WORKING WITH WOMEN WHO HAVE A DISABILITY

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Mothers with a disability – invisible or forgotten?

In Australia, 1 in 6 people have a disability, with similar numbers for both males and females[1]. Despite this, women with a disability have largely been invisible within the Australian maternity system and underpinning policies. This article aims to shed light on what we know about these mothers, an example of an Australian maternity clinic that was developed to meet their needs, and how providers can assist setting up women with a disability to succeed as mothers.

The term 'disability' has a long history[2]. Understanding this enables us to reduce the barriers that people with disabilities experience. For many decades, disability was viewed from a medical model which saw it as arising from within the person. This perspective has largely been replaced by the World Health Organisation's (WHO) International Classification of Functioning, Disability and Health (ICF) model3, in which a person's ability to interact within their communities is not primarily affected by their functional impairment; rather, it is environmental or social factors (such as physical access or others attitudes) which enable or disable that person[3]. Disability, as such, is a term that describes the limitations or restrictions for an individual to live a contemporary life (a life comparable to their peers). For young women, that includes the opportunity and choice to become mothers.

Despite difficulties in identifying women within the maternity system, mothers with a disability encompass 9-10% of the birthing population globally[4]. In Australia, these mothers are not well identified. Research from the United Kingdom4 shows types of maternal disability to include physical disability (45%), mental illness (MI) (34%), sensory disability (8.7%), intellectual disability (ID) (6.5%) and multiple disability (6%). Women may have single or multiple disabilities in which their primary diagnosis may be compounded by other comorbidities. For example, 52.9% of women with intellectual disability (ID) have mental illness (MI), and of these 9.5% experience severe MI[5]. Since identification of these mothers is limited within Australia, such statistics are likely to be higher.

What do we know about this group of mothers? A snapshot from the research reveals a picture of women with increased risk factors:

- Pre-pregnancy, they are more likely to have been sexually abused[6], experience family violence[7,8], smoke9, have existing diabetes and hypertension[10], and be socially and economically disadvantaged[5].
- During pregnancy, they are more likely to develop gestational diabetes (especially those with visual and ID), pre-eclampsia, threatened pre-term birth[11], antepartum hemorrhage, and other pregnancy complications[12].
- Women with a disability are more likely to have a caesarean birth, especially those with visual and ID, deliver preterm, or have a stillborn baby[5,12,13]. Mothers with ID are highly likely to have their infant removed from their care[14].

When women with a disability have been asked about their care within maternity systems, many report being treated with less kindness and respect than mainstream mothers[12]. They are often provided with information they cannot understand, communicated by providers who have little knowledge about their needs[15]. Many also report not being given choices, or provided adequate post-natal information[12,15].

In essence, we have a group of mothers entering maternity care, who are not well identified, have increased risks and vulnerabilities, and who themselves voice dissatisfaction with their maternity experience[4-15]. It is time to shine the light on the needs of these mothers, providing care by knowledgeable health professionals within an inclusionist policy framework. Not to do so is to discriminate against this group of mothers and sets them up to fail. The Women in Need Clinic at the Royal Women's Hospital in Melbourne, along with other strategies, provides a prime example of how we can best meet these women's needs.

Setting up women with a disability to succeed as mothers

As midwives, our role is to facilitate the transition for women and partners to parenthood. Along with approaches used for women generally, key strategies for midwives to help women with a disability succeed as mothers include:

- Increase your knowledge about mothers with a disability.
- At booking-in, explore what having a disability means for the woman, and what her needs are in regard to this.
- Discuss if she has a National Disability Insurance Scheme (NDIS) plan and the need for an NDIS Plan review for additional NDIS funding.
- Be up-front with women if you don't know about her disability – ask her to educate you where she is able to.
- Ensure adequate time at all appointments to meet her needs; encourage her to bring a support person or worker with her to appointments if she has difficulty understanding information.
- Include her in post-birth planning. Remember, planning for success after the birth starts early in pregnancy, with linking to services that will support her after the birth, and ensuring assistive technology is available if needed.
- Provide respectful, empathetic maternity care, especially when assumption of care occurs for mothers. Remember, they will always be that child's birth mother.

Women with a disability, as any other mother-to-be, look forward to the birth of their baby and becoming a mother. As midwives, we need to support them to do this, in whatever way their mothering takes shape.

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