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## ***‘Contributing our voices!’***

# **A summary of feedback from the Have Your Say! Forum with women with disabilities in the ACT**

*“...when you have the voices in the room it actually  
allows you a richer level of understanding...”*  
*(Participant)*

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Written and compiled by Jenni Gough

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# ACKNOWLEDGEMENTS

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### **About Women With Disabilities ACT (WWDACT)**

WWDACT is a systemic advocacy and peer support organisation run by women with disabilities for women with disabilities. Established in 1995, 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). It works with government and non-government organisations to improve the status and lives of women with disabilities in the ACT and surrounding region.

WWDACT is funded by a 2 year Grant from Disability ACT to employ two part time staff to:

- Undertake systemic advocacy in areas of relevance to women with disabilities;
- Provide feedback to Government on relevant policies, programs and activities; and
- Provide relevant information to women with disabilities on ACT Government and community policies, programs and activities.

WWDACT's priority areas include: violence, abuse and neglect of women with disabilities in institutional and residential settings; housing; health and wellbeing; employment and income; ageing; access to sport and fitness, and transport.

WWDACT relies heavily on the volunteerism of its members and supporters who are committed to improving the status of women with disabilities in the ACT.

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# Executive Summary

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***“...when you have the voices in the room it actually allows you a richer level of understanding...”***  
**(Participant)**

This report details the findings of consultations by Women With Disabilities ACT (WWDACT) with women with disabilities in the ACT during May and June 2015.

The goals of WWDACT’s consultation were to:

- Provide an accessible, open and genuine space for women with disabilities in the ACT to contribute their voice to the shaping of policy, service provision and broader community relations;
- Provide targeted feedback and real life stories to government, policy makers, service providers and the community about the lived experience of women with disabilities in the ACT and how to better meet their needs and;
- Collect qualitative, grassroots feedback directly from women with disabilities in the ACT with a focus on what is working effectively, what is in need of improvement and identifying practical and innovative measures which can be implemented to more appropriately cater to the needs of women with disabilities in the ACT.

For the purposes of this report, WWDACT employs the ACT Human Rights Commission ACT 2005 definition of disability whilst acknowledging, at the same time, that disability is an evolving concept and difficult to define.<sup>1 2</sup> The ACT Human Rights Commission ACT 2005 defines disability:

- as attributable to an intellectual, psychiatric, sensory or physical impairment, or a combination of those impairments;
- as permanent or likely to be permanent;
- as resulting in a substantially reduced capacity for communication, learning or mobility;
- as the need for continuing support services;
- or may, but need not, be of a chronic episodic nature.

The consultations explored the lived experiences of women with disabilities in the ACT in relation to:

- Health and wellbeing – including assumptions about disability; the need for better awareness and understanding across services; barriers to access to services and programs in the ACT; the skills of staff; information provision; and the National Disability Insurance System (NDIS).

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<sup>1</sup> United Nations General Assembly 2007, 'Preamble, Paragraph (e)', *Convention of the Rights of Persons with Disabilities*, opened for signature 13 December 2006, entered into force 3 May 2008, accessed 14/09/2015: <<http://www.un.org/disabilities/default.asp?id=285>>./

<sup>2</sup> ACT Parliamentary Counsel 2014, *Human Rights Commission Act 2005*, authorised by the ACT Parliamentary Counsel, Canberra, p.6-7, <<http://www.legislation.act.gov.au/a/2005-40/current/pdf/2005-40.pdf>>.

- Education and employment – including inclusion in the workforce; barriers to securing and maintaining employment; access to supports; perceptions of bullying and discrimination; opportunities for self-employment and volunteering; and access and barriers to education and training.
- Community participation & social inclusion – including community participation and social inclusion opportunities, barriers and challenges to community participation; and the impact of lack of understanding by the mainstream community.
- Housing, cost of living and poverty – including barriers to housing access; the impact of housing on quality of life; the impact of the costs of living, disability related expenses and lack of financial supports; affordability and availability of support, and the affordability of transport.
- National Disability Insurance Scheme (NDIS) – including feedback on the planning processes and complaints mechanisms.

These themes were selected as priority areas, which over the following years will undergo significant changes as a result of the implementation of the National Disability Insurance Scheme (NDIS), ACT policy and service delivery developments, such as the Human Services Blueprint, and the roll out of the ACT Disability Inclusion Statement 2015-2017. WWDACT identifies this moment in time as a critical point for women with disabilities to give voice to what they want for their lives as citizens of the ACT.

According to the Australian Bureau of Statistics (2013), there are approximately 31,700 women with disabilities in the ACT, making up the majority (55.5%) of people with disabilities and 17% of all women in the ACT (men with disabilities comprise 14% of the male population).<sup>3</sup> Given that women with disabilities make up a significant proportion of the ACT population of people with disabilities, WWDACT believes that it is important that we understand their experiences as members of our community, so that policies, community initiatives and services can respond well to their needs.

Women with disabilities are at the juncture of an intersectional disadvantage. Both gender and disability affect the way we are in the world, the treatment we are subjected to and the way people view us.<sup>4</sup> According to the United Nations “Women and girls with disabilities experience double discrimination, which places them at higher risk of gender-based violence, sexual abuse, neglect, maltreatment and exploitation.”<sup>5</sup> Women and people with disabilities continue to face struggles, overt and covert discrimination and exclusion on account of these combined factors in a society and culture which to perpetuate them.<sup>6</sup> As such, women with disabilities continue to internalise and be impacted by those views.

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3 Australian Bureau of Statistics 2013, *Survey of Disability, Ageing and Carers 2012*, accessed 20/07/2015: <<http://www.abs.gov.au/AUSSTATS/abs@.nsf/DetailsPage/4430.02012?OpenDocument>>.

4 Carnovale, A. 2012 Strong Women, Great City: A snapshot of findings from a survey of ACT women with disabilities, Women With Disabilities ACT & Women's Centre for Health Matters Inc., Canberra, p. 4.

5 United Nations, Women and girls with disabilities: Using both - the gender and disability lens, *United Nations* website, accessed 20/07/2015: <<http://www.un.org/disabilities/default.asp?navid=13&pid=1514>>

6 Women with Disabilities Australia (WWDA) 2015 'Gender & Disability Issues', WWDA website, accessed 12/07/2015: <<http://wwda.org.au/issues/>>.

The women with disabilities who participated in the consultation were of diverse ages and backgrounds and identified as living with a range of disabilities. Whilst the group consulted is not statistically representative of all women with disabilities in the ACT, their feedback reflects and builds on previous research conducted by WWDACT on what contributes to living a full life within the ACT as a woman with disabilities. Rather than “mere” anecdotes, their stories provide information about their views and lived experience in terms of access to support, quality and suitability of support and services and the determinants of good health and well-being, which contribute to policy and planning.<sup>7</sup>

WWDACT values the lived experience of women with disabilities and used the consultation as a way of identifying what really mattered across the life span from the perspectives of ACT women with disabilities themselves. By sharing their experiences, the women were able to feel they have a voice despite the difficult experiences they may have had. They also had the opportunity to influence discussions about decision-making mechanisms and service/policy design, and in doing so, helping to create a more inclusive and accessible community for other women who identify as having a disability.

The methods chosen to collect the women’s views meant that WWDACT was able to foster an accessible and supportive space for women to share their experiences. With the support, assistance and recognition of their voices, women were able to make an informed decision to participate and feel safe in doing so.

Whilst small in number, the voices and life experiences captured in this report highlight feedback and issues about the ACT and its inclusiveness of women with disabilities.

The major findings from the consultation are that women with disabilities continue to face a range of barriers and challenges to living a full life in the ACT. Assumptions, discrimination and lack of understanding regarding disability from service staff, employers and the broader community were found across all themes. The accessibility of venues, housing, workplaces and services was also considered a major factor impacting on women with disabilities lives. A lack of affordable and inclusive services, housing options, supports, community participation opportunities and transport so that women with disabilities can live their lives in the way they want to was also identified. In addition, feedback from the consultation uncovered the concerning and consistent view that participants were not being included with “normal people”. With the NDIS roll out in progress, women with disabilities involved in this consultation hoped, with some trepidation, that the NDIS would deliver greater choice and control in their lives and, at the same time, open up new opportunities.

The consultation has pinpointed areas for improvements, some strategies to better include women with disabilities and a snapshot of the lived experience of women with disabilities in the ACT. WWDACT will use the findings detailed in this report to continue to:

- Inform ACT government policy planning and service delivery evaluation to better reflect the lived experience of women with disabilities;
- Inform service providers to better co-ordinate and meet the needs of women with disabilities in the ACT; and

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<sup>7</sup> Consumer Health Forum of Australia, *The Real People Real Data Toolkit*, Consumers Health Forum of Australia, Canberra, p. 5, accessed 20/07/2015: <<http://ourhealth.org.au/sites/default/files/docs/rprdtookit.pdf>>.

- Provide feedback to the National Disability Insurance Agency on the views of women with disabilities in the ACT.

The feedback gathered by WWDACT demonstrates that there is still work to be done in order for women with disabilities in the ACT to access their right to equal citizenship. It is our hope that this report will contribute to the ability of women with disabilities to confidently and comfortably participate and contribute to all aspects of the ACT and that government, policy makers, the National Disability Insurance Agency and service providers will work together to make this happen.

***“...if they can go out...and spend one day in a wheelchair to get around, spend one day with a blindfold and find their way around, then they might have a much better understanding...”***  
***(Participant)***

# Methodology

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To inform the consultation WWDACT conducted a large face-to-face forum titled *Have Your Say!* and six semi-structured face-to-face interviews with a wide diversity of women with disabilities and several service providers, support workers, carers and family members.

In collaboration with Advocacy for Inclusion, WWDACT had also arranged a smaller forum hoping to attract women who preferred this medium, which we envisaged would better cater for women with communication, cognitive and intellectual related disabilities. Advertising of this event was limited and targeted, however, little interest was generated. As a result the small forum was cancelled, and WWDACT concentrated its energies on the larger forum and the option of one-to-one interviews. This example is symptomatic of how communication with some people with disabilities can be hampered especially given there is still a reliance on traditional methods of communications, such as post. In some cases, the recipients of mail may never see the correspondence as it is often sorted and assessed by carers, family members and friends, and other support people who make decisions on their behalf.

To attract participation in the large forum a flyer was distributed through WWDACT's networks, and through other community advocacy organisations, service providers, CDnet, local shopping centres and cafes and local media. Advertisements were placed on the WWDACT website and e-Bulletin, ActewAGL Community Switch, Canberra Times Fridge Door and ACT Communities Online. News stories were presented in The Chronicle and on Community FM.

As a result, 36 women from a broad range of disabilities, ages and socio-economic backgrounds contributed to the consultation. Whilst the overall numbers are small, the responses provide common insights into the experiences for women with disabilities in the ACT context.

WWDACT provided all participants with a consent form prior to participation in both consultation formats. The form explained the nature of the consultation and how the input of participants would be used and stored securely. Forms were available in print, including large format, and verbally.

WWDACT worked hard to ensure the accessibility of the forum. This included hiring a venue which was well known to the community, close to public transport and inclusive of accessible amenities. A captioner provided onsite captioning. Two Auslan interpreters and two support workers were also employed for the event. A hearing loop was arranged and confirmed, however the venue failed to deliver this on the day. (As a consequence of this, the venue has endeavoured to install a functioning hearing loop for the future). Transport assistance was provided for those needing support to attend. WWDACT reimbursed focus group and interview participants with a gift voucher in recognition of their time and willingness to participate.

Facilitators and note takers for the forum were sourced from WWDACT, Women's Centre for Health Matters, ADACAS, Health Care Consumers ACT, Equality Rights Alliance and the ACT Council of Social Service Inc. (ACTCOSS). This approach not only ensured that facilitators had a pre-existing understanding of many of the issues affecting women with disabilities in the ACT but also further developed relationships within the sector and spread information across organisations.

The forum was set up as a world café format. Unlike traditional world cafes in which participants are required to move, the facilitators and note takers were assigned topics and rotated between tables. This set up allowed greater accessibility and comfort as participants were able to remain at the tables.

A WWDACT Project Manager conducted the in-depth one-to-one interviews. These were semi-structured and employed the same questions as presented in the forum, as well as some targeted questions regarding their experiences of the NDIS.

This report is presented in chapters which are segmented into the themes explored in the consultations followed by a chapter on the NDIS. Each chapter details the overall findings from the women's feedback, and are supported by direct quotes from the consultations.

Following this, three case studies are presented which illustrate the real life experiences of three of the women.

# Chapter 1: Health and Wellbeing

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***“...the right to see...health and wellbeing as a legitimate goal.” (Participant)***

The World Health Organization (WHO) defines health as ‘a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.’<sup>8</sup> WWDACT sees this state as integral to the ability of women with disabilities to participate in the community, in such areas as education, employment and social life, free from both gender and disability based discrimination.<sup>9</sup> Supporting this is Article 25 of the United Nations’ *Convention on the Rights of Persons with Disabilities* (CRPD) which recognises that “persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability”.<sup>10</sup> Furthermore, the CRPD also outlines that persons with disability are to have access to gender-sensitive health services that have the same range, quality and standard of free or affordable health care that is provided to other persons.<sup>11</sup>

Despite the intentions of the Convention, women with disabilities may still face disadvantage and lack of access to quality health and wellbeing services in our community. Women With Disabilities Australia (WWDA) found that women with disabilities are less likely to receive appropriate health services than women without disabilities in the community.<sup>12</sup> They also continue to face discriminatory attitudes, assumptions regarding their capabilities and a lack of access to sexual and reproduction care, support and information.<sup>13</sup> In addition, they receive less access to screening services for breast and cervical cancer compared to women without disability.<sup>14</sup> This was also reinforced by feedback found in WWDACT’s *Strong Women, Great City* report 2012.<sup>15</sup>

## Assumptions about disability

***“People seemed surprised that I was working and there was always an assumption that you had a pensioner/concession card and it sometimes seemed if you didn’t...then that was a problem for people.”***

Participants identified that some health professionals held a range of assumptions about women with disabilities. This included initial assumptions about the life of the person presenting, the level of disability a person had and also what supports and benefits they were receiving as a result.

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8 World Health Organization (WHO) 1948, ‘WHO definition of Health’, WHO website, accessed 20/07/2015: <<http://www.who.int/about/definition/en/print.html>>.

9 Carnovale, *op. cit.*, p. 18.

10 United Nations General Assembly 2007, ‘Article 25 – Health’, *Convention of the Rights of Persons with Disabilities*, opened for signature 13 December 2006, entered into force 3 May 2008, accessed 20/07/2015: <<http://www.un.org/disabilities/default.asp?id=285>>.

11 Ibid.

12 Women With Disabilities Australia (WWDA), “An Overview of the Status of Women With Disabilities in Australia”, WWDA website, accessed 20/07/2015: <<http://wwda.org.au/about/snapshot/>>.

13 Ibid.

14 World Health Organisation (WHO) 2011, *World Report on Disability*, WHO, p. 71, accessed 20/07/2015: <[http://www.who.int/disabilities/world\\_report/2011/report.pdf](http://www.who.int/disabilities/world_report/2011/report.pdf)>.

15 Carnovale, *op. cit.*

***“...people often assume things about me. ‘She can walk. Everything must be ok.’” (Participant)***

Participants felt that staff should be more aware of the diversity of lived experience of people with disabilities. This was not the case across all participant interactions but was identified in specific health professionals, including general practice staff, nurses, physiotherapists and occupational therapists.

Several participants felt that a better understanding and awareness of disability was needed amongst hospital staff. In relation to hospitals, concern was also raised over a lack of understanding about how disability affects people differently and that a person’s circumstance can change. At the same time, an awareness that incidents of ill-health may not be directly related to a person’s disability needs to be understood.

***“When I ended up in the hospital ... [the nurses] said I should go home with my parents because people with a disability shouldn’t be in the hospital system, it’s wasting their time and taking up beds.” (Participant)***

Participants noted that hospital discharge staff held assumptions that people with disabilities have a range of natural supports available to them. In delivering care it is important to take into account the diverse nature of people’s support networks.

***“...after I initially acquired a physical disability, I was released at a point where I was still unable to actually open my front door, so I couldn’t turn knobs and keys. I could explain a million times I’m not going to be able to open my front door but I was still released from hospital, I suppose with the assumption that my family would pick up the pieces....”(Participant)***

Assumptions about disability combined with the need to continually prove your level of disability through retelling your story affected women’s experiences of the provision of healthcare and placed them in an upsetting and frustrating position.

***“I’ve spent a lot of time proving how impaired I may be and then seeing no positive action as a result of disclosing very private details about your medical condition.” (Participant)***

The ability to self-advocate, including being forthright about medical information and presenting the relevant paperwork, was described as a way of gaining legitimacy. Depending on individual circumstances, having the capacity to do this is not available to all women with disabilities.

#### **Access to health and wellbeing services**

Overwhelmingly, participants reported concern about the lack of linkages between the health, disability and aged care sectors. This affected the accountability of services and the quality of care that participants received. Inevitably, this also affected overall health outcomes and the fulfilment of health goals.

***“My feeling is that my health and wellbeing would be a great deal better if I was getting a decent transparent helpful process in dealing with providers of all sorts, whether it’s the NDIS or somebody else...I have an entitlement to proper process by people who are being paid to deliver it...”(Participant)***

The lack of linkages between services meant that women had to continue to retell their personal stories not only to prove their disability, but to ensure each sector knows. This added additional stress, frustration and trauma to the process of acquiring appropriate care and supports across the various sectors.

It was felt that increased interaction and cooperation between the sectors, particularly in regards to sharing information and complementing each other's service provision, would greatly increase the health and wellbeing outcomes of women with disabilities in the ACT.

***“...if you have multiple chronic conditions and chronic needs and psychosomatic problems you need case coordination. You need someone to be there to be working with you on a weekly basis managing your health and your wellbeing and being able to advocate for what your needs are.” (Participant)***

Participants suggested that there was a need for case workers to coordinate individual health care needs across different local ACT services and sectors. Case workers need to be skilled and require a strong knowledge of local services, as well as gender sensitivity and an understanding of the impact of disability on a person's life. They also have to have strong communication skills that adapt to the individual needs of their clients. This includes understanding and catering to the communications needs of people who are Deaf, hearing impaired or have a hearing disability.

***“...people really need to understand through the human rights framework that a person who's living with a disability has a right to their own dignity....” (Participant)***

A better awareness and understanding of disability by professionals in the health sector was identified as needing attention. Increasing staff understanding and awareness through rights based education and training was proposed as a way to improve service delivery and combat assumptions on disability, as well as gender.

The cost of services and transport to and from them was highlighted as a barrier to maintaining good health and wellbeing in the ACT. This was an issue for many because of their regular interaction with health services and additional therapies to increase their mobility, such as physiotherapy and complementary therapies. These costs impacted heavily on financial health.

***“I wasn't prepared for the cost. He wanted to give me three injections that I had to refuse because I didn't have the money upfront and [I had] no way of getting that money...” (Participant)***

Additional costs, such as those recently introduced for chemist prescription delivery, also put pressure on the already tight budgets of women with disabilities. This was particularly distressing for women who had to miss out on treatments which could increase mobility, better manage pain and improve quality of life generally. (Further discussion of this can be found in Chapter 4: Housing, cost of living and poverty.)

***“...the incontinence scheme does not cover them all. Not even close.” (Participant)***

Several forum participants and an interviewee raised the rising cost of incontinence aids as an issue. Despite the presence of the government subsidy, the expense of these items placed notable financial pressure on the women with disabilities who need them.

Accessing hydrotherapy was highlighted by participants as an issue which is dependent not only on finances but also on obtaining the right paperwork and expertise. Participants reported that accessing hydrotherapy,

which is often an integral part of rehabilitation and maintaining mobility, can be an arduous process and the difficulties are a disincentive to engage with this facility.

***“...then they referred me to Canberra to hydrotherapy and said ‘you might have to wait for a year before we can give you the other aspect of the exercises’...” (Participant)***

***“...I used to swim quite a bit and I haven’t swam in a long time...I used to have hydrotherapy at the Canberra Hospital pool and...I approached them to see if I could use the pool and they said ‘No, you can’t use the pool unless you’re a patient and have a therapy plan’.”(Participant)***

Participants reported feeling marginalised by ACT mainstream services, particularly in regards to health services and community participation opportunities connected with health, such as exercise and peer support. This includes instances where ACT mainstream fitness providers were considered too risk averse and would not allow women with disabilities to exercise independently. This feedback was also found in the *Strong Women: Great City Report* and is explored further in the community participation findings.

Marginalisation in mainstream services was also experienced by women who are Deaf, hearing impaired or have a hearing disability. For example, a participant reported that during a recent stay in hospital there was no captioning on any of the televisions. As a consequence, she had nothing to take her mind off the pain and instead, she lay there whilst everyone around her watched television.

#### **Access to Allied Health Professionals**

Participants identified that five sessions with allied health professionals under the Chronic Disease Management Plan was insufficient. This was identified as a “vicious cycle” which left women accessing only a few of the services that they needed to improve their health, wellbeing and ability to participate in the community. It was also reported that having to return to the doctor to adjust the plan, particularly in regards to referrals, was both time consuming and an additional cost.

#### **Access to specialist care**

***“I have to go to Sydney quite often because there’s no-one in Canberra who can manage what I have and it gets quite expensive going up there all the time.” (Participant)***

Participants identified the lack of specialists in Canberra as a barrier to maintaining good health and wellbeing, as well as the long waiting periods and the expense. Attracting more specialists to the region was considered an important part of filling the gap in service delivery in the ACT. Other considerations included the need for use of e-health or telehealth services to assist in reducing the transport costs.

Participants identified that referrals to specialists caused further expense and there was still a requirement to return to a GP to receive an indefinite referral to a specialist. This did not reflect the nature of permanent disability and could be a considerable barrier to timely and affective healthcare.

## Access to complaints mechanisms

Participants showed a general lack of awareness and understanding about the existence and role of the ACT Human Rights Commission and the ACT Health Commissioner, as well as being ignorant of alternative forms of mediation and individual advocacy. At the same time, those accessing complaints processes felt that it was an exhausting experience which often led to no action, which left them with feelings of powerlessness.

***“.....it’s just a lot of red tape....you go through the normal process and procedures of putting in a complaint in black and white in regards to your service provider. You try mediation. You go to the Human Rights Commission and that’s just another government agency. You go from government agency to another to get the service provider to give you a service.” (Participant)***

## Mental health and wellbeing

Mental health and wellbeing came up strongly as issues in both the forum and the interviews. This included not being able to access the adequate support and treatment needed to obtain and sustain positive mental health and wellbeing.

***“...the last couple of years, the last two years in particular, as I have tried to return to all those things I was doing before I had a child; my work, social engagements and relationships.... [it’s] particularly difficult when you can’t get the physical and mental respite at home for practical reasons and the frustration that you experience because you can see that these things, unlike paralysis, actually can be fixed.” (Participant)***

General mental health and wellbeing was also impacted upon by a broader lack of supports, particularly in regards to domestic help, and the isolation experienced due to a lack of accessible housing and access to employment and community participation options.

Some participants were frustrated that the limited services that did exist to cater for mental health were not adequate to meet demand nor did they provide appropriate quality of care. This was identified particularly for women with psychosocial disabilities and for women who had acquired disability from a compensable injury.

***“From my perspective and the Deaf community perspective, there’s a lot of mental health issues that are around, mostly depression...Because of [lack of] access to communication.” (Participant)***

Participants who identified as being part of the Deaf community reported that mental health was a significant issue for which advocacy and increased service provision was needed. Currently, participants reported that there is only one practitioner who caters specifically for the Deaf community in Canberra. The availability of that service is limited to two days a week in one hour sessions. Because of high demand from the Deaf community, scheduling of appointments was limited to one session per two month period for an individual.

Participants were keen for ACT Health to increase information provision on mental health issues to people who are Deaf, hearing impaired or have a hearing disability and increase accessible mental health services.

It was also suggested that having only one Deaf specialist psychologist presented a conflict of interest. This was raised in relation to deaf partners and family members accessing the same psychologist services when in dispute.

### **Aged Care for women with disabilities**

Participants raised concern over the lack of information on aged care for women with disabilities, and the accessibility of available information, particularly for women who are Deaf, hearing impaired or have a hearing disability. Participants felt that people who will not have access to the NDIS because of their age will therefore fall into a gap of limited and inaccessible information.

Communication for people who are Deaf, hearing impaired or have a hearing disability in aged care was also a concern. Namely, participants were worried that without adequately trained staff, residents who required Auslan would be isolated. This could also impact on their level of care, particularly their mental health and wellbeing.

***“They have to make sure staff understand about Deaf issues and how to sign and how to communicate effectively so they are not so isolated when they are going into nursing homes, particularly patients with dementia.” (Participant)***

### **Skills of support workers**

***“...You already have a disability, and maybe more than one, and if the people who are meant to be caring for you can’t communicate with you, that’s an additional risk.” (Participant)***

Concerns were raised over the suitability, skills and lack of training of support worker staff. Several participants felt that they or their family members had been put at risk or blamed for injuries sustained under the care of a support worker. This was particularly related to unqualified staff delivering support that they were not trained to do, and staff being paid to provide support without adequate knowledge or skills to provide that support. Participants identified that some support workers had arrived at their homes without knowledge of what supports they were there to provide.

The NDIS was noted in discussion as a way of people with disabilities being able to have more control and choice over who provides support for them, particularly who enters their homes. One participant who had already transitioned into the NDIS said that she was now able to interview support workers before they delivered services. However, this process was something she had to fight for. Other participants had experienced refusal when asking for staff to be interviewed prior to engaging the service.

### **Information provision**

***“...if information pathways were much more fluid, and accessible and collaborative...that demand factor might change a bit because people are actually channeled to the right places.” (Participant)***

Lack of information provision and pathways both generally and specifically for women with disabilities in the ACT was identified by participants as an issue. This related to knowing where and how to access certain health services, programs and information, particularly in accessible formats.

***...I guess the only other thing that I have struggled with a bit, and it seems to be getting better, is the lack of a centralised portal for information, information relating to services..., even if they're not specifically designed as a support service for people with disabilities ...There's a number of disparate organisations operating independently. Some cross over but I find it quite tricky kind of getting my head around points of contact for information and referral.” (Participant)***

For some participants by accessing one service they were then made aware of other services or information that they found useful.

Knowing what to ask your health professional and receiving an informed and relevant answer was also considered an issue of concern. Time poor health professionals, particularly general practitioners, were seen to be a barrier to receiving adequate information, problem solving and appropriate referral pathways.

Doing your own health research through trial and error online was identified as a way of receiving health information. However, accessing information online can be difficult to navigate and the quality not assured.

Participants suggested that accessible health events which included captioning, hearing loop and Auslan are needed in the ACT. This incorporated both general health events, as well as women's specific events related to topics such as menopause and breast and cervical screening. Diabetes education was also highlighted as an area which needed face-to-face accessible education mechanisms. Delivering information through various mediums was also considered important, particularly in regards to online health information provision with the inclusion of captioning.

#### **Waiting times**

Waiting times when admitted to ACT hospital emergency departments was highlighted as a concern by some participants. Lack of understanding of the interaction of the emergency condition with the existing disabling condition meant triage was not done appropriately and resulted in poorer health outcomes. This was particularly an issue when combined with a lack of understanding and provision for people with specific health needs and medication regimes.

***“I got a nail in my foot and with diabetes they made me wait – I couldn't eat anything for 40 hours and I usually am just a medication diabetic. By the time I had my first 40 hours I had to wait because there was more emergency people than me. So they ended up giving me an injection...” (Participant)***

Participant experiences of emergency treatment of mental health patients and of other acute ACT mental health service provision areas was also seen as inadequate for the needs of those with a disability.

#### **National Disability Insurance Scheme (NDIS)**

The NDIS was continually raised as an issue affecting women with disabilities' health and wellbeing. This included issues around maintaining established care arrangements and gaining access to services that were still integrating the NDIS requirements into their service delivery. There was a lack of understanding by both consumers and within services themselves about the NDIS and what would be available under the scheme.

Understanding the planning process, particularly what supportive documentation was needed from a care team, and securing the plan that you want was also identified as a challenge.

In addition, physical disability and chronic conditions are strongly linked to mental health, and it was felt that this relationship was not being acknowledged in the NDIS process. One participant noted that psychological support was valued over support given by specialists in physical disability or chronic conditions.

***“...I have a psychiatric condition as well as a physical disability and to some extent I am relieved because I imagine the process for the physical would be far easier and at least get me participant status.” (Participant)***

## Chapter 2: Education and Employment

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***“...I have to say I'm grateful to be employed...People are generally respectful...but no matter whether you have a disability or you're female or culturally diverse, you know there's always going to be issues.” (Participant)***

The right to access education and employment is specified in “Article 24 – Education” and “Article 27 - Work and employment” of the *UN Convention on the Rights of Persons with Disabilities*.<sup>16 17</sup> These two articles outline the right of persons with disabilities to engage in education and work, on an equal basis with others free from discrimination. This includes the assurance of inclusive and accessible employment and education provision to persons with disabilities.

Access to employment and education impacts on an individual's health and wellbeing and social inclusion, their economic status and their ability to reach their full potential. Having access also enables such effects as feeling a sense of purpose and having the ability to purchase goods and services, as well as being involved in an area of public life much valued by society. Without such access, women with disabilities have an increased reliance on government income supports and on their families, and suffer the resulting consequences, including struggling to meet the costs of everyday essentials and impacts on social inclusion.

Currently, sex disaggregated statistics regarding the education levels of people with disability are not available. However, it is known that the proportion of people with disability with a bachelor degree or higher is approximately half the graduation rate of the non-disabled population. Furthermore, the proportion who never attended school is five and a half times than that of those without disabilities.<sup>18</sup>

According to the Australian Bureau of Statistics women with disabilities in the ACT have a significantly lower labour force participation rates (65.1 per cent) than men with disabilities (80.1 per cent).<sup>19</sup> Coupled with this is the tendency for women with disabilities to be overrepresented in part-time jobs (56% - compared to just 22% of men with disabilities and 47% of non-disabled women nationally).<sup>20</sup> This is often related to their overrepresentation as carers.<sup>21</sup>

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16 United Nations General Assembly 2007, 'Article 24 – Education', *Convention of the Rights of Persons with Disabilities*, opened for signature 13 December 2006, entered into force 3 May 2008, accessed 20/07/2015: <<http://www.un.org/disabilities/default.asp?id=284>>.

17 United Nations General Assembly 2007, 'Article 27 – Work and Employment', *Convention of the Rights of Persons with Disabilities*, opened for signature 13 December 2006, entered into force 3 May 2008, accessed 20/07/2015: <<http://www.un.org/disabilities/default.asp?id=287>>.

18 Australian Bureau of Statistics 2013, *44300DO001\_2012 Disability, Ageing and Carers, Australia: Summary of Findings, 2012*, Table 7.2, ABS in Della Torre, E. 2015, *Facts on women with disabilities*, WWDACT, Canberra, accessed 20/07/2015: <<http://www.wchm.org.au/wp-content/uploads/2015/05/Facts-on-women-with-disabilities-in-the-ACT.pdf>>.

19 Australian Bureau of Statistics 2009, Survey of Disability, Ageing and Carers, ABS in Boyce, S, 2012 *DEEWR Question No. EW008\_13: Outcome 3 – Employment: labour force status of women with disabilities*, *Budget estimates 2012-2013 (May 2012): Education, Employment and Workplace Relations portfolio*, Parliament of Australia, Canberra, accessed 20/07/2015: <[http://www.aph.gov.au/Parliamentary\\_Business/Senate\\_Estimates/eetctte/estimates/bud1213/index](http://www.aph.gov.au/Parliamentary_Business/Senate_Estimates/eetctte/estimates/bud1213/index)>.

20 Australian Bureau of Statistics 2011, '4446.0 - Disability, Australia, 2009', ABS website, accessed 20/07/2015: <<http://www.abs.gov.au/ausstats/abs@.nsf/Lookup/4446.0main+features92009>>.

21 Australian Bureau of Statistics (ABS) 2013, '4430.0 – Disability, Ageing and Carers, Australia: Summary of Findings, 2012', ABS website, 13 November, accessed 29/07/2015: <<http://www.abs.gov.au/ausstats/abs@.nsf/Lookup/D9BD84DBA2528FC9CA257C21000E4FC5?opendocument>>.

Employment—and workplace—accessibility is also important to remove the social and environmental barriers that inhibit women with disabilities leading rewarding working lives. This includes ensuring that individual employees have the physical environment modified to suit their needs, and the flexibility, understanding and the assurance that individuals will have their health and disability needs accommodated.<sup>22</sup> The extent to which an individual's disability negatively impacts their level of productivity is also determined as much by the type of work they do and their working environment as it is by their actual disability.<sup>23</sup>

Ensuring that women with disabilities can engage in paid employment benefits the whole community, not only by maximising human resources but by promoting human dignity and social cohesion.<sup>24</sup>

### **Inclusion and valuing diversity**

Inclusion and the valuing of diversity dominated the discussion about employment. The women talked about a lack of understanding and awareness of disability by employers, as well as an undervaluing of the skills of women with disabilities and their ability to contribute. This was seen as impacting on the ability of women to secure work effectively and to maintain employment.

***“I was working with my back turned and...a manager behind me needed to talk to everyone...he finished talking and I turn around and find everybody facing the manager in the work section. Doesn't he understand I'm deaf?” (Participant)***

Having strong leadership in the workplace that values diversity was seen as an important part of creating more inclusive work environments and breaking down discrimination.

***“It's really great to be in a workplace that has a diverse range of people, and I think that targeting...people who lead organisations to say ‘we're proud to have a workplace that celebrates diversity and we invite people in’.” (Participant)***

Additionally, in order to create and maintain a workplace which celebrates and facilitates diversity, participants identified that educating staff about disability and raising awareness of the needs of employees with disabilities in the workplace was critical. They identified these strategies as creating better outcomes not just for employees but also for business, organisations and government bodies.

Some participants identified the recent recruitment of staff with lived experience to the National Disability Insurance Agency (NDIA) as a good example of how a diverse work force that understands the experiences of their constituency can boost effectiveness.

***“I really liked about the NDIA saying it wanted to employ people with a lived experience of disability. It was like WOW!” (Participant)***

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<sup>22</sup> A Skinner, 'Work wise', *Link Disability Magazine*, 20(4), pp. 28-9

<sup>23</sup> World Health Organization and The World Bank, *World Report on Disability*

<sup>24</sup> *ibid.*

## Barriers to employment

The women consulted identified the desire to find work, change their current employment or sustain their position as very important to them. However, they experienced significant and embedded barriers and challenges to making this happen.

Discrimination was identified as a key issue across all discussions relating to barriers to seeking employment - this was primarily seen as a reluctance to employ people on the basis of their disability.

***“...what I keep thinking is I’m highly resourceful. I’m well supported. I have still got good links in the workplace. I have an excellent CV. I have a whole list of things that should count in my favor and I still can’t get a job...” (Participant)***

Disclosing a disability was identified as impacting on employment opportunities. Disclosing during the recruitment process meant that candidates felt they were less likely to secure employment, whereas participants reported that if they did not disclose their disability they were more likely to gain employment. It was acknowledged that people with disabilities may need to have additional supports and expenses in their workplace and that this is something that may count against them in the job market.

***“Women with disabilities have to show people what they can do – prove themselves in the workplace before acceptance.” (Participant)***

Participants also reported that they felt because they had a disability they had to prove their skills before they were employed. This lack of awareness about disability more broadly impedes employment opportunities for women with disabilities.

Participants suggested that subsidies, incentives and resources could encourage employers to engage people with disabilities, including ideas such as a quota scheme in which employers are given incentives to attain a percentage of roles specifically with employees with disabilities. Increased and better value incentives for the employment of people with disabilities was also identified as a way to boost job availability and increase the desirability of job seekers with a disability.

Access to child care for mothers with disabilities returning to work was also identified as an issue. This was particularly related to the need to be more transparent about priority access guidelines, as well as having facilities which are accessible.

***“...it was very time-consuming and very disappointing to see that here’s a system actually in place to assist people with disabilities and it’s just not being implemented...the person with the disability has to go on fighting.” (Participant)***

It was suggested that if more parents with disabilities looking for child care knew about the priority access guidelines the time taken to access child care and return to work would decrease significantly.

It was also identified that there was a scarcity of secure flexible casual or part time employment opportunities in the ACT jobs market. This form of employment is critical for many women with disabilities, who may require flexible work arrangements. This was particularly important for women who needed flexibility because they had chronic episodic conditions.

***“For me with employment the issue is job flexibility because I have really good days and I have really bad days. So I need someone who’s quite happy for me to say ‘look I’m going to work 10 hours a week and I’ll work them when I can’...I’m very lucky in that the community service at the moment is being that flexible...”(Participant)***

Greater flexibility was also required during the process of finding a diagnosis and for an effective management strategy for chronic conditions. Several participants spoke of this process as traumatic and described their experiences with their employers as feeling like discrimination and bullying.

Caring responsibilities, living with a disability and the lack of availability of supports and transport were also identified as the main reason why women with disabilities needed flexible work options.

It was noted that women who were already engaged in flexible work arrangements felt pressured to take more work on, particularly if they were in professional positions. Yet flexibility and a more holistic approach were critical to employment sustainability for many women with disabilities in the ACT.

Participants identified that the public service was often inflexible with a culture of working longer hours, even for employees who are employed part-time. This was identified as adding additional pressure on women who could not meet this demand due to disability and responsibilities outside of work, particularly in regards to caring roles. Inevitably, in some cases, this led to becoming too sick to continue work.

The women, however, recognised that some change was taking place in the flexible ACT jobs market, with more casual contract work seeming to be available to suit the needs of people with disabilities. With the roll out of the NDIS, participants also reflected that increased employment options may become available, which would need to incorporate the needs of women with disabilities, especially in regards to flexibility.

***“...all over everywhere they just assume that everyone can use the computer, and all these modern technologies without thinking about issues like mine...”(Participant)***

Participants also commented that job seekers who did not have up to date knowledge on the use of computers and the internet were marginalised in the jobs market as there is an assumption that everyone can use technology. This impeded the ability of women with disabilities who may lack such skills or do not have the capacity to develop such skills due to their disability.

***“...I have great strengths...what goes against me is that I can’t use a computer...” (Participant)***

The requirement to have a car license was also identified as an issue for women with disabilities applying for jobs.

***“...we all know our disability. We know ways that we can work around to be able to get the job done. We are familiar with the type of work we can do, how we can do it. If there’s a type of job that you might require to travel, then there are ways to get around it.” (Participant)***

Individuals highlighted that they know their abilities and how to manage well with them, including navigating the transport system and taxi service. It was suggested that employers could be more creative when it came to these requirements as current criteria for transport and licensing needs rule out many people with disabilities.

Participants also understood that with employment came with additional costs not just to them but to their employers.

***“There is a whole lot of hidden cost when you do have a job though, because you’ve got the added cost of how you’re going to get to work [or] do you need a support worker to help you....”(Participant)***

They felt this impacted their chances of employment but also their ability to engage in employment.

***“People with disabilities seeing themselves as a ‘cost’...” (Participant)***

The cost of assistive equipment and technology was identified as a barrier for employers to invest in. Women felt guilty about the expense of supports, such as Auslan or captioning. They worried that if they were sick or could not attend a meeting with a captioner booked, that the cost of the service would be a burden on their employers or meeting host. One participant felt that her boss made her feel guilty in such instances.

***“...they organise and book interpreters, they have to pay...But on the day if I am sick and don’t come to work my boss has the shits with me. They are disappointed because they have wasted their money and their time. I am sorry I have the right to be sick. You are passing your emotional stress to me....hearing people don’t have to go through that. They don’t get that burden of responsibility put on them...” (Participant)***

In terms of access to supports, there was only one participant who reported utilising JobAccess to modify a work vehicle. This demonstrated a lack of awareness of the JobAccess service both amongst participants and the broader community. Similarly, the availability of other government schemes such as the Workplace Modification Scheme, or Supported Wage System, were not raised in discussion.

Numerous participants encountered employers who did not understand or apply Australian Standards for accessibility or know about assistive technologies. Many women had experienced employers who were reluctant to purchase assistive technologies to support them in doing their job. Reasons given for this were predominantly identified as expense. One participant stated that her employer said that they were only obligated to provide assistive technologies to clients and not to employees. Participants believed that employers should be obligated to ensure accessibility standards were followed.

Accessibility standards were highlighted as not being rigorous enough. Better standards would mean that assistive technology designers would be pushed to create more suitable products.

Barriers to career progression and job transition were also raised, including difficulty in ensuring that all accessibility needs are understood and catered for by new workplaces. This meant that even though women wanted to progress or transition to another job, even in the event they had won a new position, they could not if the right environment was not in place. This limited their opportunity and impacted on their motivation. Job advancement in the public service was considered difficult for women with disabilities. They identified a ceiling in this area.

## Access to supports

It was considered that under the Disability Support Pension (DSP) there was little incentive to return to work. With employment set at a maximum of 15 hours a week to receive the full payment or 30 hours to be eligible for part pension, women noted that it was difficult to find suitable and worthwhile employment conditions.

Losing the DSP due to increased employment activity was also identified as problematic. Without the DSP participants lost out on additional supports and entitlements that helped to sustain basic housing and domestic circumstances. Women talked about how maintaining a quality of life was a balancing act under such circumstances.

Another concern regarding the DSP arose around eligibility for women with disabilities when they were not able to work due to an undiagnosed disability. The women who had acquired a disability, such as a chronic condition, and were awaiting a diagnosis identified that they were not able to access DSP or obtain specific leave or entitlements related to disability from employers. This impacted on their quality of life.

Issues with Disability Employment Service providers were identified, which reflected previous research conducted by WWDACT for Women With Disabilities Australia in 2014.<sup>25</sup> This included providers putting jobseekers forward for positions which did not meet their capacities and placing people with disabilities in jobs which were unsustainable yet claiming their placement as a success.

In addition it was identified that many providers focused on marketing job seekers as 'disabled' rather than focusing on their abilities. This was seen as symptomatic of broader community attitudes. Services' limited understanding of living with a disability plus a high turnover of provider staff were also perceived as impacting on their ability to deliver effective continuous employment services.

One participant described a positive experience with a disability employment service provider where they had managed to secure her a long term position that met her disability and transport needs. They continued to provide regular tailored support to ensure her employment situation continues to meet her circumstances. However, she did reflect that sometimes she felt like they failed to understand her disability and expected her to be "perfect".

Finding information and support about employment was identified as both unclear and time consuming, and there was confusion around the different roles and relationship between Centrelink and Job Services Australia.

***"They have no idea what they're doing, and especially with people who have got disabilities or people who can't find work. They'll just throw a bunch of paperwork at you and try and get you to figure it out." (Participant)***

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<sup>25</sup> Women With Disabilities ACT 2014, Women with Disabilities ACT report to Women With Disabilities Australia on Women with disabilities experiences of Disability Employment Services in the ACT and surrounding region, Women With Disabilities Australia website, June, accessed 24/08/2015: <[http://wwda.org.au/wp-content/uploads/2013/12/DES\\_ReportThree\\_ACT.pdf](http://wwda.org.au/wp-content/uploads/2013/12/DES_ReportThree_ACT.pdf)>.

Once employed, women with disabilities found that without adequate accessibility and supports they were missing out on important opportunities and information. This impacted on their ability to fulfil their roles. This in turn placed them under stress and put their position under scrutiny.

It was identified that employers were often confused or uninformed about the term 'accessible' when providing staff with supports and online training courses which proved inappropriate to their accessibility needs. This issue was considered widespread throughout workplaces.

Specific assistive equipment, such as hearing aids, can be expensive and difficult to source, adjust and maintain. This was also considered frustrating and having an impact on women's productivity and confidence. For example, taking minutes at a meeting is significantly hampered if the technology used to enhance hearing, such as an audio induction loop, is not always functioning.

Available technical support within businesses and organisations was described as often being inadequate in supporting women with disabilities who required additional technical support. Lengthy waiting periods and inexperienced technical support providers made it difficult for women with disabilities who need technical support to undertake their job properly.

Not having accessible online training impeded the ability of women with disabilities to complete training in a timely manner. Training provided online through the public service was not considered accessible by many participants. This included not having available the zoom text function in training documents and incompatibility with specialised software for women with disabilities. In some cases, action was taken to provide more accessible documents in Microsoft Word instead of pdf. This, however, seemed difficult and stressful to achieve and remains an issue in the further development of training programs, ultimately affecting employees' ability to fulfil their job requirements.

Women found that they experienced added stress from their bosses if they were unable to attend work due to their disability.

Training for management and staff to work with employees with disabilities was identified as essential. An example was given that in the case of one woman who was also Deaf, that the earlier people have this training, the better the change in their attitude. Deafness awareness training made a big difference in people's attitudes and behaviours in the workplace. This can be applied to disability awareness training in general with employment.

***"I think it would be really helpful, particularly when you first join as a person with disabilities, to have a mentor to assist you through the processes in delving [into] issues that might come about..."***  
***(Participant)***

Having a mentor or a strong relationship with an individual within the workplace and/or a network of working people with disabilities, was identified as a way to help create a better working environment for women with disabilities. A mentoring relationship could also assist new employees with disabilities to settle in and to be able to have their accessibility needs better met, as well as dealing with any bullying and harassment they may be subject to (based on both disability and gender). It was also seen as a way of building knowledge for the mentor and, in turn, awareness in the workplace.

Without strong support and leadership from management, participants felt that it was easy to 'give up or withdraw' from work. A supportive employment environment complete with employers who advocate on behalf of their staff was seen as integral to creating a productive workforce.

### Feelings of bullying and discrimination in employment

***"I was pretty good at what I was doing, but I was never given the opportunity to learn new things, and one day my boss said to me 'oh well, I don't know how much longer you can keep working for'."***  
***(Participant)***

Women reflected on numerous instances where they felt they were discriminated against or bullied due to their disability. For example, participants reported that it was easy to lay blame on people with disabilities for troubles in the workplace, and that they were identified as 'easy targets', and there were instances where women were made to feel vulnerable by threats made to their employment status. This was particularly relevant to women with an acquired disability.

***"People become easy targets for blame in situations. It's like they will get rid of the responsibility and the blame to someone who is less able to respond."*** ***(Participant)***

Women identified instances of being excluded from important conversations or not being able to access training and education available to others due to accessibility requirements. For example, one participant who is Deaf worked in the public service where she felt that people continued to forget that they worked with a person with disabilities. This made everyday communication difficult. When she switched to work in a service for people who are Deaf, hearing impaired or have a hearing disability, she no longer experienced this.

Fostering a better understanding and awareness of disability in the workplace, strong leadership and a commitment to celebrating diversity, as well as having adequate supports in place to deliver accessible opportunities, was identified as a way of tackling discrimination.

The ACT Public Service Respect, Equity and Diversity Coordinators Program was highlighted as an avenue for employees to gain support for discrimination and bullying issues they experienced in the public service workplace.

### Representation of people with disabilities

Dwindling representation of people with disabilities was identified as an issue in relation to both a lack of recruitment options in recent times and non-inclusive work environments and culture.

Participants suggested that the ACT Government should work towards increasing its employment of people with disabilities. This would also complement the development of the ACT Disability Inclusion Statement. .

## Self employment

Owning your own business was seen as a good employment alternative as it meant that women could profit from activities they enjoyed, have greater independence and work in a flexible manner suitable to their lifestyle.

***“I thought [owning your own business] was just for normal people.” (Participant)***

Barriers to establishing your own business were identified including discouragement from family, and a lack of information and access to programs, such as the New Enterprise Incentive Scheme. It was hoped that the NDIS will open this space up for women and provide opportunities for self-employment.

## Access to volunteering opportunities

Many women with disabilities were engaged in volunteering capacities. Available volunteering opportunities were seen as narrow and scripted. One participant recounted her sister's experience of accessing a volunteering position.

***“...a really exciting thing that's happened for us recently has been that Sophie<sup>26</sup> and one of Sophie's support workers have approached the local St Vinnies shop looking for some employment as a volunteer....it was very clear with them from the outset that Sophie wasn't interested in joining a disability specific programme but wanted just to be an ordinary volunteer....it was one of the fastest experiences we've had with an organisation. There was no wait list....no assessment....no multidisciplinary report. It just happened and it was really great.” (Participant)***

There was also a need for more volunteering opportunities where women could contribute and learn new things outside disability specific volunteering spaces.

## Access to education and Training

Education and training offer invaluable opportunities to advance employment options, but without support and access, women with disabilities identified that their ability to expand their job prospects, including promotion, were curtailed. This was compounded by the reality that you need additional money or income to be able to access the additional supports to undertake the education and training. Without increased income arising from promotion, which is often unattainable, this left many women with disabilities in a predicament. There was significant frustration about this issue amongst participants, particularly for people who are Deaf, hearing impaired or have a hearing disability.

They felt there was a need for more training pathways to be identified. This was seen as a way to increase access to employment opportunities. Retraining opportunities for women who acquired disability later in life were also identified as lacking. Participants suggested that alternative training models, similar to programs

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<sup>26</sup> Name changed for confidentiality purposes.

assisting Aboriginal and Torres Strait Islander people to undertake training and work placement, could assist with this.

Due to a lack of funding and support, women with disabilities who require interpreters, note taking or additional supports often miss out on education and training opportunities. Studying is hard work and having to continually fight to get access to assistance makes the process especially arduous.

***“Why should we have to fight for this when a hearing person can come straight in? Where is the access and equal opportunity?” (Participant)***

Inflexible access to higher education for women who have exceeded their government assistance for financing tertiary study was identified. This included one participant who had acquired a disability after finishing her study and wanted to return to university to refresh her learning, which was affected by her absence from the workforce and by the nature of her disability. The university offered her no flexible opportunities. In the end she commenced a Masters through FEE-HELP<sup>27</sup> but the funding was insufficient to cover her study for the full degree. As a result she withdrew from the course.

Flexible learning opportunities at CIT were considered an effective alternative to stressful classroom based learning. However, participants noted that an improved attitude and understanding, as well as better coordination, on behalf of CIT would improve outcomes of women with disabilities participating in education. This could include understanding and catering for individual student needs.

Positive experiences were reported by participants currently participating in university. They reported that disability supports available at university had provided them with good alternatives to exam based assessment.

***“The universities feel like they have to hang on to every student they’re got, so they are really nice to you. So they cope with problems. They’re polite, transparent. Education is lovely, but it’s a luxury.” (Participant)***

### **Barriers to education and training**

Accessing Auslan interpreters and hearing loops was raised as a significant challenge for women who are deaf, hearing impaired or have a hearing disability to participate in education. The availability and cost of these services and technologies in Canberra impacted significantly on the women who require them and inevitably, limited their choices in this space. It also impeded their ability to contribute and achieve in certain education and training setting.

It was also reported that navigating the sourcing, availability and cost of these requires a great deal of planning and hard work. Women who spoke about this acknowledged they knew they had a right to education but felt adequate assistance was not there for them to fulfil this right. The hard work and lack of supports and understanding in this area were identified as impacting negatively on mental health.

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<sup>27</sup> FEE HELP is a loan scheme that assist eligible fee paying students pay all or part of their tuition fees. For more information: <http://studyassist.gov.au/sites/studyassist/help/payingmyfees/fee-help/pages/fee-help>.

***“Captioning can be good but it’s not my preferred language, not my natural language. I can read it okay but to express I need to use my own language otherwise I am forced to talk and that’s not natural for me.” (Participant)***

CIT training of Auslan interpreters declined in 2015.<sup>28</sup> It was identified that - with the arrival of the NDIS - the demand for interpreting will inevitably rise, and this will put added pressure on the interpreter workforce. Whilst captioning is still a valuable resource, it was not considered a replacement for Auslan.

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<sup>28</sup> Walmsley, H 2015, 'Auslan sign language courses axed at Canberra's CIT, despite interpreter shortage', ABC website, 5 February, accessed 3/09/2015: <<http://www.abc.net.au/news/2015-02-04/auslan-course-for-canberra-axed/6067068>>.

# Chapter 3: Community Participation & Social Inclusion

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## **“We are part of the community and we have a right to participate in everything.” (Participant)**

“Article 30 - Participation in cultural life, recreation, leisure and sport’ states the right of persons with disabilities to take part on an equal basis with others in cultural life”.<sup>29</sup> Participation in community life is a central part of living a fulfilled, happy and healthy life.<sup>30</sup> It is also key to fostering strong community spirit. Community participation includes interpersonal interactions and relationships with others, involvement in education, employment and economic life and inclusion in community life, such as recreation, sport, and leisure, religion and spirituality. In addition, participation in human rights, political life and citizenship are part of this.<sup>31</sup>

Women With Disabilities Australia identified that women with disabilities continue to experience the recognised markers of social exclusion, including “socioeconomic disadvantage, isolation, multiple forms of discrimination, poor access to services, poor housing, inadequate health care, and denial of opportunities to contribute to and participate actively in society.”<sup>32</sup>

WWDAACT’s Strong Women, Great City report also revealed that of the respondents 1 in 5 women were not satisfied with their level of social interaction, did not have support networks to call on and did not feel recognised for their community contribution. <sup>33</sup>

Social connectedness and social inclusion are also key determinants of mental and physical health. It is recognised that some groups in society are at greater risk of social isolation, and therefore at greater risk of experiencing poorer health outcomes combined with the multiple disadvantages described above. People with disabilities are one of these groups.<sup>34</sup>

To be socially included people must be given the opportunity (among other things) to: connect with family, friends, work, personal interests and local community, deal with personal crises and have their voices heard.<sup>35</sup>

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29 United Nations General Assembly 2007, ‘Article 30 – Participation in cultural life, recreation, leisure and sport’, *Convention of the Rights of Persons with Disabilities*, opened for signature 13 December 2006, entered into force 3 May 2008, accessed 20/07/2015: <<http://www.un.org/disabilities/default.asp?id=290>>.

30 Carnovale, *op. cit.*, p. 24.

31 Productivity Commission 2011, *Disability Care and Support*, Report no. 54, Canberra. p. 202, accessed 21/07/2015: <<http://www.pc.gov.au/inquiries/completed/disability-support/report/disability-support-volume1.pdf>>.

32 Women With Disabilities Australia (WWDA), ‘An Overview of the Status of Women With Disabilities in Australia’, *op. cit.*

33 Carnovale, *op. cit.*, p. 25.

34 *ibid.*

35 Australian Social Inclusion Board, *Social Inclusion Principles Explained*, Australian Government, Canberra, 2008,

<<http://www.socialinclusion.gov.au/sites/www.socialinclusion.gov.au/files/publications/pdf/social-inclusion-principles.pdf>>

## The importance of community participation

***“To make you feel involved, part of the human race, rather than isolated.” (Participant)***

Community participation was identified as an essential part of having a good life and being a valuable part of the community. Participants identified numerous ways in which community participation boosted their quality of life and enriched the wider Canberra community.

***“For me community participation is also important because I’m part of the community too, so if I’m denied the ability to participate in the community, not only do I lose something, but the community loses as well.” (Participant)***

Being part of the community, like everyone else, was stated as a fundamental part of why community participation is important for women with disabilities. Not only was this recognised clearly as a right but including women with disabilities meant that the community could fully realise and enjoy its diversity and richness.

***“I think it’s good for the general populace to see people with disabilities to be out there in amongst it and doing things... The more people out there doing things, the more people become comfortable with diversity. That’s a benefit to the community.” (Participant)***

Increasing visibility of people with disabilities in our community was identified as an important element in breaking down social stigma and exclusion. Participants reflected that often the broader community holds fears about saying the wrong thing or acting disrespectfully around people with disabilities. There was agreement that these fears appeared common and could be dealt with by greater visibility and open discussion within the community about inclusion.

Attendees reported that participating in community life enabled better supports and access to information. They suggested that greater participation in the community translated into more support and reduced expenditure on other areas. Building relationships with others, both inside and outside the disability community, meant that women with disabilities had more opportunities and stronger networks.

Making a contribution to the community and being involved was also a significant part of community participation for a majority of participants. This, in turn, resulted in feelings of responsibility, being needed and being known in the community.

A sense of value, fulfilment and achievement was gained from such experiences. This also contributed to feelings of ownership and making a contribution that made a difference to others. Certain forms of community participation, such as volunteering, were identified as a good example of making a contribution without the pressures of employment.

***“... [It’s] good for my mental health because sometimes I get stuck at home because I don’t have transport and I get cabin fever... So to be out and feel like I’m actually participating and contributing holds me together.” (Participant)***

Participants reported better mental health and wellbeing as a result of community participation. This was linked to having companionship, learning new things and being able to contribute to the community. Being

able to engage with others in both informal and formal ways bolstered self-esteem and improved emotional wellbeing. This was particularly important for women who felt that their social circles had shrunk following acquired disability.

***“It gives me a reason to get out of bed in the morning.” (Participant)***

Community participation was identified as a motivating force which provided participants with purpose, a diversity of experience and improved their mental health and wellbeing. Being involved in the community also cut down boredom and isolation and gave women with disabilities a sense of routine, empowerment and independence.

Keeping active through community participation was also identified as a method of maintaining health and wellbeing. Exercising with others was identified as a valuable way to both socialise and boost fitness.

Socialisation was seen as an enjoyable part of community participation which nurtured women’s feelings of connection and worth.

***“I like to go shopping with my friends...We go and have lunch together and talk. Those things are really important for me...” (Participant)***

Community participation was an effective way of balancing your life, particularly in regards to participating in things not related to your disability. This was also noted as helping to build on identity based on your interests rather than by your disability.

Community participation was also seen as bolstering feelings of safety.

### **The types of community participation needed**

Overwhelmingly participants wanted to participate more in community activities and life. For the few women who stated they were happy with the amount of participation they had or they wanted to do less, this was connected with their stage of life or the demand or nature of their current responsibilities and disability.

The types of community participation women were keen to engage in ranged from informal and relaxed participation to more formal structured engagement. Spontaneous, unstructured and casual hanging out was a high priority for many participants, particularly younger women. There was also a need for participation to be ongoing but flexible, and for women to have choice and variety in what was available to them.

***“So, if you’re ready to connect with community but you don’t want to get out of your uggies, it’s nice to have a neighbor that you can visit but if you’re ready to get dolled up and go out on the town then that’s something you can do as well. So, the community kind of adjusts to where you’re at, ideally.” (Participant)***

The types of participation women wanted more of included:

- Recreation which focused on socialising and companionship, such as having people over to hang out and BBQs, coffee and going out for meals. This also included having access to or owning pets. Access to entertainment, such as theatre, movies and live music, and Canberra’s cultural institutes

and attractions, such as the Arboretum, zoo and art galleries were also referenced by many participants. Women also wanted to engage more in night life, shopping, travel and activities, such as dancing.

- Group learning opportunities on topics such as music, art and craft, hobbies and drama. Women were also interested in clubs based on interest, such as book clubs.
- Health and wellbeing activities, such as fitness and group exercise. This included swimming, bowling yoga and meditation and roller derby.
- Seeing family and friends
- Education, paid employment, or volunteering
- Advocacy

### **Barriers to community participation**

Participants identified that non-inclusive attitudes and stigma shut down opportunities for women with disabilities to participate. Some participants identified feeling silenced by these attitudes and behaviours and not being able to have an open discussion or legitimise their capacities to do a certain activity.

Participants also connected stigma to a reluctance to include people with disabilities. This was strongly felt across the forum. The reasons behind this were varied and included difficulty in accepting difference, a lack of interest in making the effort and a fear of embarrassing themselves or others by saying or doing the wrong thing. This reluctance was also demonstrated in a lack of effort to make events and activities accessible.

***“...people shout at me. I'm not deaf!” ([Participant in wheelchair].***

***“People often talk to my partner rather than me [agreement from many around the table], they go “what would she like?” and he says to me “hey she, what would you like?” (Participant)***

It was agreed that work is needed to change attitudes and behaviours which stigmatise women with disabilities and not just in the realm of community participation. Participants spoke of the need for better education and awareness on the inclusion and abilities of people with disabilities.

***“...the perception of the general public – they still need a lot more information to understand – you either get one or the other extreme. You either get people that really want to help, they are over helping. You try to get direction to cross the road and instead of trying to give you direction or give you an elbow they drag you across the road.” (Participant with vision impairment)***

The existing stigmas against women with disabilities wishing to participate in community life were seen as a major barrier. Open and inclusive dialogue, as well understanding and compassion, were just a few of the steps to overcoming this as nominated by participants.

When seeking to participate in activities, particularly sport, participants reported that they came up against people and services who were risk averse and made assumptions about their capacities. Participants stated that they were able to manage risk and understood their own limitations. This suggests that lack of awareness

is not just imbedded in public attitudes but also service policies and occupational, health and safety measures. It also points to the need to find ways to manage risk that incorporates the voices of people with disabilities.

***“Sometimes they won’t let you have a go or they’ll turn you away because they’re worried what could happen.” (Participant)***

The barriers to community participation were reported as impacting on participant’s willingness and interest to get involved. The two main barriers included non-inclusive social attitudes and behaviours towards disability, especially others not wanting to be inclusive, and the energy invested in ensuring a venue was accessible.

***“I think to be able to get around the city that you live in is...a really important thing and it’s a right.” (Participant)***

Participants felt frustrated by a lack of accessible community participation opportunities and identified it as inhibiting their right to participation and independence in the ACT community.

***“Swimming is a really good thing for me. It gets calipers off, crutches away, it takes pressure off joints. But accessing that regularly is tricky. Accessing the great programs that are available are just not appropriate for me because half the stuff is aimed at able-bodied women basically...” (Participant)***

Having the opportunity to engage in activities suitable to your needs was identified. This was a matter of accessibility but also of diversity and flexibility in the programs currently available.

Finding the community participation programs that do exist was also considered difficult and information sharing was limited. Furthermore, information on such programs was noted as often arising from already being involved in community.

Participants sensed that whilst there had been an improvement in accessibility some years ago, this had declined and facilities and public spaces no longer placed much rigor on accessibility. With many public spaces and facilities lacking accessibility, some participants identified their homes as the only real places they felt comfortable entertaining in.

***“I can feel a little bit isolated but my house turns out to be the area that I know I’m going to be fine in and sometimes you have to really push yourself to try new things because...it’s all about checking and re-checking and then sometimes with the best of intentions people think they’ve got an accessible premises only to find out that they don’t.” (Participant)***

The need to check and recheck the accessibility of venues and events was identified as adding an additional challenge to engaging in community participation. This was particularly associated with women who used wheelchairs, walkers, scooters or who needed aids such as audio description, hearing loops and interpreting services. This also applied to women who have assistance animals. What participants found to be particularly exhausting and frustrating is that many venues identified themselves as accessible but were actually not.

***“I like to travel but you always have to really kind of prepare yourself for it to be harder than it needs to be because people will say ‘Yeah we’ve got an accessible room, it’s just up the steps’ or ‘Yeah you***

***can get into the shower, you just have to get over the step' or 'Yeah you can get into the bathroom if you walk into the bathroom' ". (Participant)***

Access to accessible toilets was also raised as a barrier to participation. The misuse and lack of such facilities were the two major concerns. The group felt that this demonstrated a lack of understanding of what accessibility is and a need to educate venues and their staff on what constitutes accessibility, particularly in regards to toilet facilities and mobility aids.

Participants who spoke English as a second language reflected that they experienced a twofold barrier to participation in community, social and political life. This was identified as a problem when accessing activities but also when complaining about lack of access.

Participants observed that venues can play a critical role in facilitating community participation for women with disabilities. It was also identified that whilst selected venues may be considered accessible they were not facilitating an inclusive experience for all their clientele. Not being able to book accessible spots at certain venues online was identified as frustrating and inconvenient. The need to call and negotiate a spot added barriers to participation, especially when the accessible request was not followed through with upon arrival at the booked event. This was sometimes in the layout of seating plans in such venues as theatres and movies. Whilst some venues assisted participants to sit where they wanted, it was an experience that was hard fought for.

***"It seems that sometimes people think the most important thing is that you're in a wheelchair and you need your wheelchair space, not that you're with this group of people and you need to have a wheelchair space and be with this group of people." (Participant)***

Expense was also considered a substantial barrier by the majority of participants to being involved in the community, social and political life of Canberra. This was not just about the cost of social events and activities themselves but particularly about transport, accessing support workers and captioning, hearing loop and interpreting services.

This was also identified as a barrier to travel, with the cost of accessible rooms being more than the average accommodation rate.

Participants identified that the NDIS would potentially assist in the cost of community participation, however it was unclear where this financial support would be directed.

Transport was identified as a significant issue in accessing community participation. Mostly, this related to the quality of roads and pavements and the cost, timing of events and the availability of transport.

Safely navigating the place you live in is an important part of participating in social, cultural and political life. This was considered difficult in the ACT, especially in older areas where pavements are uneven and poorly maintained and curbs too steep. Maintaining pathways is crucial for people who are dependent on these for transport to local shops and facilities, community participation opportunities and employment and healthcare. Without well maintained pathways, greater reliance on transport systems places an otherwise avoidable burden on finances.

Newer areas of Canberra, whilst considered more accessible, still suffered from steep curbs and inaccessible design. Participants suggested that some newer developments were not adhering to design principles which enable their participation in those spaces.

Whilst some people reported the need for road or pathway maintenance to the ACT Government and received a prompt response, others were not aware of the ability to do this or were reluctant to do so because they felt like nothing would be done in response. This feedback suggests that greater awareness of the ACT Government feedback form Fix My Street and the Access City Hotline should be facilitated.

The timing of activities and events and the availability of accessible buses, community transport or the transport assistance of friends and family was raised as a challenge to participation for women with disabilities.

***“The weekends are the problem to getting out to see or do anything. Like right now there is going to be festivities...for Norway’s National Day and I’ve missed the last few years because I just couldn’t get there. Despite the fact that I’ve got family and everything here, they’re busy in university and are working...I can’t rely on them. The only thing I could rely on is the taxi service probably but if I was taking a taxi there and back. It’s going to make it an expensive day... It’s too far for me to go on the scooter.” (Participant)***

Opportunities which occurred during the evenings or on the weekend were especially hard to access if reliance was on such forms of transport. Participants made mention that they would like to know more about ACTION bus services, particularly the Night Rider service because of its flexibility and home service.

The timeliness of bus services was also raised as an issue which impacted on uptake of the service. This was a particular concern for women whose health was further jeopardised by being out in the elements and for women who relied exclusively on buses to get to destinations at a particular time.

The accessibility of buses and bus stops was raised by several participants. This included a shortage of accessible buses, as well as inaccessible buses being used during times allocated for accessible bus runs. Several women reported not being able to access the buses from their local bus stops due to limited or damaged pavement, drains, roads and steep curbs. In one case, after a complaint was made, efforts were made to make the bus stop accessible.

Several participants reflected that they had experienced or witnessed poor service from bus drivers who were unfriendly and observably annoyed at having to put the accessible ramp down if needed. Whilst participants did recognise that this was not a feature of all bus drivers, they did call for better disability awareness training to be delivered to bus drivers.

Security was also identified as an issue on public transport. Concern was raised over people taking advantage of women with disabilities.

Feedback on taxi services identified a lack of wheelchair taxis and reluctance by taxi services to go short distances, including to the local shops for appointments, shopping and social outings. Concern was also raised over an additional ‘lift fee’ cost being charged for wheelchair taxi services.

***“...the wheelchair taxi service just drives me insane any time I have to use it...I just get outraged that there aren’t many and that they seem to assume that you have some sort of concession thing. And a few times I’ve been in taxis and they’ve charged this lift fee thing which is an additional fee and I’m like ‘But you have a wheelchair accessible taxi, the fare should be the fare’.” (Participant)***

Many participants reflected that if they could drive themselves independently they would have a wider array of opportunities. Having your own transport modified to your needs was identified as both helpful and liberating. But maintenance costs on older vehicles was identified as a notable expense.

***“...there’s lots of support during the week to attend things, but you don’t necessarily have access to that support on the weekends...” (Participant)***

Being reliant on a support person or carer to go to events was seen as a barrier to participation. Some participants stated that it was difficult to find someone to support them at night, on the weekends or at any time outside of business hours. The logistics of this put a strain on participation.

For women living in supported accommodation it was identified that the house rules could put a strain on engaging in out-of-hours community participation options, as well as travel with others.

***“Amy<sup>36</sup> has an unusual situation where because of the staffing in the house where Amy lives there’s apparently only one staff member there from 9pm and because of some OH&S things it means... two people have to put you to bed...no one else is allowed to come into the house and help...I’m also not allowed to travel in the same vehicle as Amy.” (Participant)***

Participants reflected that fluctuating ability due to a range of factors affected their involvement. This was significant to people with episodic conditions.

***“You’ve made your plan, you know what you’d like to do, and you’ve worked out what you think you can do, and then you can’t. So it’s the fact that you can’t depend on yourself to be able to participate.” (Participant)***

Participants lamented that not being able to participate when they said they would left them feeling unreliable.

Juggling the many demands of life, in addition to managing disability, was identified as a major challenge to participating in community life. This including navigating family and caring responsibilities, domestic work, employment, education and any disability related activities, including medical appointments, negotiating with support providers and organising transport. Time poverty and exhaustion was also acknowledged as an obstacle to community involvement and a balanced life.

Family commitments were raised as impacting on wider community participation. This was noted as a barrier specifically relating to women because of their traditional gender roles as care-givers. With many women with disabilities carers themselves, it is understandable why such a barrier exists.

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<sup>36</sup> Name changed for confidentiality purposes.

Some participants felt that involvement in employment and education enabled better community participation. This was as a result of fostering wider engagement with people and also, having the funds to facilitate opportunities which cost money. In contrast, for some women who were engaged in employment and education, they felt that this limited their opportunity to engage in community participation due to time poverty.

***“...there’s two worlds; the people who work and the people who don’t.” (Participant)***

Interestingly, participants identified a divide in people that did work and those that did not, and that this division impacted on the ways in which they engaged with community participation and the opportunities that arose.

Having someone or a group to go out with was identified as a challenge to engaging in community participation. This was considered a consequence of accessibility but also of not being able to participate in the first instance to make such connections.

Companion cards were identified as a way of facilitating more opportunity to socialise with others, because through such means participants could enjoy an event or activity with a companion at half the cost.

Participants who connected with people online as a form of community participation identified technology and online literacy as an issue. They found that it was difficult to connect with people who were not connected or had limited technology literacy. This prevented them from expanding their networks online and organising meet ups face-to-face.

Participants from the Deaf community noted that opportunity was also an issue due to participation numbers. Given the cost of services, such as Auslan, outings for the Deaf community who rely on such services are limited.

“...the Deaf community is very small...at the art gallery we always get good numbers...but I am not interested in art....I like to find other activities but there is very limited opportunities. I have always liked the idea of a book club.”(Participant)

### **Improving community participation for women with disabilities in the ACT**

Participants brainstormed ideas to increase their access to community participation.

#### **Building networks of women**

Proactively fostering networks of women was a critical step, in not only increasing social opportunities and boosting confidence but also finding information and making a difference to the treatment of women with disabilities in general. Both formal and informal networks, conversations and mentorship relationships were identified as needed.

Participants also recommended a whole of life approach to networks and community participation for women. This was particularly important for younger woman as they transition out of the education system.

Participants wanted networks to be broader than just women with disabilities. They wanted to include a diversity of women. They especially wanted to foster networks with women in positions of power and influence

from areas such as politics, business and sport. Connecting with women in power was recognised as a method of creating change to the discrimination and exclusion women felt across all areas discussed in the forum.

### **Discrimination and awareness raising**

Participants called for a concentrated effort to tackle imbedded and ongoing discrimination in the community. Educating the community to break down stigma was identified as one method. Increasing visibility through more accessible participatory opportunities was also identified.

Social media was seen as a powerful tool for challenging discriminatory attitudes and behaviours. This could be better employed by organisations, service providers, government and members of the wider community.

### **Listening to women with disabilities**

Participants felt that it was critical that government, organisations and services actively listen to women with disabilities. This included creating more accessible forums, such as the WWDACT forum, where women could come together and raise issues that affect them.

### **Accessible and inclusive information events**

Participants called for an increase in local accessible and inclusive information events and workshops. These events did not need to be disability specific. However, participants did identify a need for more inclusive activities for women with intellectual disabilities.

When conducting an accessible information event, participants from the Deaf community stated that it was essential to provide a hearing loop, captioning and Auslan interpreting. There was mention that such workshops had been conducted in the past but for funding reasons had not been continued.

A dedication on behalf of hosts to make community information events accessible would not only combat exclusion but also raise awareness of disability in the community.

### **Foster connections between organisations in the ACT**

Participants identified the need to build stronger connections between local organisations in order to boost community participation opportunities. Through closer relationships organisations in the ACT could potentially work together to pool resources and ideas, improve information provision and as a consequence, enable women with disabilities to have more opportunities and a clearer understanding of what is available and accessible.

### **Facilitate social outings**

***“It might be a group that gets together, just that sort of informal stuff that if you all get together and go for a walk once a month, and so sometimes those connections help that way.” (Participant)***

Participants expressed strong interest in the development of opportunities for more social interaction. This included regular unstructured opportunities to foster friendships.

### **Child care support**

Increased access to child care would also enable mothers with disabilities to enjoy and participate in the community more. This also may be related to a lack of awareness about the Government Priority Access Guidelines.

## Chapter 4: Housing, cost of living and poverty

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Canberra has one of the highest cost of living rates in Australia.<sup>37</sup> The ACT Council of Social Service identifies this, particularly in regards to the cost of housing, as a major driver of poverty and homelessness in the ACT.<sup>38</sup> For women with disabilities, including those both on welfare support or not, this increases their rate of poverty and their ability to cover the costs of basic essentials, such as food and healthcare.

Article 19 of the *Convention on the Rights of Persons with Disabilities* calls for the recognition of the “equal right of all persons with disabilities to live in the community, with choices equal to others.”<sup>39</sup> This includes having the opportunity to choose how and where you live and who you live with. It also includes having access to adequate support measures, including community services, which enable inclusion and prevent isolation.

Nationally, the majority of people with disabilities live in private dwellings (94%) and the remainder of people with disabilities (6%) live in non-private dwellings, with nearly two-thirds of these (4%) living in cared accommodation.<sup>40</sup> At present, there is no publicly available sex-disaggregated data that helps us understand the situations of women with disabilities in the ACT.<sup>41</sup>

People with disabilities face a higher risk of poverty than people without disability.<sup>42</sup> WWDACT’s Strong Women, Great City report found that “Compared to other households, households that include a person with a disability tend to have lower incomes, less wealth, greater reliance on government pensions and allowances, and a higher incidence of financial stress.”<sup>43</sup> The report also noted that almost half of Australia’s population with disabilities lives in or near poverty, with the median gross weekly income approximately half of non-disabled people’s income.<sup>44</sup> The higher than average risk of poverty for people with disabilities is likely related to lower employment rates and prospects, reliance on government welfare and subsidy and increased expenditure associated with disability.<sup>45</sup>

Access to economic resources has a significant impact on the health and wellbeing of an individual and their community, as it determines peoples’ ability to access goods and services.

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37 ACT Council of Social Service (ACTCOSS) 2015, ACT cost of living report: Tracking changes in the cost of living, particularly for vulnerable and disadvantaged households in the Australian Capital Territory, ACTCOSS, Canberra, p. 5.

38 Ibid.

39 United Nations General Assembly 2007, ‘Article 19 – living independently and being included in the community’, *Convention of the Rights of Persons with Disabilities*, opened for signature 13 December 2006, entered into force 3 May 2008, accessed 20/07/2015: <<http://www.un.org/disabilities/default.asp?id=279>>.

40 Australian Bureau of Statistics 2011, ‘Living Arrangements’, *4446.0 - Disability, Australia, 2009*, accessed 01/08/2015: <<http://www.abs.gov.au/ausstats/abs@.nsf/Lookup/4446.0main+features132009>>.

41 Della Torre, E. 2015, *Facts on women with disabilities*, WWDACT, Canberra, p. 2, accessed 20/07/2015: <<http://www.wchm.org.au/wp-content/uploads/2015/05/Facts-on-women-with-disabilities-in-the-ACT.pdf>>.

42 Australian Council of Social Service (ACOSS) 2012, *The Poverty Report 2014*, ACOSS, Sydney, p. 27.

43 Australian Institute of Health and Welfare, ‘Australia’s Welfare 2011’ cited in Carnovale, *op. cit.*, p. 35.

44 COAG Reform Council, *Disability 2010-11: Comparing performance across Australia* cited in Carnovale, *op. cit.*, p. 35.

45 ACOSS, *op. cit.*

## Access to housing

***“...Let’s fix the house, not put the woman on drugs.” (Participant)***

Housing was a major concern for the women who participated in both the forum and the interviews. Housing that was accessible, affordable, and sustainable was identified as a foundational element to quality of life.

***“When you’re accommodation is threatened, you suddenly come out of that low need category into a high need category because if you can’t get into your bathroom, can’t get into your kitchen, all those things cause a real challenge.” (Participant)***

Without a solid home base, managing the other facets of living, such as health and employment, were heavily impacted.

The persistent problem of housing shortage in the ACT across all housing sectors was raised consistently throughout the consultation. This was particularly in relation to housing that meets the specific needs of women with disabilities.

Having a disability heavily influenced the type and location of accommodation required. The need to reside close to services and amenities meant that the price of housing was more expensive. With limited employment options and reliance on government pension, finding appropriate accommodation in an accessible area was identified as difficult for some participants.

The choice to live in and move to certain places was raised as an issue that impacted wellbeing. The freedom to relocate was identified as being hindered by the availability of affordable and accessible housing and compounded by the amount of effort involved in modifying existing dwellings. This was also exacerbated by the need to be in locations that are well connected to services and transport systems.

***“I get a bit jealous sometimes of friends who can move just because they feel like living somewhere else...I might feel like living somewhere else but it doesn’t seem so easy.” (Participant)***

For women with disabilities living in supported accommodation the freedom to choose where you live and who you live with was impacted on by current supported housing arrangements.

***“It would be really exciting, [she] has never had the chance to choose who she lives with, she has only ever lived with people who have the [same] support needs as you, and so that’s really hard.” (Participant)***

The implementation of accessible design principles across all ACT housing sectors was identified as a fundamental key to increasing inclusive housing options. This was largely identified as an issue in the private rental market, where accessible design principles were lacking in the ACT.

In addition to the implementation of such design principles in the private sector, it was noted that there is significant work to be done through the NDIS’ supports for housing and independent living. It was hoped that through the NDIS support will be given to help women with disabilities meet their housing needs.

Accessing expertise for modifications in private housing was reported as difficult, since the limited expertise in accessible housing in the ACT was felt to be largely consumed by the public housing sector.

The expense of modifications was also highlighted as a concern. Making modifications to pre-existing dwellings was expensive and often not fully achievable. Provision of a financial subsidy or support to women to assist in accessibility modifications in private dwellings would alleviate significant housing stress and its impact on quality of life. It was hoped that through the roll out of the NDIS, this need will gain attention and much needed support.

Having access to government housing was identified as important to some participants who would like to move out from group houses or family supported living arrangements to have greater independence. Some participants reported that the significant length of waiting lists for government housing was putting undue pressure on other services and family supports.

Ongoing harassment and disturbances by other residents in public housing apartment blocks was raised as an issue by one participant who has an intellectual disability. Individual advocacy and support from friends had assisted in sorting out this challenge. ACT Housing, however, was not seen to provide adequate assistance to alleviate the harassment.

The low quality of some public housing was also raised by participants. This included being moved into residences in poor condition with numerous maintenance issues.

***“I’ve been involved in the system for 20 years and I’ve seen great improvements and I’ve seen a lot of heart in the people who work there but the outcomes – you have to fight over maintenance. It can take weeks to get a response.” (Participant)***

Maintenance was seen as an issue in public housing. The main concern was the waiting period to get maintenance done, inconsistent communication and a “Band-Aid” approach to maintenance issues. Some participants were supported by advocacy groups, such as ADACAS, so they could challenge Spotless, the maintenance service provider for ACT Housing.

Many of the participants spoke of their personal advocacy efforts to better their own government housing circumstances. In instances where the provision of public housing did not meet the needs of women with disability, particularly in regards to their person safety, they felt they had to put significant effort into advocating for themselves to make change in their circumstances.

Accessible private rental options were identified as few, with little enthusiasm for modifications from landlords. This was seen as a particular challenge for participants who were ineligible for government housing.

A push on behalf of the broader housing sectors in the ACT for the private rental market to modify homes was seen as necessary. However, this was not seen as sustainable or achievable, particularly because universal design principles on accessibility are not mandated in this sector as yet.

## Cost of living and poverty

Costs associated with having a disability were reported as heavily impacting on the purchasing of everyday essentials. This was noted as affecting both women with disabilities both not receiving and receiving government pensions or housing.

A sense of frustration was felt amongst women who were working hard alongside people who did not have disabilities and therefore did not have the additional costs associated with maintaining their health and mobility.

In the case of hearing aids, whilst the government subsidy for hearing aids was appreciated, it only covered the most basic of equipment. This meant that if women wanted higher quality hearing aids they had to pay more themselves.

When the expenses relating to their or their children's disability were too much, one participant discussed how emergency food outlets became the stop gap measure.

It was suggested that more support be allocated to assisting people to cover the costs of disability related expenses.

Many participants referred to the supports, both financial and non-financial, they received from family and friends. Some participants reported that they still received or relied on finance from their parents to pay for living costs, particularly those related to disability and medical supports. Others spoke of fundraising for particular medical expenses.

Some participants who felt that they were well supported by family and friends were less likely to utilise or know what home supports were available to them. This was particularly true for a participant who worked full-time and was not connected to the NDIS or the DSP.

At the same time, it was identified that there was limited financial support for parents caring for dependent and independent children with disabilities. Without adequate financial supports, additional pressures are placed on families. This was identified as a specific issue for locating appropriate housing options.

***"...in my case, because I'm a dependent and have no income, there's that constant underlying feeling that you're bludging off someone else."***

A sense of guilt or dismay was conveyed by several women who still relied heavily on such family and friend supports. Independence was valued highly and under the current financial constraints of living with a disability, this was difficult to achieve. Over time it was hoped that the NDIS will alleviate such pressures and enhance the independence of women with disabilities.

Participants who received the Disability Support Pension (DSP) reported living on tight budgets which left little to no money to use on anything other than essentials. As discussed previously, expenses relating to disability and lack of employment options meant that women with disabilities on the DSP had limited options to increase their incomes. They felt this not only disadvantaged them in maintaining their health and wellbeing but also their access to better accommodation, supports and engagement in community participation.

Short term financial support during periods of financial stress due to disability was seen as an area in need of attention. This was particularly related to episodic conditions or periods of unemployment related to caring responsibilities for children with disabilities.

***“You’re not asking for support for the rest of your life. You’re just asking for a bit of support to get you through a spot.” (Participant)***

Having access to short term support during such periods was identified as a way of easing the pressure on already strained budgets and alleviating some of the financial pressures arising from having to take time off work. Coupled with flexibility in the workplace and a better awareness of disability more broadly, this would assist women with disabilities to maintain continuity in their lives.

Women who identified as being mothers with dependent and/or independent children spoke about a lack of support and information in the ACT.

***“I’ve been to a lot of sessions, information sessions, seminars, attended a lot of meetings, case studies et cetera, that the focus has been on families where there’s disability and maybe an adult with a disability but nothing that relates to parents with a disability.” (Participant)***

They told of the difficulty of locating and navigating services, government subsidies, employment, housing, child care and balancing cost of living. For example, one participant spoke about the difficulty of negotiating her government housing arrangements when her son turned 18, began to work and continued to remain in the family home.

Participants identified that there was limited or no community support available for new mothers with disabilities. This was particularly in regards to domestic support, including cleaning, cooking, as well as shopping, gardening or leaving the home with children.

There were also numerous personal stories from participants who identified as mothers who continued to support their children into adulthood albeit at their own financial detriment.

The lack of support for mothers with disabilities was seen as directly related to a lack of awareness that people with disabilities can be and are parents too. It was also noted that this lack of awareness was also found in the roll out of the NDIS.

***“...look at something like the NDIS, there is a focus on parents, particularly ageing parents of people with disability...but nothing about people with disability as parents...” (Participant)***

It was noted that if the NDIS is to focus on control and choice, it is critical that they take into account parents with disabilities and the supports they may require.

Transport was identified as a significant contributor to poverty. Taxis travel accounted for a large proportion of transport costs. For participants who were dependent on this form of transport due to their disability and/or their health care needs. Whilst the NDIS and government was recognised as assisting with this expense, it was not considered adequate.

***“...my issue is I’m having to keep paying for taxi fares every Wednesday to get to the hospital to have my therapy...I’m only on DSP...and it’s costing a lot of money for taxis...”(Participant)***

Whilst participants who received taxi vouchers stated that it alleviated some pressure on their income or pension, the expense of taxis was still largely considered a gap in need of attention for women with disabilities, particularly those in the workforce.

***“Even with the taxi subsidy...I’m still out of pocket each time... [It] is more than I earn.”(Participant)***

For those not eligible, for the ACT Taxi Subsidy Scheme (TSS) the cost of taxis placed additional pressure on already strained budgets. This was predominantly felt by women who tended to utilise taxis during points of decline in their health and condition. Some of the participants who were eligible spoke positively about the taxi vouchers they received from the government to access taxis.

As the NDIS rolls out it is important that women who require the use of taxis know that they need to ask for transport costs to be included in their plans, and to collect documentation about their average taxi travel costs as evidence to take to their meeting with the planner.

Government subsidies for public transport were seen as a valuable resource which assisted women with disabilities to travel to and from work and appointments and also for leisure. The combination of the MyWay card benefits and government concession card assisted some participants to get to places affordably.

## Chapter 5: National Disability Insurance Scheme

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Through the National Disability Insurance Scheme (NDIS) it is envisaged that people with disabilities will have greater control and choice in meeting their long term needs. Given the marginalisation and intersectional disadvantage women with disabilities face, it was seen as critical that the NDIS is sensitive to the needs of women with disabilities in our community.<sup>46</sup>

In the ACT, the roll out of the NDIS commenced on 1 July 2014 for people up to age 65.<sup>47</sup> The roll out of the scheme to the whole population of people with disabilities in the ACT aims to be completed by July 2016.

Many participants expressed hope in the scheme and looked forward to having the opportunity to making choices regarding their access to new and existing supports. However, there was concern, confusion and frustration expressed by women participants who were at all stages of the application process.

### Planning process

***“...It’s ridiculous that [for] many people with NDIS plans, we can’t read our own plans or understand [them]...” (Participant)***

The need for a diversity of plan formats was raised. This included incorporating pictures. Whilst one participant mentioned that there are people that can help you to develop a multimedia plan, concern was raised that people are scared or unwilling to venture outside the standard planning options.

***“...there’s lots of people that are too afraid, too fearful or feeling even too intimidated to venture out there....They don’t have the voice to come out, and they don’t have the confidence to come out...”(Participant)***

The planning process asks applicants to identify their existing care networks and provides suggestions such as family, friends and neighbours. It was felt that the phrasing of the questions in this section presumed pre-existing care networks.

***“They’ve made all these presumptions that all these people are supposedly in my network helping me and supporting me.” (Participant)***

It was seen as important to understand that women with disabilities’ care networks are diverse and that many women with disabilities are themselves carers. Furthermore, many women felt guilt around relying on others and that the discussion of such networks should be scoped and phrased in a sensitive way.

***“...if you feel you’re imposing on your friend and relative every time you see them. That’s a lot of burden on your own part.” (Participant)***

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<sup>46</sup> Women With Disabilities Victoria 2015, ‘Fact sheet 5 - The NDIS for Women with Disabilities’, Women With Disabilities Victoria, Melbourne, accessed 2/09/2015: <[http://www.disabilityloop.org.au/resources/wwdv\\_ndis.html](http://www.disabilityloop.org.au/resources/wwdv_ndis.html)>.

<sup>47</sup> National Disability Insurance Agency, ‘NDIS in the ACT’, NDIS website, accessed 1/09/2015: <<http://www.ndis.gov.au/about-us/our-sites/act>>.

It was suggested that more comprehensive and accessible supports by the NDIA during the planning process are needed. Participants reported feeling overwhelmed by the concept, process and delivery of the NDIS. The assistance of an independent planner in some circumstances was identified as a way of easing this feeling. The planning process was reported as being especially difficult for people with memory and concentration issues.

### Complaint mechanisms

The NDIA complaints process was also identified as problematic. This included feeling that complaints were not handled fairly or with adequate communication. As an example, one participant reported that her complaint and the review of that complaint was handled by the same person.

***“If I didn’t care about having the financial security of the NDIS it would be really easy to walk away because it’s too hard, but I don’t have that option. I have no choice. It’s the rest of my life...”***  
***(Participant)***

## Conclusion

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The forum and associated interviews have enabled a small cross section of women with disabilities in the ACT to give their perspective on issues which are important in their lives, and to identify ways in which policies and programs can be improved to enable them to lead more economically viable and less stressful lives. Providing a safe environment for sharing personal stories is important for women whose most common interactions in the workplace and in the community are in situations where neither disability nor gender is understood, and where the impact of the intersection of these attributes is minimised or overlooked. The findings of this report amplify and build on previous investigation undertaken by WWDACT, and indicate where additional work is still need to improve outcomes for women with disabilities across all life areas in our community.

# Recommendations

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1. That WWDACT work with Disability ACT and the NDIA to ensure that appropriate and accessible information is available for women with disabilities in the ACT about the issues raised in the consultations (noting that this will also support men with disabilities).
2. That WWDACT use the findings from the consultation to engage with and inform the ACT Health Directorate, the Community Services Directorate (including the Human Services Blueprint service model team), and the Capital Health Network (for General Practitioners) so that current service delivery models are adapted to be inclusive of the needs of, accessible to, and able to engage effectively with, women with disabilities.
3. That all ACT Government Directorates review their internal and cross-directorate information sharing policies so that the Future Directions Strategic Priority 5 “I want to tell my story once” can be realised.
4. That the ACT Government require that tenderers for human service delivery in the ACT demonstrate that their services understand the needs of, are accessible to, and are able to engage effectively with women with disabilities.
5. That the ACT Government Public Procurement policy ensures that equipment and services purchased incorporate universal design and maximise compatibility with assistive technologies.
6. That WWDACT work with the ACT Human Rights Commission and ACT Health Services Commissioner to identify ways to improve their visibility and the understanding of their role and of the complaints process to women with disabilities in the ACT.
7. That the ACT Government lead the way in employment of people with disabilities through an increased focus on actively recruiting people with disabilities for the public service and ensuring that their accessibility, training and flexibility needs are met; and that workplace education and awareness programs on disability and gender are incorporated during the process.
8. That WWDACT use the findings from the consultation to engage with the NDIA to ensure that the views of participants about NDIA processes, and the skills and processes of service providers, are considered and addressed.

# Case studies

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## Case study 1

*I've had a disability all my life which has seen me mostly be a wheelchair user, particularly in the last 30 years. My needs are quite mainstream.... I see my GP and he's a regular GP in a regular building... Generally I find my health and welfare needs are pretty well looked after. ..I don't know how many times in setting up appointments...I had to tell people that I needed to have a lunch time appointment or a before or after work appointment.*

*My GP doesn't have an adjustable examination bed so sometimes I do worry that he's not suggesting things that I should be having, like pap smears... I feel like there's a lack of information for women with disability about where to go for those things. Mammograms and all that sort of thing...I do a lot of my own research and just a lot of trial and error by myself, trying to figure things out.*

*It seems like some health programs...equate having a disability with being on the pension. Last year I had an ulcer on the bottom of my foot and I became involved with the community nurses and they came out to the house.....people kept asking me if I'm on the pension, if I was connected to the NDIS or who else was funding me to live independently.*

*...I am well supported by family and friends. I don't know what the options are to get other support. ...my family and I kind of work it out ourselves. I must admit, I don't know how to get home support if I need it.*

*I guess with education, and I think this reflects how I grew up... I have two ....[siblings] and so we always just did things together ..So sometimes it's a bit of a rude shock when I go somewhere and expect that I'll be able to access a building or access the lecture theatre or the tutorial room and then find that I can't.*

*[At work] I've always had people in to ask me what I need and there's always been that flexibility to get me special equipment or a car spot or something like that if I need it. ...I did once apply for a job...and they just couldn't get me a car spot and I couldn't take the job because without somewhere to park the car, I just can't do it...*

*I've been able to buy a house ... and get it modified. I've modified the kitchen and the bathroom which were really the two areas that I needed... when I bought the house...it was hard to find people who had experience in accessible modification...*

*Often at the theatre I've ended up being separated from my group even though we've gone together and I've made sure that we're going to be able to sit together. I've now got a little dog and I'd love to be able to go places with him but it's either sort of pet friendly or wheelchair friendly...those two things very rarely meet.*

*I'm still amazed at how there can be these new areas that have really steep curbs.... I want to be able to get around the city independently. [but].if I wanted to catch the bus I don't think I'd be able to because I can't get from my house to the bus stop without using a car.*

*...with the NDIS I'm a bit fearful that it'll somehow be connected with receiving the pension and that to me would just undermine the whole thing....I think that I'd be eligible for the NDIS but I don't know.*

## **Case study 2**

*I'm 41, I live with my partner, and my child. I work three days one week and four days the following week. I obtained my joyous spinal cord injury in 1996...that was the result of a hereditary condition...I was 22 when I discovered it, just sheer accident really... I was very active...So obviously it was a huge shock*

*I do a combination of wheelchair use. I have to wear callipers to [walk]... So there's lots of going on behind the scenes that enables me to walk. I've used the chair in the last three years more so than ever...because of my child I need my arms free on a domestic level.*

*The [first government] place that I lived in was wheeling distance to the shops, and doctors, et cetera. So when I finished my degree and started working, pretty much it didn't take long for me to reach the point where I was paying market rent for that house. I lost all entitlements to absolutely anything because of my fairly meagre wage. [When] I met my partner...we continued to live there.*

*...when I got pregnant we tried really hard because I just knew that I wasn't going to be able to care for a child in that house with all of the paraphernalia that I have, wheelchair accessible cots, changes tables, all of that. It wasn't going to fit. We had no choice but to turn to the private [rental] market.*

*We looked for four months, over 200 properties. We finally found this place... it had sufficient living space for wheelchair turning circles. We built a temporary ramp because I couldn't get in and out of the house. The bathrooms weren't accessible. And there's the kitchen, there's the clothesline, there's the carport, there's thick carpet, there's the garden...the damage that's been done to my body as a result of living in this house is ongoing. [Everything] is threatened if you don't have an independent house....there's a huge emphasis on modifying existing rental properties, which we cannot believe is still being promoted.*

*[When] I returned to work three days a week. And that was delayed because we couldn't get our child into childcare. We were on a waiting list for two years.... One night I discovered this tiny little print that said "Do you qualify for priority access?" So I rang them and asked. And nobody knew what I was talking about. I found out that [priority access] is the law if you are government-subsidised [and] we needed somewhere I could actually get in the door.*

*{In my work} certainly in my experience the immediate teams that I've worked within have generally been supportive of things that I require. And at the moment, and certainly in the past, flexible working arrangement is really important. And the type of job I do allows for that to a point. The main terrible experience I had was trying to modify a car, one of our work cars...It's a long, complicated story but basically it was funded through Job Access. At one point the car had to be off the road because of the modifications. The car was not drivable. I lost the Job Access funding.*

*I feel like I've been very much on a tipping point mentally for the first time in 20 years. I've really had to work very hard at maintaining a mental strength in the face of all of this. And, sure, throw in a lot of sleep deprivation that comes with having a child and that makes you a bit more vulnerable...*

*The main disappointment was that postnatal care... all of that lack of care prolonged my stay in hospital unnecessarily. There was things that I asked them to do that just didn't happen. So there was flow-on effects of not having a bit of an awareness of a spinal cord injury of my particular medical condition. I printed out stuff about my medical condition and handed it out to these people before I arrived at the hospital with "Here's the birth plan. Here's the care management plan because I'm not going to be able to talk to you."*

*...I tried to be as organised as I could as soon as I found out I was pregnant. It became quickly very obvious to me that there wasn't an awful lot around and what was around wasn't well-documented...it was just kind of corridor conversations and comments in passing that...*

*It was a Women With Disabilities meeting several years ago that I spoke to someone who said "I had my child 12 years ago and TADACT modified the cot...they were absolutely fantastic. And I bought the cot and they modified it to a design that I wanted. And it wasn't just about being practical, it was about making something or modifying something that was practical and beautiful...it's fabulous for a wheelchair user, absolutely fabulous, same with this change table... There was a host of other equipment, little things that I could have done with at the time for a short period. It just wasn't out there.*

*...after I had my baby I really did look to every form of possible community help I could get because I was struggling on a domestic level. I've really quickly realised that there's very little support for parents with a disability.*

*...I've really struggled on the domestic front... when two things - you've got a baby and you're living in a house that's not accessible. ...I pay for a cleaner to come in fortnightly...I can barely afford to do that...*

*...Exercise is another story altogether. I find that really frustrating, trying to find a program that fits, that works for me. I've tried the ones that were aimed at people with disabilities and, I have to say, I had a pretty poor experience...I cried in my car for 20 minutes after that because I just thought "is this the only option?"*

*Work and the domestic management is where my energy's split. It's a bit isolating. It's more than a bit, I have to admit. And there's times recently where I have felt really quite despondent about it all. And I've spoken to my GP about this. And she said "Oh, okay, let's look at what we can do about this." I won't go on medication because I resent the fact that I have to take a happy pill because my house isn't good.*

### **Case study 3**

*I'll be 67 in July. I've lived here virtually all of my life...I'm separated, not divorced. I've worked for the public service through three different stages of my life...*

***...I developed RSI in 1991 in the public service. ...the doctor I was seeing at the time was not a great believer in RSI, and he was of no help. I was in screaming agony.***

***When I came back I was basically told I was no longer required and I was being made redundant, and I said "You can't do that". ...I was forced into a situation that I had to go to the Administrative Appeals Tribunal. Comcare stopped my claim for my RSI. I was the person who was the primary income earner in my family. I got to a point of suicidal thoughts...We had a house, a mortgage and all those sorts of things. Times were difficult...***

***In 2000 my father was diagnosed with dementia, and my mother really wasn't capable of caring for him... Situations would occur during the day and my mother would ring me in a panic, my stress levels built up then my respiratory problems came in to force.***

***I did 12 months study at the CIT for childcare. I went in to do childcare [practical] and discovered that I wasn't good around little children because they carried all sorts of bugs... I chose to go on to University of Canberra to do education. In my second year...I finished up with a severe flu infection, which developed into pneumonia. I had to pull out of uni at that stage.***

***I eventually went back into the public service. [Then] I was diagnosed with a Grade 2 [breast cancer]... I lost my entire breast, and then turned out to be allergic to the chemotherapy, and follow up therapies... I had side effects for that for five years. My sister that used to help me with mum and dad [but] my daughter wasn't supportive...I didn't feel supported. I felt neglected and I felt as if I was an inconvenience.***

***As a result of having cancer in 2008, I ran into problems again with time off. The executive level officer decided that I was surplus to requirements, they made my life pretty damn awful, I reached a point of suicide.***

***I sought help through the Tuggeranong Mental Health Service, through the ACT government, and through that I was put in touch with a support officer from PHaMs [Personal Helpers and Mentors]... They put me in touch with Care Financial Services ...I was entitled to the equivalent of two years of the pension under a special section of the Act.***

***[The worker from Woden Community Service] was a Godsend. [They] introduced me to some services and ...got me...re-engaged in community. I went to a philosophy class. I went to the reading classes at the Woden Library. The meditation one was great...***

***I've been able to...return to work. Now I'm on six hours a day, Monday, Tuesday, Thursday and Friday and I only do four hours, a half day, on Wednesday....The rehabilitation people have suggested I should go back to work full-time [but] once you've been through this, I'm distrustful. I've only just begun to really start to feel close to people again.***

***I've learnt to pace myself. I've got proper supports. [Now] and I have a really good programmable trackable mouse that works very well for me. So they're very effective. I can manage.***