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Submission to the Senate Standing Committees on Community Affairs

The National Disability Insurance Scheme Bill – 2013

By Women With Disabilities WA Inc – February 2013

Women With Disabilities WA Inc is an unfunded non-profit organization for women with disabilities in Perth, Western Australia. We are run and managed entirely by women with disabilities. We work to promote the participation of women with disabilities in Western Australia in all aspects of social, economic, political and cultural life.

Due to time and capacity limitations our submission will be brief. We have included our original submission to the Productivity Commission on the NDIS, as it is still relevant to many of our concerns about the NDIS Bill. On reading the Bill our additional concerns are as follows

1. The timing of the request for submissions to this Bill, as well as the short time frame for people with disabilities to read and respond to the Bill mean that our organization has been unable to fully consult with our members due to the Christmas and New Year holidays, when most people in the community are unavailable.

This short time frame meant we had no chance to consult with our members aside from a request in our newsletter and on our electronic mailing list and Facebook page. We have also been unable to provide detailed information on the Bill in formats that are accessible to members who have difficulty understanding government jargon, or who do not have access to a computer and the Internet.

We are concerned by the severe lack of support to ensure that people with intellectual disabilities and from CALD backgrounds can understand and have input into the Bill. If the government isn't willing to make the first stages of the NDIS accessible to all people with disabilities, how can we trust it to create a system that will not marginalize those people with disabilities who are already terribly disadvantaged and who need the most support.

2. Lack of a gender perspective in the Bill.
Many CEDAW reports to the UN have continually noted that women with disabilities are often caregivers as well as recipients of care, and it is not

uncommon for them to be caring for children with disabilities as well as aging and disabled parents as well as having to deal with their own disabilities.

As Women With Disabilities Australia has detailed in their many years of research on this issue, women with disabilities are less likely than men with disabilities to have access to the support, equipment and resources that could assist them to lead better lives, and are subject to increased discrimination due to the intersection of gender and disability.

Women with disabilities are also more likely to have more than one disability and 'invisible' disabilities such as chronic fatigue syndrome, fibromyalgia and lupus that are still poorly understood by the medical profession and society in general. Mental health concerns are also often significant and this overlap between disability and health needs to be duly acknowledged and addressed in the new scheme.

3. Lack of acknowledgement in the Bill that people with disabilities, especially women with disabilities, are at higher risk of abuse and neglect from their families, partners and caregivers.

Many of our members have had family members and partners dissuade them from asking for help from support services, or from pursuing insurance claims that would assist them in funding their own supports.

4. The CEO of the agency having control and 'ownership' over participant's life plans.

People with disabilities already have too much of their lives under the control of professionals. The concept of a life plan ignores the fact that the very nature of disability and its effect on the person with a disability and the people around them, means that our 'plans' and lives can change rapidly, often and unexpectedly.

Finally, a quote from one of our members:

The way the NDIS Bill is written, it seems like there are so many "get out clauses" and ambiguities where many things can be twisted so a person is not covered.

People with disabilities already live with a great deal of unavoidable uncertainty in our lives. It is essential we have more clarity and certainty in whether or not we can access the supports we need, in a timely and dignified manner, to lead a fulfilling and productive life so we may contribute to society.

WWDWA Inc endorses the submissions to this inquiry from:

- *Women With Disabilities Australia
- *Women With Disabilities ACT
- * and The Bolshy Divas.

Written on behalf of Women With Disabilities WA Inc by Rayna Lamb, WWDWA Inc Coordinator.

**SUBMISSION TO THE PRODUCTIVITY COMMISSION
ON AN NDIS
Women With Disabilities WA Inc
May 2011**

Women With Disabilities WA Inc is a non-profit organisation for women with disabilities in Perth, Western Australia. We are run and managed entirely by women with disabilities. We work to promote the participation of women with disabilities in Western Australia in all aspects of social, economic, political and cultural life. WWDWA Inc actively participates in providing support, information and education to women with disabilities, by regularly engaging the participation of women with disabilities in forums to address their identified needs. WWDWA Inc undertakes, where possible, relevant systemic advocacy and research as well as providing support and advice to individuals, agencies and governments which relate to the objectives of WWDWA Inc.

We currently have over 100 women with disabilities throughout WA as members. There is widespread agreement from our membership that the current disability support system has many flaws and often fails to provide women with disabilities in particular with the supports they need to live a safe, happy and productive life. In addition, there is a great deal of disagreement with the WA state government's assertion that the needs of people with disabilities in WA are well met by our current state system. The difficulties members have had with our state system include, but are NOT limited to; difficulties in finding out what supports are available and how to access them, lack of information on eligibility – particularly when dealing with the Disability Services Commission, complicated and repetitive assessments, and very long waiting lists to receive services – if they are not denied assistance in the first place.

Women with disabilities have particular needs and vulnerabilities that must be taken into account in any new support system. Women with disabilities are also more likely to have invisible disabilities and more than one type of disabilities, often disabilities that are caused by abuse, mental illness, long term disabling injuries from physical or sexual assault. There needs to be a greater awareness of these issues in general and support and funding must not in any way trap women with disabilities in abusive family or care situations. Services and supports need to acknowledge the gender differences between women and men with disabilities. Contrary to stereotypes about women with disabilities, we are as likely to be providers of care as we are to receive care ourselves,

often at the same time Particularly in regards to providing adequate care for children, partners and parents, any national support scheme needs to acknowledge the complex identities of women with disabilities.

“I need support for my role as a mother within the household. For example, I want the [support] person to hang out not just my washing but also my husband's and children's.”

Having said that, not everyone has the “natural supports” of family or friends that the government would like to depend on providing care and support to us. Many of our members live very isolated lives, with family breakdowns and abandonment often a result of partners and families being unable to deal with the dependence and care needed by a woman with a disability. People with disabilities in general are at risk of a higher rate of neglect and abuse at home and in the community, and women with disabilities specifically are abused more frequently and for longer periods than able-bodied women and men with disabilities.

Having an appropriately accessible house can impact on the quality of services women with disabilities receive. While we understand that the NDIS cannot cover all of our needs, we need to make the government aware of how the difficulty in finding accessible housing in both the private and public housing markets impacts women with disabilities in profound and serious ways, often exacerbating our disabilities, and setting back the effects of any treatment. Several of our members have experienced great physical and emotional distress as a result of being in unsuitable and often dangerous housing and have found WA's state housing authority very slow and often indifferent in its response to our needs. There is no requirement for any percentage of public housing in this state to be wheelchair or otherwise disability accessible, leaving many people waiting for 10 or more years for accessible and affordable housing.

As WA covers a large geographical area and is at a great distance from the eastern states, there needs to be consideration of this in any development of new services. Travelling to service providers and specialist disability professionals in larger towns and cities can take a great deal of time, energy and money, something that women with disabilities are often very low on. Assessment services need to be provided as close to rural and remote areas as possible, and current services need to be expanded into these areas. For example, women with disabilities in rural and remote areas who need Pap smears and other women's health services often have to travel for hours into Perth as surgeries and clinics in those areas do not have accessible facilities and appropriately trained staff.

We have concerns about the proposed system of person-centred funding. Although many of our members would be very keen to use this form of funding, we found no clear direction within the report on whether training and development for people with disabilities would be available to assist people to be able to do this.

A number of members would have liked greater clarification about what happens when a person with a disability turns 65. Would they continue with the disability support services scheme or if you transfer to the aged care support services? As aged care suffers from a similar lack of funding and resources that the disability system does we would not like to see a system where people with disabilities are 'downgraded' after this age.

Any national support scheme needs to have people with disabilities involved in the development of the overall full conceptualisation, design, delivery and implementation. The governance of it must include people with disabilities from the outset, on the advisory and commercial boards. The commercial board should include a targeted number of people with disabilities with the appropriate professional training.

There needs to be a way to make sure that the people who are working in the system for us are held responsible and accountable. This must include quality management of assessors who determine eligibility for the scheme.

There has to be an appeal process for the assessments designed in such a way that the process of appeal is not seen as a negative one. The person complaining is not seen as a 'whiner' but has a right to understand their assessment. There needs to be training for people with disabilities to understand the assessment, what their rights are within the system and support in making a complaint.

The NDIS has the potential to transform our lives and enable us to contribute to the community in many different ways, financially, professionally and socially. Women With Disabilities WA Inc strongly believes that a society where people with disabilities are trapped in a prison of poverty, social isolation and erratic support is a society that is itself impoverished, isolated and unsupported. We believe that Australia can and should do better at supporting people with disabilities and an NDIS is absolutely necessary.