be measured and prescribed to suit an individual's body size.

> *Recently a member was prescribed and measured for a wheelchair. Having experienced the reallocation style with her previous piece of equipment, she asked that if she had to accept a second had wheelchair, she would. However, concerned that sitting in a recycled wheelchair also meant sitting in another person's bodily accidents, the woman wanted to know whether the seating could be new to the wheelchair. Upon seeking clarification that she could receive new seating, she was told the seating would be steamed cleaned as opposed to purchasing new seating.*

WWDSA is of the opinion that the recycling of such equipment is inappropriate and unhygienic. This is because given that the mere steam cleaning of seating could potentially have detrimental health effects on the women with disabilities who use it.

While our primary concern is for women with disabilities not getting the equipment that suit them and accommodates their lifestyle, WWDSA is also aware that under this limiting and recycling of equipment has resulted is local and trusted equipment companies have gone out of business. Not only does this mean that the equipment is no longer available but the ongoing maintenance has gone to one or two companies. The concern for our members is that they can no longer receive equipment or maintenance service that they have previously had confidence in but the wait time for having equipment fixed or service is much longer. This is particularly so for our members living in rural and remote South Australia. It is in the rural and remote communities that having the right and 'fit for purpose' equipment is crucial to a woman's independence.

The disability sector within South Australia is subjected to constant change, most notably in regards to funding. Given these concerns that the members of WWDSA have raised we would like to have a reassurance that the National Disability Insurance Scheme would be a long term commitment towards lifelong independence and choice of women living with disability.

Employment

WWDSA also has concerns about the lack of employment opportunities and support for women with disabilities. Many of our members share stories about not having enough support once they were employed. Others share the fear of once gaining full time employment and being unable to sustain this in the long term. While we are all aware that there is a two year grace period in retaining the DSP and Health Care Cards, the fear for some is about what happened when a woman finds she is able to work for three or four years; and their disability deteriorates or its just to exhausting for her to keep working at a full time capacity.

Women with disabilities are too often rendered invisible in policies and programs, despite the fact that disability affects men and women differently. Women with disabilities are considered as being passive, and are stereotypically thought to adjust to disability more easily than men, and to be more able to manage domestically than men with disabilities. Yet they have had fewer employment opportunities, and when employed have tended to be in lower paid jobs than men, thus live in greater poverty. Because they do live longer that their male counterparts they endure this extreme poverty for longer.

It is for this reason that WWDSA is of the firm consensus that the introduction of the NDIS would work in favour of South Australian women with disabilities. Highlighted through this paper, to date many women with disabilities have had to struggle their way through various circumstances, perhaps even more so than men with disabilities.

Selling the NDIS

While this question had not been asked by the Commission, one of our members offered a suggested way for The Australian Government to ‘sell’ the NDIS. Her suggestion is to invite “thinkers in residence” from countries where they champion the rights of people with disabilities. A thinker in residence program would allow for the sharing of knowledge from the international disability rights movement and provide a focus point for up skilling people with disabilities to contribute to the wide ranging public campaign and debate that will need to surround the introduction of the NDIS. Thinkers in residence would help raise the profile for the NDIS and contribute to the social paradigm shift needed to accompany the NDIS.

REFERENCES

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