



Women With Disabilities ACT

Submission to the

Inquiry into

Maternity Services in the ACT

Standing Committee
on Health, Ageing and Community Services

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

Winner 2012 International Women's Day Award, Community Category

Winner 2015 ACT Chief Minister's Inclusion Awards, Excellence in Championing Human Rights

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Maternity Services in the ACT

WWDACT

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1. About WWDACT

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

2. Background

The Universal Declaration of Human Rights establishes that every human being is born free and equal in dignity and rights. Building on this, the Convention on the Rights of Persons with Disabilities (CRPD) recognises that the *family is the natural and fundamental group unit of society* (Preamble Para. [x]). This is further elaborated in Article 23 of the CRPD which outlines the obligation of States Parties to take *effective and appropriate measures to ensure equitable access without discrimination to things relating to marriage, family, parenthood and relationships*. This includes the right to found a family, and to have age-appropriate information, and the means necessary to enable people with disabilities to exercise their rights under this article.

An increasing number of people with disabilities are exercising their right to experience the full range of human relationships and in consequence, many more women with disabilities are exercising this legitimate right to become mothers. Yet, their experience of planning a pregnancy, during the birth and after the baby is born is often diminished because they do not have equitable access to maternity services and experience significant prejudice in their interactions with the health system. Although women with disabilities are the experts in their own conditions they are legitimately unsure of how pregnancy might interact with existing symptoms, so that access to information coupled with choice is important.

The issues which face women with disabilities in their desire to become parents and in their subsequent mothering have been documented in the UK, Australia and elsewhere but remain consistently unaddressed. These issues have been summarised in a 2009 policy paper from Women with Disabilities Australia (WWDA) of¹:

- Discriminatory attitudes and prejudicial assumptions
- Lack of access to information , services and support

¹ Frohmader, C., *Parenting Issues for Women with Disabilities in Australia: A policy Paper by Women With Disabilities Australia*, Women With Disabilities Australia, 2009

- Dependence versus independence
- Service providers lack of knowledge & understanding of disabled women's maternity needs
- Removal and/or threat of removal of babies/children by authorities
- Lack of research and data

The embedded prejudices and negative societal attitudes too often mean that adequate supports are overlooked or done in a haphazard manner along all stages of the mothering process.

We know that parents with disabilities are more likely to have their children removed by the child welfare system. There is increased likelihood of having their parental rights terminated. Moreover, disabled mothers are less likely to gain access to custody or visitation of their children. Even in cases where domestic violence has been present in the relationship custody is too-often awarded to the violent parent.

For all women, there is a problem of over-medicalisation of the natural process of becoming a mother. For women with disabilities this problem is exacerbated, and the risk that professionally determined 'help' will be imposed on the woman is high. We need to ensure that when medical services are involved with women with disabilities, that these authorities have understood and adopted a social, rather than a deficit and medical model of disability.

WWDACT would like to note that not all "mothers" or "parents" referred to in this submission identify as women, and that maternity services should be inclusive of trans and non-binary people, who are left out of most research in this area.

3. Considerations

3.1 Models of care for all maternity services offered at the Centenary Hospital for Women and Children (CHWC) and Calvary Public Hospital (CPH), including, but not limited to, the Birth Centre, the Canberra Midwifery Program, and the Home Birth Trial and whether there are any gaps in care;

When a woman with disabilities presents at any stage of her pregnancy journey, it is likely that most health professionals and health service providers are reactive rather than there being any pro-active model in place. This may mean that accessibility adjustments are ad hoc and haphazard. Given that the range of disabilities that are encountered is diverse, and there is a need for supports on a case-by-case individual basis. However, there is also an argument that provision of more generalist disability awareness training, especially in the area of disability culture, would make the journey more positive for both the parents and all health professionals with whom they interact. Non-disabled women have commented that models of care seem to be developed

independent of input/feedback from consumers themselves. Certainly mothers with disabilities need to be involved in the planning of midwifery policies and programs, such as the CaTCH program².

There is not an established model of maternity care for mothers with cognitive impairment, although numerous pilot programs have been conducted interstate and overseas.

3.2. Provision of private maternity services including centre and non-centre services;

Parents with disabilities report the full range of experiences in their pregnancy journey from excellent to very poor. The supports and services provided are very dependent on the knowledge level of the individual health professionals and service providers.

Mothers with disabilities may feel that they have greater choice in the private sector, that they have more flexibility in choosing who is involved in their care, and that they have greater chance of engaging someone with appropriate expertise. However, it must be remembered that many people with disabilities are in low socio economic strata and may not have the luxury of choice.

In both public and private systems, parents with disabilities have to confront assumptions of incapacity to parent, questioning of their decision to have a baby, and reluctance (particularly of gynaecologists and obstetricians) to enable them to elect to use the birth centre. A medical model approach to disability is common.

The assumptions that we [women with disabilities] are not parents I think comes from the fact that we are not shown to be parents anywhere, that it's just not considered an option for people with disabilities to be parents³.

- Woman with physical disabilities, ABC Radio
- Life matters

There is little space for the woman to be the expert in her own condition, to be acknowledged as competent, or to make choices for herself. Too commonly these are professionally determined, rather than cooperatively developed. The woman is left feeling disenfranchised and disempowered. Too often decisions are made which do not work optimally for the woman, her baby, and the family.

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

² Continuity of Care at Canberra Hospital

³ ABC RN, *We've Got This Monday 12 November 2018*, accessed online on 16 January 2018 at: <https://www.abc.net.au/radionational/programs/lifematters/weve-got-this:-queer,-disabled-and-parenting/10481068#transcript>

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'

WWDACT *Contributing Our Voices* Report, 2015

Conversely, there is a risk that in asking for help, she will be judged as incompetent and an inadequate mother. This has a negative effect on the provision of good services.

3.3. Management of patient flow, including, but not limited to, wait lists, booking services, and capacity constraints;

Parents with disabilities are often persuaded from using their preferred option as a patient because of the lack of understanding of their situation from the professionals with whom they are dealing. When programs already have waiting lists, such as the CatCH program, or space in the Birthing Centre are limited, women with disabilities are often given low priority for entry to the programs because of the perceived additional support needs, or a mistaken anticipation of complications in the birthing process. Arguably continuity of care is of most benefit when the mother has disabilities, and that a continuity of care program would be beneficial.

My referral to the Fetal Medicine Unit was delayed. The FMU were shocked that I wasn't enrolled in the CATCH program, but because of the delay in my care it was full.

WWDACT Community Member

3.4. Management of patient birthing preferences, including, but not limited to, professional advice offered to patients, and the practices associated with birthing emergencies;

Prejudice against the reproductive and parenting rights of women, trans and gender diverse people with disabilities has a profound effect on the management of birthing preferences. It is strongly related to the availability of information for both the woman and the people with whom she is dealing. This extends to Disability Service Providers which, in general, do not have information about parenting. Post-birth, DSPs service providers need to have the flexibility in their rules for workers, to be able to support the woman in her mothering role, not confined to the personal care, or community participation solely for the mother. Similarly health services lack information about disability. Moreover their knowledge relates to a 'cure' of the disability, or medicalised treatment of it, rather than to integrated information that incorporates both disability and pregnancy needs.

There is little information about assistive equipment that is available for mothers with disabilities. It is difficult to find in Australia, and is costly. There are no established avenues for mothers with disabilities to share their information with prospective parents/mothers in the ACT and region. This all means that planning the pregnancy can have challenges every step of the way.

A crucial gap is that there is no pathway for interaction between the National Disability Insurance Agency (NDIA), the health system, and the expectant mother (and possibly the Disability Service Provider). Therefore the system is not responsive to her changing support needs.

I had hoped that my GP would be able to take the lead, unfortunately not the case...My husband and I are searching for some extra care ... while I am applying for the NDIS, but all the processes for accessing help are long, and I am pregnant right now. My GP doesn't know of any services that could help me - we are finding all this out by ourselves.

WWDACT Community Member

Similarly there needs to be pre-emptive communications with emergency staff to alert them to the fact that a woman or person with (perhaps) complex pregnancy is a patient. In 99% of cases, this will not be needed, but having information relevant to her individual circumstances will save angst and poor treatment should an emergency arise.

Parents with cognitive impairment often have their preferences and opinions overlooked. At the same time they are at constant threat of child removal, and often their parenting is held to a higher standard than that required of non-disabled women. All new first-time mothers are uncertain about their baby's behaviours and care actions that they need to take. It is often assumed the mothers with cognitive impairment are incapable of learning how to care for their babies. The scant research that has been done shows that, with proper supports, they are able to learn new skills, and apply them^{4 5}.

An interview with a young mother with Intellectual Disabilities, aired on ABC RN, illustrates the problems:

⁴ Lamont, A., & Bromfield, L., 2009, *Parental intellectual disability and child protection: Key issues*, National Child Protection Clearing House, Australian Institute of Family Studies, viewed online on 19 January 2019 at: <https://aifs.gov.au/cfca/sites/default/files/publication-documents/issues31.pdf>

⁵ Frontline – the Irish Voice of Intellectual Disability, 2016, *The Social Wellbeing of children of parents with intellectual disability*, viewed online on 19 January 2019 at: <https://frontline-ireland.com/social-wellbeing-children-parents-intellectual-disability/>

*If we got formal supports involved, often they used to come in and they would immediately go to a child protection mode, didn't they, they would immediately want to go, 'Oh, are the children at risk?'*⁶

- Mother with intellectual disabilities

*Because they [Child Protection] had that assumption that being a parent with an intellectual disability, that she wouldn't be able to do it, they looked for problems, instead of going, well, how do we actually support this?*⁷

- Critical friend for mother with Intellectual Disabilities

Information is not provided in accessible formats for people who are blind or vision impaired. This can be addressed by making sure that materials are available both in print and online and online materials conform to WCAG 2.0 standards. In addition, materials should be made available in Easy English formats for people with cognitive impairments and for persons whose first language is not English.

3.5. Interaction between the CHWC and CPH with other service areas, including, but not limited to, emergency departments, and operating theatres;

As outlined in Para.3.4. there is no established chain of referrals in case of need for additional care. This is made more difficult because the referrals may need to involve health services, disability services and the NDIS.

3.6. The efficiency and efficacy of maternity services;

People with disabilities report that maternity services are mostly unable to meet their needs or be responsive to changing needs. This results in inefficiency of service for mothers who are sometimes treated as more complex than is the case, and who are sometimes not able to see the same midwife or professional on consecutive visits so that the circumstances and characteristics of the individual's disability have to be explained again and again. There are no systems in place which enables quick responses in disability emergencies, for example if a piece of assistive equipment breaks suddenly, the referral system to borrow a replacement from the Equipment Loan Scheme while the replacement item is on order, i.e. within the hospitals system itself, is cumbersome. Inefficiencies are therefore due to the lack of communication between

⁶ ABC RN, *We've Got This Monday 29 October 2018*, accessed online on 16 January 2018 at: <https://www.abc.net.au/radionational/programs/lifematters/weve-got-this:-parenting-with-an-intellectual-disability/10429814#transcript>

⁷ Ibid.

parts of the hospital and externally not necessary related to the maternity services themselves. There needs to be better sharing of information so that a patient with disabilities has to tell their story only once. One WWDACT community member described an exceptional experience, where their midwife wrote a note telling all other professionals to call them before asking for their history again. This sort of arrangement should be standardised, to reduce the burden on parents.

Some women with disabilities report that there is no information on mothering for those with disabilities or ante natal or post-natal services.

The main disappointment was that postnatal care... all of that lack of care prolonged my stay in hospital unnecessarily.

WWDACT *Contributing Our Voices* Report, 2015

3.7. The impact on maternity services on regional participants;

Regional participants with disabilities are negatively impacted in trying to access maternity services. Transport to check-ups may be problematic, particularly from rural locations. There are additional costs involved for patients with disabilities in getting to hospital and in getting equipment delivered to them. Women with cognitive impairment do not get consistent support in regional areas. Maternity services need to account for these additional barriers in the flexibility of their models of care.

3.8. Patient satisfaction with the services;

Feedback from people with disabilities who have used maternity services in the ACT show that there is a wide range of experiences, from those that are very positive, to the other end of the scale. The overall experience is very tied to the performance of individuals with whom the woman comes in contact, ranging from the GPs, the gynaecologists and obstetricians, through to the nursing staff, as well as the allied health professionals who might be involved.

For women, trans and gender diverse people with disabilities, the choice to parent is questioned by the medical profession and the wider community⁸. This assumption of lack of capacity to parent dehumanizes and disenfranchises the prospective parents.

In planning a pregnancy, potential parents with disabilities research what information is available to get an idea of what it is like to parent with disabilities. They find that

⁸ ABC RN, *We've Got This Monday 10 December 2018*, accessed online on 16 January 2019 at: <https://www.abc.net.au/radionational/programs/lifematters/weve-got-this-nine-months-of-questions/10591208>

information is scarce and often only remedied when they write their own materials to share through social media.⁹

There need to be appropriate referral pathways and guidelines available to assemble a team of health professionals (e.g. Psychologists, dieticians, physiotherapists and occupational therapists) to support a woman with disabilities through pregnancy and adjusting to caring for a new baby¹⁰. Recommendation 11 of the 2009 Commonwealth Report into Maternity Services was for consideration for a range of pregnancy-related information and resources be made available for women with disabilities (among other diverse communities) for informed decision making. Little action has been taken.

This submission does not deal with mental health conditions which arise post partem. Once parents with disabilities leave the hospital, they are likely to have least input from the health sector in their post-natal care, and report that they feel they are not listened to, that there is no continuity of care, inadequate support and conflicting information.

3.9. The impact on staff including, but not limited to, rostering policies and practices, staff-to-patient ratios, optimum staffing levels, and skills mix;

In caring for women and people with disabilities, staff are hampered by lack of understanding about disability culture, lack of trust in the person's expertise and knowledge of their own condition, inflexibility in hospital protocols to enable reasonable adjustments to be made in a timely manner, or assistive equipment to be used. Patients are made to feel that their presence is an imposition on the staff and a disruption to routines. Most staff are not intentionally being negative but have not had an opportunity for disability awareness training, and protocols are inflexible. There is no flexibility in rosters to give additional care to those with disabilities, and no ability for disability support staff to assist.

3.10. The impact of technological advances and innovations;

Use of information and communications technologies and assistive technologies should be maximized to enable better information sharing for parents with disabilities, and to enable her to communicate comfortably. WWDACT has not received any feedback on innovative technologies which parents with disabilities have used in the ACT, or of suggestion of new technologies in use elsewhere which would have helped in their pregnancies.

⁹ ABC RN, *We've Got This Monday 22 October 2018*, accessed online on 16 January 2018 at: <https://www.abc.net.au/radionational/programs/lifematters/we've-got-this:-the-early-years/10395862#transcript>

¹⁰ Commonwealth of Australia, 2009, *Improving Maternity Services in Australia*, Report of the Maternity Services Review, ISBN: 1-74186-833-5; Publications Number: P3-4946

Mothers should be encouraged to use the assistive equipment they are familiar with, preferably their own, and staff need to be able to recharge batteries as needed.

3.11. Relevant experiences and learnings from other jurisdictions; and

The most important change that could be made in maternity services in the ACT would be to put appropriate supports in place to enable people with cognitive impairment to be successful parents, and minimise or eliminate the practice of child removal. There are examples in Australia and overseas, for example, the **Health Start** program at the Parenting Research Centre at the University of Sydney an initiative that supports professionals working with parents who have learning difficulties.¹¹ The **BOLD Network** run by WWILD in Brisbane supports professionals and organisations seeking social change for parents with intellectual disabilities in Queensland¹². Professor Gwynnyth Llewellyn, Director of the Centre for Disability Studies at the University of Sydney is a leading researcher into parenting supports for people with intellectual disabilities.

3.12. Any related matters.

Improvement of services means an improvement to respecting the wishes of the person with disabilities, and acknowledging that they know their body best, whilst also giving staff better disability awareness training. Think 'can do' rather than 'can't'.

3. Conclusion

People with disabilities are increasingly exercising their right to become parents, and maternity services in the ACT need to ensure that models of care are appropriate to facilitate this. Current models of care are likely to be reactive to the medicalised disabilities presented to the health care professionals, rather than pro-active and collaborative with the mother. Current models of care must update to respect the authority of mothers in their own needs, reflect the diversity of disabilities, and include respectful support for parents with cognitive impairment to reduce the rates of child removal.

Mothers with disabilities are experiencing more barriers to choice in their care, which is reinforcing poor experiences and medical trauma. It is imperative that Maternity Services consider the needs of disadvantaged people in the planning and prioritization of their services, so that they do not become yet another source of that disadvantage. This can be improved by better communication of patient information, increased capacity of the CATCH program, greater flexibility in procedure, disability awareness training and inclusion of mothers with disability in the planning process.

¹¹ <https://www.parentingrc.org.au/programs/healthy-start/>

¹² <https://wwild.org.au/parents-with-intellectual-disabilities-2/>

Maternity services should be easy to follow, from GP to, clinic, to hospital or birthing centre, to home, inclusive of services within the NDIS and community. Where gaps exist, mothers are left in inappropriate care settings or without necessary resources and must work harder to give their child the best start in life. The opacity and complexity of the current system places an undue burden on parents-to-be, which combines with daily discrimination against people with disabilities to create an extremely difficult experience for many to navigate.

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