Women with
Disabilities ACT

Women With Disabilities ACT (WWDACT)

Parenting Peer Support Group Report 2021

Issues facing women* with disability who are parents in the ACT.

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.

*** Note:** Throughout this document, and generally, WWDACT uses *"Women* with disabilities"* to refer to women, girls, feminine identifying and non-binary people with disabilities.

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

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Abstract

Women with disabilities who are pregnant, parenting or planning to become parents face a range of barriers to successful parenting. They experience higher rates of domestic violence, poverty, social isolation and reproductive coercion than their non-disabled peers. Women with disabilities who are pregnant are less likely to breastfeed and less likely to have control over decisions during their labour than their non-disabled peers. Women with disabilities are significantly more likely to be involved with the child protection system and have their parenting capacity questioned. This is a big fear for parents and may reduce their likelihood of engaging with a mainstream parents group. Though rates of breastfeeding are low for parents with disabilities, disability specific parenting peer support groups may increase rates of breastfeeding. Knowing these issues, it must be acknowledged that women* with disabilities who are pregnant, parenting or planning to become parents may be more likely to experience structural oppression that intersects, or overlaps, creating greater levels of disadvantage.

Although the Women with Disabilities ACT Parenting Peer Support Group aimed to focus on the strengths of participants, it is important to acknowledge these experiences of oppression and work towards reducing them through our work at WWDACT.

It must also be acknowledged that there are limitations to this research. The literature used in this review is of varying quality due to the limited literature available in an Australian context. International and older work has been included as well as non-peer reviewed data. Studies fail to consider parenting with a disability through a gendered lens and there is limited data regarding the parenting experiences of gender-diverse and non-binary people with a disability. Finally, as a scoping review, this report aims to make several recommendations for further research. This report recommends that further research be conducted into:

- The pregnancy, parenting and planning experiences of gender-diverse and non-binary people
- The impact of stigma on children of parents with a disability
- Ways to support primary carers who are financially impacted by their caring responsibilities
- Women in the ACT's experiences of the Continuity of Care model in the ACT Fetal Medicine Unit
- Ways to better support and include WWDACT members with communication disabilities to participate in WWDACT events.
- ACT Public Transport accessibility audit

Introduction

Given that more than 670,000 parents identify as having a disability in Australia (Australian Institute of Health and Welfare [AIHW], 2020a), the issue of parenting with a disability is significant and prominent. It can be argued that the wellbeing of parents with a disability can be improved by identifying and mitigating issues that impact them. Fifteen percent of children live with one or more parent with a disability (AIHW, 2020a). Issues impacting people with disabilities who are parents, pregnant and planning to become parents in Australia, include the shift from the medical model of disability to the social model of disability, lack of accessible services, the disproportionate rate at which parenting capacity is questioned for those with a disability, and heightened rates of involvement with child protective services agencies in families with disabled parents or carers (Australian Institute of Family Studies, 2021).

While there is an abundance of research exploring the various experiences of parents of children with a disability (Bray et al., 2017; Pesch, 2019; Bretherton & McLean, 2014), there are significant gaps in the literature surrounding parenting with a disability, especially in an Australian context. Internationally, organisations such as TASP – The Association for Successful Parenting - exist. TASP provides support for parents and families whose members experience learning difficulties, TASP also conducts research and training to support parents with disabilities (TASP, n.d.).

Before exploring the issues relevant to parents with a disability, it is important to understand and define the complex and multifaceted concept of parenting with a disability. The first consideration is the broad concept of parenting. Historically, family has been defined ‘by common residence, economic cooperation and reproduction. It includes adults of both sexes, at least two of whom maintain a socially approved sexual relationship, and one or more children, own or adopted, of the sexually cohabiting adults’ (Murdock 1949 as cited by Wilson, 2015 p 8). A more modern understanding of parenting considers the social, cultural, and societal responsibilities of support and caregiving which may include economic, educational, and domestic responsibilities for biological or non-biological children or other dependents my individual or multiple adults (Wilson, 2015).

Disability is an equally difficult concept to define. According to the Convention on the Rights of Persons with Disability (United Nations, 2007), disability includes physical and intellectual conditions, sensory issues, and mental illness. The World Health Organization (2011) emphasises the importance of understanding individuals within their social context and knowing the impact that health issues have on functioning when determining potential disability. Further, the Australian Institute of Health and Welfare (2021) identifies that a disabling condition must be ongoing for a period of 6 months or more.

When understanding the challenges faced by parents with a disability, it is helpful to understand the current and historical narratives that guide policy and public opinion regarding the issue. This report academically explores a number of issues identified by members from the Women with Disabilities ACT (WWDACT) Parenting Peer Support Group. The group is a peer network that connects women, non-binary, gender-diverse and feminine identifying people with a disability who are pregnant, parents or planning to become parents. To be concise, this report will refer to women, non-binary, gender-diverse and feminine identifying people as 'women*', refer to women, non-binary, gender-diverse and feminine identifying people with a disability who are pregnant, parents or planning to become parents as 'parents with a disability' and refer to the Women with Disabilities ACT Parenting Peer Support Group as 'the group'.

Women with Disabilities ACT Parenting Peer Support Group

Funded by the Office for Women, the Women with Disabilities ACT Parenting Peer Support Group aims to build peer based social connections for women, feminine identifying and non-binary people with a disability who are pregnant, parents or planning to become parents. Peer support is defined as 'emotional and practical support exchanged between people who share similar experiences' (Collings et al., 2019 para 2). Research regarding peer support groups for mothers with intellectual disabilities shows that engagement with these groups can improve parenting confidence, increase trust in community services, and improve parenting skills (Collings et al., 2019). One aim of the group is to provide members an opportunity to connect with other parents who share their experience of parenting with a disability. The group also aimed to provide information and support to improve participant health and wellbeing, and that of their families. The group provided support to members in various ways including: regular face-to-face meet ups, Zoom meetings and a private Facebook group. This multi-modal approach provided members with the opportunity to connect in a way that was most appropriate for them.

The group has approximately 45 members. Over the course of eleven months, the project completed:

- Seven face-to-face groups with between 3 – 12 members
- Nine individual coffee meet-ups
- Six online sessions, including sessions with themes focusing on identifying strengths in parenting with a disability, self-care and hosting guest speakers such as author and disabled parenting advocate, Eliza Hull.

The group also ran a well-attended Christmas event, Representatives' event, Mother's Day event and end-of-project luncheon. Members were also connected with community services on several occasions and many friendships were formed within the group. During the duration of the project, a news article about the group and Representatives program was published. Through the course of the project, the Peer Support Project Officer also undertook several other tasks in line with the objectives of the project, including:

- Connecting with Canberra Health Services and ran an information session regarding Nurse-led walk-in centres as well as creating an easy-English brochure regarding this service.
- Meeting with the ACT Minister for Transport and Transport Canberra Senior Policy Director and highlighted issues regarding lack of accessible transport options. This has resulted in WWDACT being invited to participate in a reference group to improve accessibility within public transport services in the ACT.
- Advertising, organising and co-facilitating a community services forum, aiming to improve the profile of WWDACT and raise awareness of gendered issues of disability.
- Providing consultation advice to Child, Youth Protective Services on their Supported Decision-Making policy for parents with a disability involved with child protective services
- Providing advice to Canberra Film Festival Directors about the appropriateness of media which portrays a woman with a disability and her journey of parenthood.
- Completing a research paper addressing issues of coerced and forced sterilisation and the reproductive rights of people with disabilities.
- Speaking with the Australian Breastfeeding Association and Canberra Health Services to obtain specific advice on breastfeeding and disability and breastfeeding.
- Contributing to a number of funding applications
- Providing consultation on the National Strategy to Prevent and Respond to Child Sexual Abuse

Methodology

A scoping study was chosen as the methodology for this research study, due to the broad nature of the research topic, parenting with a disability. A further reason for this research methodology was the limited existing research, particularly in the context of Australian parents with disabilities. The Joanna Briggs Institute (2020) identifies that scoping studies are appropriate for research of this broad nature. Scoping studies aim to map existing research, summarise key findings, identify gaps in existing research and make recommendations for possible further research opportunities (Arksey & O'Malley, 2002). This scoping review follows the methodological framework outlined by Arksey & O'Malley (2002). As per Arksey and O'Malley's (2002) framework, the process included developing a research question, identifying existing research, assessing and selecting relevant research, coding the data, identifying themes and finally, reporting the results.

Initially a research question was identified – *What issues impact the parenting capacity of women* with a disability?* This research question was posed as a result of anecdotal challenges faced by participants of the Women with Disabilities ACT Parenting Peer Support Group. To better understand and contextualise the scope of the proposed research question, a preliminary search of the literature was conducted of available journals, using the University of New England Library federated search tool (University of New England, 2021). Throughout the research process, hand-searching was the primary search method used to locate data due to the specific nature of the research question.

After identifying relevant existing literature, the next stage of the scoping study involves thematic analysis, an analysis of the literature to understand the key emergent themes and discourses relevant to the research question (Arksey & O'Malley, 2002). For this study, themes were predetermined by way of recommendation from members of the group. Although this study relates generally to the experiences of the Women with Disabilities ACT Parenting Peer Support Group, ethical approval for this research was not sought, due to the chosen methodology which did not include any aspects of human research as defined by the National Health and Medical Research Council (2015).

Discussion

A Strengths Perspective

Inherent strengths and skills are an often overlooked, but are an important factor in understanding the challenges of parents with disabilities. According to Teater & Kondrat (2010), a strengths perspective is a social work approach that moves away from focusing on individual needs and issues and moves towards focusing on their inherent strengths, abilities, and natural resources. A key element of the WWDACT Parents Group is the focus on the strengths that women* with a disability possess and use in their roles as parents, and the strengths and skills they develop through their experience of pregnancy and maternity care. A strengths perspective acknowledges that individuals experience adversity and emphasises that individuals have inherent skills, knowledge, and strengths to manage the adversity that they experience (Teater & Kondrat, 2010). The group aimed to support participants in identifying their inherent strengths and skills, and to build their natural supports. This included the development of social supports and connection to community and professional services where required. One limitation to the research identified in this report is that many studies focuses on challenges and barriers faced by parents with a disability rather than their strengths (Kirshbaum & Olkin, 2002). It must be acknowledged that this research also focuses on the challenges of parenting with a disability. There is an opportunity for further research in the area of identifying the strengths of parents with a disability.

Social Isolation

One issue identified by the group was the significant levels of social isolation in parents with disabilities. According to research by Rivera Drew (2009), mothers with disabilities identified fear of judgement and of being reported to child protective services for parenting failures as a key reason for lacking meaningful social connections, particularly with other parents. Collings et al. (2019) identified that peer support groups provided mothers with disabilities an unbiased, non-judgemental platform to communicate shared experiences. This sentiment is echoed by WWDACT, we identify that mothers with disabilities may not feel accepted in mainstream parenting groups. The Women with Disabilities ACT Parenting Peer Support Group aimed to provide mothers with a non-judgemental platform to discuss shared experiences and develop essential social connections.

Stigma

Women with disabilities face more stigma and stereotyping around their choice to become pregnant than their non-disabled peers (Litchman et al., 2019). According to research, this stigma may contribute to reduced self-esteem and reduced self-confidence (Hasson-Ohayon et al., 2018). Hasson-Ohayon et al. (2018) further found that mothers with psychiatric disabilities experienced greater stigma than mothers with physical disabilities. A systemic review of literature showed that mothers who experience psychiatric disorders identified a direct correlation between doubt in their parenting ability and a label of “mental illness” or “disability” (Dolman et al., 2013). Further adding to the stigma is the societal narrative that children of mothers with a disability will be disadvantaged by their parent’s disability (Lappeteläinen et al., 2018). Contrary to this belief, it must be acknowledged that children of parents with disabilities may also be at risk of stigmatisation. A literature review by Collings and Llewellyn (2012) identified that children of parents with disabilities are at risk of being impacted by stigmatisation, bullying and social exclusion. These experiences were less common in female children, according to the research (Collings and Llewellyn, 2012). An exhaustive analysis of the research failed to find evidence on how children of mothers with a disability may be impacted by this stigma. A number of members identified that their children related to experiencing stigmatisation, therefore there is validity in potentially further exploring the impact of this stigma on children.

The Reproductive Rights of People with Disabilities

The sexual and reproductive rights of women with disabilities is an important consideration in the discussion around challenges faced by women who are parents, pregnant or planning to become pregnant. It can be argued that the denial of these sexual and reproductive rights contradicts Article 23 of the Convention of the Rights of People with Disabilities (United Nations, 2007) which identifies that people with disabilities have equal rights to make decisions about pregnancy and fertility (United Nations, 2007) and Article 16 of the Universal Declaration of Human Rights which identifies that all people have the right to start their own family (United Nations, 1948). Increasing in popularity from the 1910’s, the sterilisation of people with disabilities was historically justified due to increased sexual promiscuity in women with disabilities and their perceived risk of being subject to sexual violence (Rosser, 2013). This practice was also justified due to a societal desire to prevent people with disabilities from reproducing, in order to reduce unwanted or unhealthy genes in future generations (Rosser, 2013).

This process of selective gene reduction is known as eugenics, which is defined as "the study of hereditary improvements of the human race by controlled selective breeding" (Stebnicki & Marini, 2012 p 449). Historically, this process of selective breeding occurred through sterilisation and segregation (Rosser, 2013). Soniewicka (2015) identifies that current and historic eugenics practices have been implemented not only to eliminate unwanted genetic traits, but also to ensure the promotion of preferred genes. Notable occurrences of positive eugenics in history can be seen through the promotion of the white-skinned, blue eyed and abled-bodied Aryan race by both the German Nazi party in the 1940's and Norweigian Vikings in the late 1800's (Hochman, 2015). Arguably, modern practices of eugenics still exist today in the form of tests throughout pregnancy which aim to screen for, and potentially terminate, pregnancies showing foetal genetic conditions, disabilities, and abnormalities (Royal Australian and New Zealand College of Obstetricians and Gynaecologists, 2019).

Domestic Violence

Domestic violence is a pattern of controlling behaviours that includes physical, sexual, emotional and other violence (World Health Organization, 2012). Thirty-five percent of women have experienced intimate partner violence (World Health Organiszation, 2012). Pestka & Wendt (2014) emphasises that the risk of prenatal domestic violence is significantly higher in women with intellectual disabilities than in their non-disabled peers. This is possibly due to an increased levelof dependence and desire for companionship contributing to women remaining in violent relationships. Research suggests that women experiencing domestic violence are more likely to reach out to a friend or family member than an organisation (Collings et al., 2019). This highlights the importance of peer groups in developing strong and meaningful friendships for parents with disabilities, an identified at-risk population.

Another significant issue to consider in relation to people with disabilities and their reproductive rights is reproductive coercion. Reproductive coercion has been identified as type of domestic violent behaviour that occurs more frequently towards women with disabilities (Women with Disabilities Australia, 2012). General Comment 3 of Article 6 of the United Nations Convention on the Rights of

People with Disabilities (United Nations, 2016) explicitly identifies reproductive coercion as a form of violence. Hakim (2020) identifies that reproductive coercion may include:

- Causing intentional pregnancy by damaging or withholding contraception or through emotional or physical manipulation.
- Coercing an individual to continue or terminate a pregnancy against their wishes.
- Getting someone to use a method of contraception without their knowledge or agreed consent,
- Coercing or manipulating someone into agreeing to a permanent sterilisation procedure. (Hakim 2020).

As with all forms of domestic violence, there are significant and undeniable human rights considerations - Article 1 of the United Nations Declaration on the Elimination of Violence against Women (United Nations, 1993 p2) defines violence against women as "any act of gender-based violence that results in, or is likely to result in, physical, sexual or psychological harm or suffering to women, including threats of such acts, coercion or arbitrary deprivation of liberty, whether occurring in public or private life". People with a disability are 1.8 times more likely to experience physical or sexual intimate partner violence than the general population (Australian Institute of Health and Welfare, 2019). Despite the significantly high rates of domestic violence in women with disabilities (Australian Institute of Health and Welfare, 2020a), reproductive coercion remains a largely hidden issue, the impact of which is hard to measure and truly understand.

The Impact on Partners

The group identified that consideration should be given to the ways in which the lives of partners of women* with disabilities may be impacted as a result of pregnancy or parenting responsibilities. Research undertaken by Pakenham et al. (2012), identified that partners of parents with disabilities often have a higher burden of caring responsibility than the partners of non-disabled parents. Partners of mothers with a disability may be required to provide physical assistance in breastfeeding and other practical parenting tasks (Powell et al., 2013). It is important to acknowledge that peripheral tasks may include more than child-rearing and may extend to household maintenance, transport and supporting children to undertake extra-curricular activities. Darbyshire & Stenfert Kroese (2012) identify that mothers with disabilities valued their partners contributions to 'sharing the mental load', more than financial support. This valued support may be in the form of increased parenting knowledge, support to manage parenting challenges and improved social opportunities

(Darbyshire & Stenfert Kroese, 2012). Some members of the Women with Disabilities ACT Parenting Peer Support Group identified that their partners required significant time off work to undertake caring responsibilities. The WWDACT Project Officer was unable to find research relating to the financial impact on families due to primary carer disability. It is recommended that further research is undertaken in this area and that supportive measures are put in place to reduce financial burden for families of women* with disabilities.

Poverty

An American study identified that women with disabilities who are parents experience increased rates of poverty than their non-disabled peers (Kirshbaum & Olkin, 2002). Pakenham et al. (2012), identified that one contributing factor to increased household costs was the need for women with disabilities with caring responsibilities to rely on paid supports such as childcare, cleaning service or in-home supports. It must be acknowledged that the National Disability Insurance Scheme aims to reduce the financial burden in a number of these areas. The National Disability Insurance Scheme funds individualised supports such as transport, home modifications and capacity building activities to people with disabilities (National Disability Insurance Scheme, 2021). Despite the National Disability Insurance Scheme, 45% of single-parent families with a disability are considered low-income earners and 27% of families with at least one parent who has a disability are considered low-income earners (Australian Institute of Health and Welfare, 2020a). A low-income earner is considered a person who earns $383 or less per week (Australian Institute of Health and Welfare, 2020). The ACT Council of Social Services (n.d.) identifies that poverty can prevent families from participating in extra-curricular activities, limit access to adequate housing as well as prevent families from eating nutritious or fresh foods.

Maternity Care Services

In general, group members reported below average maternity care throughout pregnancy and childbirth. Unfortunately, this is consistent with research about the pregnancy and birth experiences of women with disabilities. A 2013 study regarding the experiences of women with disabilities through pregnancy and birth identified a number of interesting discrepancies between the experiences of women with a disability and those without a disability during pregnancy, labour and birth.

Compared to women without disabilities, women with disabilities are:

- 8% less likely to be offered choice in comfortable position during labour
- 11% more likely to remain in hospital for 3 days or more after birth
- 9% less likely to breastfeed their newborn
- 6% less likely to involved in decisions about their care during labour
- 4% less likely to report being treated with kindness throughout their experience of maternity services. (Redshaw et al., 2013).

Another comprehensive study identified the benefits of a ‘continuity of care’ model of maternity care for women with disabilities (Australian College of Midwives, 2017). This model allows pregnant women to see the same midwives and health professionals throughout pregnancy, labour, and birth (Australian College of Midwives, 2017). The Australian College of Midwives (2018) identify that this model improved health outcomes for newborns, reduces health-related financial burden and improves maternal satisfaction. Many of the parents from the WWDACT parents group birthed through the Fetal Medicine Unit. This specialist service provided maternity care to women with high-risk pregnancies (ACT Health, 2021). Fetal Medicine Unit identifies as providing a continuity of care model (ACT Health, 2021), however anecdotal evidence from members shows that mothers with disabilities may receive inconsistent and varied levels of care from a variety of midwives and health professionals in the ACT. It is recommended that further research be undertaken into the experiences of women with disabilities participating in specialised maternity services to ensure they are accessing the model of care that patients are expecting.

Communication Barriers

A communication disability affects a persons’ ability to understand and be understood by others (Speech Pathology Australia, n.d.). More than 1 million Australians identify as having some form of communication disability (Speech Pathology Australia, n.d.). Chin et al. (2013) identifies that mothers with communication disabilities face significant barriers in accessing clear and accurate health information. Often, health information is not provided in Easy English, with most brochures requiring the reading level equivalency of an approximate 12-year-old (Chin et al., 2013). It must be acknowledged that there are inherent challenges for mothers with hearing loss and other communication disabilities in engaging meaningfully with a multimodal peer-support parenting group. Griffiths et al. (2015) further identified that those with communication barriers may struggle to engage with mental-health related peer-support groups due to technological barriers. As peer support is part of Women with Disabilities ACT’s core business, it is recommended that further research be conducted into how WWDACT could better include members with communication disabilities for future peer-support projects.

Breastfeeding

Breastfeeding has several significant benefits for infants, including reduced illness in infancy, reduced childhood obesity, improved immune systems and reduced rates of Sudden Infant Death Syndrome (Queensland Health, 2020). Breastfeeding also has significant benefits for mothers, such as improved parent/child attachment, reduced rates of gestational diabetes and reduced risk of ovarian cancer (Queensland Health, 2020). Redshaw et al. (2013) identify that breastfeeding rates are lower for mothers with a disability than their non-disabled counterparts. Research further shows that mothers with disabilities receive conflicting advice about the appropriateness of breastfeeding due to their disability (Williams et al., 2019; Veiby et al., 2015). This research identifies a primary source of this confusion is related to maternal medication use and medical professionals being unable to clearly articulate potential risks to babies as a result of medication absorption through breastfeeding. One issue identified by the group was that issues such as Sensory Processing Disorder in mothers significantly impacted breastfeeding. Despite a thorough literature review, there was limited available literature of an acceptable academic standard regarding this issue. It is recommended that further research is undertaken to better understand how Sensory Processing Disorder in mothers impacts rates of breastfeeding in infants.

Chin et al. (2013) identified that mothers with communication disabilities experience a variety of barriers that reduce their likelihood to breastfeed. The research further identified protective factors that may increase the likelihood of successful breastfeeding, these include the provision of accessible breastfeeding information and education and meaningful social supports (Chin et al., 2013).

Health Literacy

Health literacy relates to how people access, understand, and use health information in ways that benefits their health. People with low health literacy are at higher risk of worse health outcomes and poorer health behaviours (Australian Institute of Health and Welfare, 2020b para 1). Upon thorough investigation, there was extremely limited literature regarding the maternal health literacy of people with disabilities. However, research from Hollar & Rowland (2015) shows that people with disabilities experience poorer health outcomes than their non-disabled peers, often due to limited accessible health information. As an example, a 2020 article published by Health Times identified that Covid-19 information presented in mainstream media was often inaccessible to people who are blind or have low vision.

The Australian Commission on Safety and Quality in Health Care (2014) identifies that there are several ways to improve health literacy, including:

- The coordination of health services
- Encouraging services to share clear reliable health information in an easy-to-understand way
- Sharing evidence-based health literacy practices, such as Easy English and Teach Back strategies with health networks.

Parenting Capacity and Child Protection Involvement

The questioning of parenting capacity in parents with a disability shows that one prominent discourse in public perception and allied health professionals. According to Rivera Drew (2009), parenting capacity can be understood through a parents' ability to effectively undertake day-to-day tasks of child-rearing. Arguably, this belief is portrayed by the idea that parents with a disability lack the skills to provide adequate care for children. People with disabilities have many barriers that prevent them from potentially having their own families, such as increased rates of child protection involvement (S*igurjonsdottir, & Rice, 2020)* and issues with equality regarding child custody (S*igurjonsdottir, et al., 2017).* While there is a historic narrative that people with disabilities may be unfit parents (Rosser, 2013), their rights to be a parent are clearly protected in the CRPD. Article 23 (b) of the CRPD (United Nations, 2007) identifies that people with a disability have the right to make decisions to start a family and Article 23.2 of the CRPD (United Nations, 2007) acknowledges that some people with disabilities may have challenges with child-rearing and should be provided with support to undertake child-rearing tasks. The Convention on the Rights of Persons with Disability (CRPD, 2007) identifies that disability alone is not sufficient reason for children to be removed from their parents, however parents with intellectual disability are significantly overrepresented in the child protection system, with higher reported levels of child neglect (Lleweellyn & Hindmarsh, 2015). Research by Lamont & Bromfield (2009) indicates that, in the context of parents with a disability and child neglect, decisions are often made based solely on current parenting capacity without considering protective factors, social or professional supports or other contexts. The CRPD (2007) outlines that States signed to the declaration will provide required assistance to people with disabilities to undertake their parenting responsibilities successfully. However, parents with disabilities experience significant barriers in accessing services in their journey of parenting, pregnancy and planning to become pregnant. These barriers may present as assumptions about lack of parenting ability and lack of accessible health services.

Transport

Being unable to access transport for people with disabilities may prevent them from accessing education, employment and community activities in a meaningful way (Australian Government, 2009). According to research by Kirshbaum & Olkin (2002), more than 80% of parents with a disability identify issues with accessing transport. The group identified that lack of appropriate transport options was an issue for parents with a disability. During the parenting project, members identified that they had difficulty accessing public transport. Due to the diverse nature of disability, transport may have been inaccessible for a variety of reasons including limited ramp access, narrow doorways, limited Braille or other limited language accessibility and increased cost (Disability Resource Centre, n.d.; National Disability Service, n.d.). Further, it is important to acknowledge, that personal safety is a concern for people with a disability when considering lack of access to public transport (Disability Resource Centre, n.d.).

Models of Disability

An influencing narrative for parents with a disability has been the shift from the medical model of disability, through the social model, to now the human rights model of disability (Degener, 2016). The medical model identifies biomedical issues and aims to cure these issues so individuals can participate in mainstream society and was the catalyst for the institutionalisation of people with disabilities (Scullion, 2010). This way of thinking was followed by the social model of disability in the 1980's, which posed that disability was a result of societal issues and barriers which lead to ostracisation and oppression (Ellem, Chui & Wilson, 2017). The National Disability Insurance Scheme is founded on the social model, in that it aims to reduce or eliminate societal barriers to equity and access and is based on the concept of 'consumer choice and control' (National Disability Insurance Scheme, 2021). While the social model has arguably good intentions, Degener, (2016) identifies that it fails to acknowledge the individuality of people with disabilities or acknowledge their human rights.

The Disability Advocacy Resource Unit (2020) goes on to identify that one weakness in the social model of disability is that it aims to help people fit in better with mainstream society rather than acknowledging or embracing difference. Moving beyond the social model of disability, there has been a recent shift to a human rights model of disability which focuses first on a person's human rights and second on disability/health status (Degener, 2016). According to Degener, this ensures that the person is considered first and is central to all decision making and while it promotes disability inclusively, it ensures that disability is not the focus of the model. From a social work perspective, this lens is person-centred, empowerment focused and has a clear understanding of person-in-environment and the impacts of failing to consider human rights for people with a disability.

Intersectionality

It is important, of course, to acknowledge that these issues do not occur in isolation for women with disabilities and parents with disabilities. Intersectionality is the theory that people, particularly women*, experience structural oppression that intersects, or overlaps, creating greater levels of disadvantage (Gopaldas, 2013). Bereron et al. (2012) acknowledge that evidence shows parents with disabilities experience higher levels of intersectional disadvantage than non-disabled parents. This may appear in the forms of disability, intersected with poverty, social isolation and/or family conflict, however parents with a disability are known for developing creative, imaginative and personalised ways of overcoming the obstacles they face in their parenting responsibilities (Bereron et al., 2012)

Limitations

It must be acknowledged that the research included in this scoping review varies in quality. This is partly due to the broad nature of the research subject, and the limited available data in the context of Australian parents with a disability. Therefore, it is acknowledged that some research included in this review is of an international context and cultural considerations must be taken into account. Due to limited available research, some older research and grey literature has been included to provide a richer overview of the subject matter. There are a variety of methodological frameworks used in the research, though the accuracy of findings cannot be verified in all cases. Some research relied on self-reporting and convenience sampling. Liamputtong et al. (2010), identify that convenience sampling allows researchers to use participants who are available, willing, and able to participate in the study. Jager et al., (2017) note that convenience sampling may not be representative of the broader target population regarding age, gender, and other demographic factors. Therefore, some research included in this report fails to address the gendered lens of parenting with a disability. Further, except where specifically stated, research overwhelmingly fails to account for the experiences of non-binary and gender-diverse feminine identifying people who are pregnant, parenting or planning to become pregnant and have a disability.

Recommendations for further research

A number of areas of concern were identified by the group which could not be addressed meaningfully due to a lack of relevant and recent peer-reviewed research. It is recommended that further research is undertaken into the experiences of feminine-identifying, gender-diverse and LGBTIQA+ people with a disability who are pregnant, parents or planning to become parents. It is also recommended that qualitative research be conducted to better understand the impact of disability on partners of people with a disability. Research identified that schools and childcare services may not be physically accessible for parents who use mobility aids, however there is limited data on this in the context of the ACT. It is recommended that the ACT Government undertake further research, including an accessibility audit of all public schools and child-care facilities eligible for the Federal Government Child Care Subsidy to ensure these centres are accessible. Finally, this report has identified that further research would be beneficial to better understand how Sensory Processing Disorder in mothers impacts rates of breastfeeding in infants.

Conclusion

This report has identified that women* with disabilities who are pregnant, parenting or planning to become parents are a resilient cohort who face a variety of challenges in their caring responsibilities. It is undeniable that parenting with a disability is a difficult task, however the literature shows that parents with disabilities are adaptable and have inherent strengths to manage these obstacles. Women with disabilities who are parents experience higher rates of domestic violence, reproductive coercion, involvement with protective service and social isolation than their non-disabled peers. The benefits of peer support groups, include increased rates of breastfeeding, reduced social isolation and a shared sense of common experience. It is hoped that the members of the WWDACT Parenting Peer Support Group have been able to gain these and other positives from the group over the past 11 months.

References

ACT Council of Social. (n.d.). Factsheet: Poverty and inequality in the ACT. https://www.actcoss.org.au/publications/advocacy-publications/factsheet-poverty-and-inequality-act

ACT Health. (2021). Pregnancy care and birthing options. https://www.health.act.gov.au/services-and-programs/women-youth-and-children/pregnancy-and-birth/pregnancy-care-and-birthing

Arksey, H. & O'Malley, L. (2002). Scoping studies: towards a methodological framework. International Journal of Social Research Methodology, 8(1), 19–32. https://doi.org/10.1080/1364557032000119616

Australian College of Midwives. (2017). Continuity of care – A summary of the evidence. https://www.midwives.org.au/sites/default/files/uploaded-content/field_f_content_file/continuity_of_care.pdf

Australian College of Midwives. (2018). Midwifery Continuity of Care. https://www.midwives.org.au/midwifery-continuity-care

Australian Commission on Safety and Quality in Health Care. (2014). Health literacy: Taking action to improve safety and quality. https://www.safetyandquality.gov.au/sites/default/files/migrated/Health-Literacy-Taking-action-to-improve-safety-and-quality.pdf

Australian Government. (2009). Shut Out: The experience of People with Disabilities and their Families in Australia.

Australian Human Rights Commission. (n.d.). The Sterilisation of Girls and Young Women in Australia. https://humanrights.gov.au/our-work/disability-rights/publications/sterilisation-girls-and-young-women-australia#:~:text=documents%20and%20developments-,Summary,human%20right%20to%20bodily%20integrity

Australian Institute of Family Studies. (2021). Parents with disabilities. https://aifs.gov.au/cfca/bibliography/parents-disabilities

Australian Institute of Health and Welfare. (2021). Australia's children, Parental health and disability - Australian Institute of Health and Welfare. Retrieved 14 March 2021, from https://www.aihw.gov.au/reports/children-youth/australias-children/contents/social-support/parental-health-and-disability

Australian Institute of Health and Welfare. (2020a). People with disability in Australia. https://www.aihw.gov.au/reports/disability/people-with-disability-in-australia/contents/justice-and-safety/violence-against-people-with-disability

Australian Institute of Health and Welfare. (2020b). Health Literacy. https://www.aihw.gov.au/reports/australias-health/health-literacy

Australian Institute of Health and Welfare. (2019). Family, domestic and sexual violence in Australia: continuing the national story. https://www.aihw.gov.au/getmedia/b180312b-27de-4cd9-b43e-16109e52f3d4/aihw-fdv4-FDSV-in-Australia-2019_in-brief.pdf.aspx?inline=true

Bray, Lucy, Carter, Bernie, Sanders, Caroline, Blake, Lucy, & Keegan, Kimberley. (2017). Parent-to-parent peer support for parents of children with a disability: A mixed method study. Patient Education and Counseling, 100(8), 1537–1543. https://doi.org/10.1016/j.pec.2017.03.004

Bretherton, Susan Jane, & McLean, Louise Anne. (2014). Mediating Effects of Perceived Control in the Relationship Between Optimism and Adjustment in Parents of Children with Disabilities. Journal of Developmental and Physical Disabilities, 26(3), 357–369. https://doi.org/10.1007/s10882-014-9371-7

Collings, Susan, & Llewellyn, Gwynnyth. (2012). Children of parents with intellectual disability: Facing poor outcomes or faring okay? Journal of Intellectual & Developmental Disability, 37(1), 65–82. https://doi.org/10.3109/13668250.2011.648610

Collings, Susan, Strnadová, Iva, Loblinzk, Julie, & Danker, Joanne. (2019). Benefits and limits of peer support for mothers with intellectual disability affected by domestic violence and child protection. Disability & Society, 35(3), 413–434. https://doi.org/10.1080/09687599.2019.1647150

Darbyshire, Laura Valerie, & Stenfert Kroese, Biza. (2012). Psychological Well-Being and Social Support for Parents With Intellectual Disabilities: Risk Factors and Interventions. Journal of Policy and Practice in Intellectual Disabilities, 9(1), 40–52. https://doi.org/10.1111/j.1741-1130.2012.00326.x

Degener, T. (2016). Disability in a Human Rights Context. Laws, 5(3). https://doi.org/10.3390/laws5030035

Disability Advocacy Resource Unit. (2020). How does the human rights model differ from the social model? http://www.daru.org.au/how-we-talk-about-disability-matters/how-does-the-human-rights-model-differ-from-the-social-model

Dolman, Clare, Jones, Ian, & Howard, Louise M. (2013). Pre-conception to parenting: a systematic review and meta-synthesis of the qualitative literature on motherhood for women with severe mental illness. Archives of Women's Mental Health, 16(3), 173–196. https://doi.org/10.1007/s00737-013-0336-0

Ellem, K., Chui, W. H., & Wilson, J. (2017). Social work and human services best practice (2nd edition.).

Family Advocacy Inc. Family Advocacy Inc - History. Retrieved 14 March 2021, from https://advocacyfordisability.org.au/docs/Family_Advocacy.pdf

Gopaldas, Ahir. (2013). Intersectionality 101. Journal of Public Policy & Marketing, 32(1), 90–94. https://doi.org/10.1509/jppm.12.044

Griffiths, Kathleen Margaret, Reynolds, Julia, & Vassallo, Sara. (2015). An Online, Moderated Peer-to-Peer Support Bulletin Board for Depression: User-Perceived Advantages and Disadvantages. JMIR Mental Health, 2(2), e14–e14. https://doi.org/10.2196/mental.4266

Hakim, J. (2020). Hidden Forces – A white paper on reproductive coercion in contexts of family and domestic violence. https://www.mariestopes.org.au/wp-content/uploads/Hidden-Forces-Second-Edition-.pdf

Hasson-Ohayon, Ilanit, Hason-Shaked, Meiran, Silberg, Tamar, Shpigelman, Carmit-Noa, & Roe, David. (2018). Attitudes towards motherhood of women with physical versus psychiatric disabilities. Disability and Health Journal, 11(4), 612–617. https://doi.org/10.1016/j.dhjo.2018.05.002

Health Times. (2020). Covid-19 information accessibility lacking for blind and low vision Australians. https://healthtimes.com.au/hub/covid-19/74/news/ht1/covid19-information-accessibility-lacking-for-blind-and-low-vision-australians/5349/

Hochman, Adam. (2015). Of Vikings and Nazis: Norwegian contributions to the rise and the fall of the idea of a superior Aryan race. Studies in History and Philosophy of Biol & Biomed Sci, 54, 84–88. https://doi.org/10.1016/j.shpsc.2015.09.003

Hollar, David & Rowland, Jennifer. (2015). Promoting health literacy for people with disabilities and clinicians through a teamwork model. https://digitalcommons.library.tmc.edu/cgi/viewcontent.cgi?article=1286&context=jfs

Jager, J., Putnick, D. L., & Bornstein, M. H. (2017). II. MORE THAN JUST CONVENIENT: THE SCIENTIFIC MERITS OF HOMOGENEOUS CONVENIENCE SAMPLES. Monographs of the Society for Research in Child Development, 82(2), 13–30. https://doi.org/10.1111/mono.12296

Joanna Briggs Institute. (2020). Why a scoping review? https://wiki.jbi.global/pages/viewpage.action?pageId=3178748

Kirshbaum, Megan, & Olkin, Rhoda. (2002). Parents with Physical, Systemic, or Visual Disabilities. Sexuality and Disability, 20(1), 65–80. https://doi.org/10.1023/A:1015286421368

Lamont, A & Bromfield, L. (2009). Parental intellectual disability and child protection: Key issues. https://aifs.gov.au/cfca/publications/parental-intellectual-disability-and-child-protection-key-i

Lappeteläinen, A., Sevón, E., & Vehkakoski, T. (2018). 'Celebrating diverse motherhood': physically disabled women's counter-narratives to their stigmatised identity as mothers. Families, Relationships and Societies, 7(3), 499-514. http://dx.doi.org.ezproxy.une.edu.au/10.1332/204674317X15034137417334

Litchman, M. L., Tran, M. J., Dearden, S. E., Jia-Wen, G., Simonsen, S. E., & Clark, L. (2019). What Women With Disabilities Write in Personal Blogs About Pregnancy and Early Motherhood: Qualitative Analysis of Blogs. JMIR Pediatrics and Parenting, 2(1)http://dx.doi.org.ezproxy.une.edu.au/10.2196/12355

Llewellyn, Gwynnyth, & Hindmarsh, Gabrielle. (2015). Parents with Intellectual Disability in a Population Context. Current Developmental Disorders Reports, 2(2), 119–126. https://doi.org/10.1007/s40474-015-0042-x

Mercerat, C. & Saïas, T. (2020). Parents with physical disabilities and perinatal services: defining parents' needs and their access to services. Disability & Society, 1–24. https://doi.org/10.1080/09687599.2020.1788513

National Disability Insurance Scheme. (2021). Overview of the NDIS Operational Guideline – About the NDIS. https://www.ndis.gov.au/about-us/operational-guidelines/overview-ndis-operational-guideline/overview-ndis-operational-guideline-about-ndis

National Disability Insurance Scheme. (2021). Supports Funded by the NDIS. https://www.ndis.gov.au/understanding/supports-funded-ndis

National Health and Medical Research Council. (2015). National Statement on Ethical Conduct in Human Research. https://www.nhmrc.gov.au/about-us/publications/national-statement-ethical-conduct-human-research

Open Society Foundation. (2011). Against Her Will – Forced and Coerced Sterilisation of Women Worldwide. https://www.opensocietyfoundations.org/publications/against-her-will-forced-and-coerced-sterilization-women-worldwide

Pakenham, K. I., Tilling, J., & Cretchley, J. (2012). Parenting difficulties and resources: The perspectives of parents with multiple sclerosis and their partners. Rehabilitation Psychology, 57(1), 52-60. http://dx.doi.org.ezproxy.une.edu.au/10.1037/a0026995

Pesch, Megan H. (2019). Driving in the Minivan—Life as a Pediatrician and Parent of a Child With Disabilities. JAMA : the Journal of the American Medical Association, 322(13), 1255–1256. https://doi.org/10.1001/jama.2019.14889

Pestka, Katrina, & Wendt, Sarah. (2014). Belonging: women living with intellectual disabilities and experiences of domestic violence. Disability & Society, 29(7), 1031–1045. https://doi.org/10.1080/09687599.2014.902358

Powell, Robyn M, Mitra, Monika, Smeltzer, Suzanne C, Long-Bellil, Linda M, Smith, Lauren D, Rosenthal, Eliana, & Iezzoni, Lisa I. (2018). Breastfeeding Among Women With Physical Disabilities in the United States. Journal of Human Lactation, 34(2), 253–261. https://doi.org/10.1177/0890334417739836

Queensland Health. (2020). Importance of breastfeeding. https://www.health.qld.gov.au/clinical-practice/guidelines-procedures/clinical-staff/maternity/nutrition/breastfeeding/importance#exclusive

Redshaw, M., Malouf, R., Gao, H., & Gray, R. (2013). Women with disability: the experience of maternity care during pregnancy, labour and birth and the postnatal period. BMC Pregnancy and Childbirth, 13(1)http://dx.doi.org.ezproxy.une.edu.au/10.1186/1471-2393-13-174

Rivera Drew, Julia A. (2009). Disability and the Self-Reliant Family: Revisiting the Literature on Parents with Disabilities. Marriage & Family Review, 45(5), 431–447. https://doi.org/10.1080/01494920903048734

Rosser, D. (2013) Eugenics (1910s – 1950's). https://www.findandconnect.gov.au/ref/wa/biogs/WE01029b.htm

Royal Australian and New Zealand College of Obstetricians and Gynaecologists. (2019). Prenatal Screening for Chromosomal and Genetic Conditions. https://ranzcog.edu.au/womens-health/patient-information-resources/prenatal-screening-for-chromosomal-and-genetic-con#:~:text=This%20blood%20test%20can%20be,of%20pregnancies%20with%20Down%20syndrome.&text=Only%20a%20diagnostic%20test%2C%20such,a%20genetic%20or%20chromosomal%20condition.

Soniewicka, Marta. (2015). Failures of Imagination: Disability and the Ethics of Selective Reproduction. Bioethics, 29(8), 557–563. https://doi.org/10.1111/bioe.12153

Stebnicki, M. A., & Marini, I. (2012). The Psychological and Social Impact of Illness and Disability, 6th Edition. (6th ed.).

Speech Pathology Australia. (n.d.). Communication disability and communication access. https://www.speechpathologyaustralia.org.au/SPAweb/whats_on/Speech_Pathology_Week/Communication_Disability/SPAweb/What_s_On/Speech_Pathology_Week/Communication_disability.aspx?hkey=19fa3a7d-521d-4cf6-a728-e10c560e1e5e

TASP. (n.d.). About TASP. https://achancetoparent.net/about-tasp-2/

Teater, B., & Kondrat (2010). Introduction to applying social work theories and methods. ProQuest Ebook Central https://ebookcentral-proquest-com.ezproxy.une.edu.au

Transport Canberra. (2021). News and Events. https://www.transport.act.gov.au/

Uber. (2021). Home. https://www.uber.com/au/en/

United Nations. (2007). Convention on the Rights of People with Disabilities https://www.un.org/disabilities/documents/convention/convoptprot-e.pdf

United Nations. (1993). Declaration on the Elimination of Violence against Women. https://www.un.org/en/genocideprevention/documents/atrocity-crimes/Doc.21_declaration%20elimination%20vaw.pdf

United Nations. (2007). Convention on the Rights of Persons with Disabilities (CRPD). (2007). https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html

United Nations. (1989). Convention on the Rights of the Child. https://www.ohchr.org/en/professionalinterest/pages/crc.aspx

United Nations. (2016). General Comment No. 3 (2016) - Article 6: Women and girls with disabilities. https://www.ohchr.org/Documents/HRBodies/CRPD/GC/Women/CRPD-C-GC-3.doc

University of New England. (2021). Library. https://www.une.edu.au/library

Veiby, Gyri, Bjørk, Marte, Engelsen, Bernt A, & Gilhus, Nils Erik. (2015). Epilepsy and recommendations for breastfeeding. Seizure (London, England), 28, 57–65. https://doi.org/10.1016/j.seizure.2015.02.013

Williams, Denitza, Webber, Jessica, Pell, Bethan, Grant, Aimee, Sanders, Julia, Choy, Ernest, Edwards, Adrian, Taylor, Ann, Wu, Meng-Chieh, & Phillips, Rhiannon. (2019). “Nobody knows, or seems to know how rheumatology and breastfeeding works”: Women's experiences of breastfeeding whilst managing a long-term limiting condition – A qualitative visual methods study. Midwifery, 78, 91–96. https://doi.org/10.1016/j.midw.2019.08.002

Wilson, T. (2015). Working with Parents, Carers and Families in the Early Years: The Essential Guide, Taylor & Francis Group. ProQuest Ebook Central, http://ebookcentral.proquest.com/lib/une/detail.action?docID=3570078.

Women with Disabilities Australia. (2012). Briefing Paper: Sterilisation of Women and Girls with Disabilities – An Update on the Issue in Australia. https://wwda.org.au/wp-content/uploads/2013/12/Sterilisation_of_Women_and_Girls_with_Disabilities_UpdateDec2012.pdf

World Health Organization. (2012). Intimate Partner Violence. http://apps.who.int/iris/bitstream/handle/10665/77432/WHO_RHR_12.36_eng.pdf;jsessionid=B13910800A97452E1B3E2F6AFC586B61?sequence=1

World Health Organization. (2011). Disability. https://www.who.int/health-topics/disability