



**Women with
Disabilities ACT**

ABN: 74 908 530 982

Women With Disabilities ACT

Submission to

**Inquiry into the implementation, performance and governance
of the National Disability Insurance Scheme
in the ACT**

ACT Legislative Assembly

Standing Committee on Health, Ageing and Social Services

30 MARCH 2018

**Sue Salthouse
Chair WWDACT**

Women With Disabilities ACT acknowledges and pays respect to the Ngunnawal peoples, the traditional custodians of the ACT Region, on whose land our office is located. We pay our respects their Elders past, present and emerging. We acknowledge their spiritual, social, historical and ongoing connection to these lands and the contribution they make to the life of the Australian Capital Territory.

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About WWDACT:

Women With Disabilities ACT (WWDACT) is a systemic advocacy and peer support organisation for women and girls with disabilities in the ACT. WWDACT follows a human rights philosophy, based on the Convention on the Rights of Persons with Disabilities (CRPD) and the Convention on the Elimination of (all forms of) Discrimination Against Women (CEDAW). WWDACT is a Disabled People's Organisation, governed by women with disabilities, and its proposals and recommendations to government are consistent with Article 4 (3), and Article 29 of CRPD which outline the imperative for consultation with disabled peoples.

Women with Disabilities in the ACT

The WWDACT constituency is of significant size. The 2015 Survey of Disability Ageing and Carers gives an estimate that in the ACT there are 32,600 women with a disabilities. We make up 52.5% of the population of people with disabilities and 8.5% of the total population of the ACT.¹

There are approximately the same numbers of women (19,600) and men (20,500) with disabilities in the 0-64 year age group who may be eligible for the National Disabilities Insurance Scheme. In the younger 0-14 age groups, it is much more likely that boys will be diagnosed with disabilities than girls, with 3,200 boys in this age group compared to 1,400 girls.² As with the non-disabled population, women with disabilities tend to survive longer than their male counterparts and there are 12,700 women with disabilities aged over 65 years, compared to 10,100 men.

Nearly 2500 children with disabilities aged 0-14 years are participants in the NDIS. However, since there is also a preponderance of Participants with a primary disability of autism, it is likely that there are greater numbers of male participants with an active plan in this age group.³

However, the preponderance of male participants in the scheme (3560) compared to women (2347), cannot be explained by diagnosis. As in past decades under the National Disability Agreement and its predecessor the Commonwealth State Territory Disability Agreement, men still make up 40% of the total ACT active participants with approved plans.⁴ This does not reflect the demographic distribution of the 0-64 age group.

¹ Australian Bureau of Statistics, Survey of Disability Ageing and Carers, 2015, Cat. No. 4430.0

² Because of the size of the ACT sample in the SDAC surveys, both figures are estimates with a 25% to 50% relative standard error.

³ National Disability Insurance Scheme, Quarterly Report 2018 (2) ACT-Dashboard-31 December 2017

⁴ COAG Disability Reform Council Quarterly Performance Report, Australian Capital Territory, 31 December 2017 <https://ndis.gov.au/medias/documents/performance-act-31dec-17/ACT-Performance-Report-31Dec-2017.pdf>

It is not accurate to intermix the December 2017 NDIS data in conjunction with the 2015 SDAC data. However it can be seen that approximately 10% of women with disabilities are active NDIS participants, with approximately 30,000 still in need of some supports and services in the ACT.

Female Participants' Experience of the NDIS

WWDACT developed and disseminated a short survey of its constituents, to gather feedback about female participants' experiences with the NDIS. The survey was distributed on 21 February 2018 and remained open until 18 March 2018. Survey questions included: type of household tenure; types of support/assistive equipment used; services accessed (both mainstream and disability-related); funding sources for services; new services/activities available since the introduction of the NDIS and an assessment of quality of interaction with the NDIA; an assessment of experience in interacting the LAC (FerosCare), and an opportunity for open-ended comment.

Respondent numbers were too low to draw any specific conclusions so that information in this report is given by way of 'example' from individual responses. All respondents were Participants, with the exception of a female parent who is the primary carer of an adult daughter with disabilities.

Considerations

The relationship between the ACT Government/Australian Government with respect to NDIS/NDIA

One respondent was a Participant who lives in Queanbeyan. This alerts us to the cross border issues which confront participants in the region. One important theoretical advantage of the Scheme is package portability, that is the ability to move between jurisdictions without loss of service or amenity. At present there are gaps. There needs to be closer liaison between the ACT and NSW governments to ensure that participants do not fall through gaps in services, especially where one jurisdiction has maintained access to services for non-participants, and the other has reduced or withdrawn a service.

There is potential for interface battles between NSW Department of Children's Services, the ACT Office of Children and Youth Protection Services and the NDIA when natural supports break down leaving a child without supports or accommodation or support services and and/or access to specialists. Similarly the interface between Health departments in each state, and the NDIA Agency can potentially leave an individual without a solution to a personal care need.

In addition there are considerations for the services needed for those women who are not eligible for the NDIS. Advocacy Services need to be continued for these women who need minimal assistance in the areas of access to housing, transport and employment.

The WWDACT survey did not give any examples, but there is anecdotal evidence that where services deemed as 'reasonable and necessary' by the NDIS are insufficient to enable ageing parents to provide natural supports, that adult children with disabilities are likely to be relinquished to support services which then have to provide accommodation and supports which are not in a Plan, and where there is no longer an ability to cross-subsidise a service from block funding.

Practical outcomes of implementation with respect to disability workforce development strategies.

Workforce development needs to be supported by the ACT government, through funding increased numbers of training places at CIT, through support of National Disability Services workforce development programs. At present, workforce development lags behind the need and this is a limitation to implementation of plans in some cases.

In addition, improved access to personal supports should enable women with disabilities to return to work or increase their hours of work. WWDACT does not yet have data which supports this projected outcome. Survey respondents did not give any examples of improved access to employment. Lack of access to employment remains a challenge for women with disabilities irrespective of whether they are NDIS participants or not.

Human Services Registrar (Official Visitor Role and & Quality and Safeguards Framework)

The current ACT Quality and Safeguarding mechanism is overseen by the Human Services Registrar, and largely implemented through the Official Visitor Disability Services Scheme. At full scheme rollout the Quality and Safeguards Commission will deal with matters relating to the NDIS, participants, workers and service providers in the Scheme. There is a risk that services provided to people who are not participants will have no standards oversight. In the interim, the ACT Official Visitor Scheme in cooperation with the Human Rights Commission and the Office of the Public Advocate plays an important role in oversight of service quality, particularly in relation to accommodation. It is important that coordination of the Quality and Safeguards mechanism through the Human Service Registrar continues.

Availability of services for eligible NDIS participants

Respondents to the WWDACT survey report that they do not access any new services since becoming NDIS participants. If anything, their access to services and the type of services has diminished. They report confusing changes in services arising from amalgamations of organisations.

Unfortunately NDIS Participants who responded to the survey did not give positive feedback at this time. WWDACT reiterates that not many women responded, and it is likely that a survey of this nature self-

selects people who have negative experiences and therefore want to have their voices heard. Anecdotal evidence indicates that women with disabilities remain committed to the Scheme but their current experiences are frustrating and counterproductive.

Comments⁵ include:

- 1, *I have less access than before because no one will repair or replace the [equipment I use] so I have been stuck in my house since it broke 14 months ago unless I struggle to walk with great pain for important medical appointments.*
2. *The activities have been largely the same, the way they are funded is what is different. We have also accessed funding for a major bathroom modification in order for [the Participant's] wheelchair to be used.*
3. *No new services - service has switched from one name to another with same organisation.*
4. *I have not even been able to keep doing as much as I was before, plus with less help for the cleaning & shopping I have received multiple injuries from trying to do it myself, then I get more hurt & sick from the stress, etc. And my first goal was to visit my [family member] more but I am actually getting to see [them] less than ever.*

Availability of early childhood intervention services

WWDACT survey respondents were all adults.

Implementation of Local Area Coordination

The interaction that women with disabilities have had with FerosCare has been 'shaky', with women rating their experience as very poor. This may be due to the relative inexperience of the LAC in the ACT, rapid expansion of staff numbers leading to inconsistency of interactions for Participants, lack of time for women to build a relationship with any particular staff member, and lack of ability of the LAC to make decisions or rectify problems with plans without referral to the NDIA.

When I rang NDIA about a problem the person did not know how to help, everything my coordinator asks about previous 'promises' now has a negative response, & FerosCare are too busy to interact with me.

⁵ Comments have been made less specific in content to de-identify the respondents. Brackets have used to indicate where generalisations have been made.

Supports for people with psycho-social disabilities

Women with disabilities report difficulty in accessing Mental Health services. Women who were assessed as eligible as Participants in 2016 have been deemed ineligible at the time of Plan Review in 2017. There is an ongoing need for Mental Health programs and peer support programs, especially for women who are not eligible for the NDIS.

Unique factors relating to provision of disability services affected by the implementation of the NDIS in the ACT.

Women with disabilities who are Participants have a range of support needs. There are a significant number of ACT women with disabilities who live in their own homes, but need services such as house cleaning and gardening. The majority of ACT women with disabilities live in the community with less than 1% living in institutional and residential settings⁶. The SDAC 2015 also shows that there is high level of home ownership for people with disabilities in the ACT, although sex disaggregated data is not available. Over twenty thousand people with disabilities aged 15-64 in the ACT are home owners with the majority owning their home outright. An additional approximately 10,000 are in rented accommodation with the majority being in private rentals. This pattern of home ownership indicates a higher than usual need for cleaning and gardening services, as people with disabilities age in their own homes.

The largest numbers of women with disabilities (7,600) in the ACT are in the 35-55 age group (compared to 7,800 men with disabilities), so are still of working age.

Quality of interaction with the NDIS.

Respondents to the survey outlined their frustrations with lack of transparency, lack of responsiveness, and inappropriate interactions with Planners. Interactions occur as a result of a Plan Review, and the pathway for their reviews is problematic at the moment, whilst much effort is going into improving the Participant Pathway.

Comments include:

- 1. Communication is very poor in relation to information given on request, information not provided and sourced from other agencies or individuals, numerous requests for return phone calls not received, lack of accurate record keeping by NDIS staff.*
- 2. Complete lack of accessible formats in forms and communication processes and lack of training and understanding for these requirements e.g. when large print word document*

⁶ This figure is an estimate only calculated from the 2016 Annual Report of the Official Visitors for Disability Services and the SDAC 2015.

format was requested, the NDIS worker said "can't you just get your carer to read it to you?"

- 3. Very poor time frames and communication around waiting periods, e.g. a 6-month wait from acceptance into scheme till planning meeting; then 6-month wait from OT report till equipment approved, then still waiting for equipment a year and a month from acceptance into the Scheme.*
- 4. Disempowering planning meeting which appeared to be a 'Paint by Number' approach to planning, e.g. the Planner [pushed] certain services that I did not need or want, and [wrote] goals and personal information in my plan that was incorrect, poorly written, and in some cases incomprehensible.*

Conclusion

It remains difficult to assess the effect that the NDIS is having on the lives of women participants in the NDIS. The process of plan implementation has difficulties with the lack of availability of services because workforce development lags behind the increased need. There is not yet enough data to assess whether women's participation in the workforce has increased because personal care, support and assistive equipment needs are being met. WWDACT did not receive feedback from women for whom the NDIS experience has been positive. The Plan Review pathway remains problematic and lacks transparency. Delays in approval of house modifications and long lead times for approval and then supply of assistive equipment mean women can be temporarily worse off.

WWDACT does not have data on the support needs of women with disabilities who are not participants in the NDIS. The implementation of the National Disability Strategy needs have precedence for the ACT Government and to be harmonized with any focus on the implementation of the NDIS itself.