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Mothering and Disability

According to the 2012 Canadian Survey on Disability (CSD), approximately **3.8 million** Canadians (**13.7%**) live with a disability. This includes **14.95%** of Canadian women, and **12.5%** of Canadian men.[1]

It is estimated that more than **15%** of all parents have some form of disability.[2] In Canada, there are around **1 million (999,110)** parents with disabilities with one or more child living in their home; **580,825** of these parents are **mothers** with disabilities.[3]

The term disability can include mobility, sensory, and intellectual or mental impairments, as well as chronic or episodic illness, mental health challenges, and physical differences that limit ability. **Disabled women and mothers are not a homogenous group.** They have varied life experiences, needs, and supports depending on their impairments, time of onset, and their social, geographical, and economic positions.

In every area of Canadian society, women with disabilities continue to experience oppressive attitudes and stigma, social exclusion, and disadvantage.[4] This includes the realm of motherhood, where barriers and disadvantage can be exacerbated by high rates of **poverty, inadequate housing, and inaccessible public spaces** such as daycare centres, schools, and recreation centres.[5,6,7] Mothers with disabilities are more likely to parent without adequate supports; and as a result, their children are more likely to live in poverty.[8]

Research and social policy surrounding the pregnancy, childbirth, and motherhood experiences of women with disabilities is very limited.[9] As a result, mothers with disabilities are rendered **invisible** in research and in social policy. Accurate and relevant research, as well as more inclusive social policy is sorely needed to assess and address the needs of mothers with disabilities and the needs of their families.

Reproductive Rights and Childbirth

Forced sterilization of women with developmental disabilities was a common and legal practice in Canada that continued into the 1990s,[8] based upon the

oppressive assumption that individuals with cognitive impairments could not be sexually "responsible" and should not be permitted to bear children.[10]

Today, mothers with disabilities do not experience equal access to reproductive and family planning education. Women with disabilities are often discouraged by helping professionals and family members from having children, based upon concerns that bearing children will exacerbate their conditions, that their disabilities will be passed on to their children, and that they won't be competent mothers.[7,10,11]

In research conducted in Canada and worldwide, mothers with a range of impairments have reported that health professionals have suggested immediate termination of the fetus upon learning of their pregnancies.[4,11]

Research also suggests that deficits exist in the Canadian health-care system in dealing with the combined factors of pregnancy and disability. Canadian mothers with physical disabilities have reported that medical professionals lack knowledge of, and experience with, their impairments and the ways in which they might impact their pregnancies.[11]

Women with disabilities have also reported a lack of referral to appropriate agencies and resources, as well as limited caregiving instruction and support tailored specifically to mothers with disabilities.[12]

Motherhood

In our society, women are encouraged and expected to aspire to norms of ideal motherhood and femininity.[13] In this respect, the nurturing role of the ideal mother does not fit well with societal perceptions of women with disabilities as receivers of care.[5,10]

Once women with disabilities become mothers, research has shown that they face stigmatizing views that label them as inadequate or inappropriate in the mothering role to a greater extent than mothers without disabilities, as well as experience **increased levels of scrutiny and surveillance**, and a **greater risk for child apprehension.**[5,11,13] Many experience the threatened and actual loss of their children, as well as barriers for adoption, bringing their children home from the hospital, and maintaining custody of their children after a separation or divorce.[7,11]

Mothers with disabilities have reported a reluctance to ask for help even when it is needed, due to fears that their children will be removed from their care.[7,14] In some cases, asking for help has been used as evidence that physically disabled mothers are not adequate parents.[5]

As a result of the stigmatization and social exclusion they experience, mothers with disabilities are more likely to internalize society's rejection and experience **isolation, depression, and feelings of** inadequacy.[9,15,16]

Motherhood can also be a **positive and empowering** experience for women with disabilities and their children. Some mothers with disabilities have reported that having children allows them to claim or reclaim a "lost" gender and adult sexuality, and to see their bodies as valuable creators of life.[5,13] Canadian mothers with a range of disabilities have also reported **enhanced mothering**, where they are more attuned to their child's needs, particularly when their child also has a disability.[13]

Impacts on Children

"Young Carers" can be defined as "any child or young adult whose life is or may be affected because they are involved with someone who is restricted by illness, disability, mental distress, or substance misuse".[17]

- Other scholars have put forth a more concise definition of young carers, defining them as children or young adults who assume a <u>primary</u> caregiving role for their loved ones.[18]

In 2012, **1.9 million** Canadians aged 15 to 29 reported providing care to a family or friend living with a disability, long-term health condition, or aging needs. **27%** of these young carers cared for parents, with **young women reporting higher rates of caregiving** responsibilities.[19]

In a recent survey conducted with high school students living in Vancouver, Charles, Marshall, and Stainton (2010) found that **12% of students ages 12 to 17 assume a caregiving role for a family member**.[20]

There is a widespread belief among professionals and in society that disability hinders parenting ability and leads to negative outcomes for children.[21] Concerns about child outcomes include: impaired educational careers, mental health problems, low self-esteem, and relationship difficulties.[22,23,24] These consequences are believed to be the result of the major caregiving responsibilities that can be required of children with parents with disabilities. Often called **"parentified"** children to describe the adult responsibilities adopted by these children in their caregiving roles,[25] these children and their families are pathologized and further marginalized.

Most children of parents with disabilities do not have major caregiving responsibilities, with most providing **2 to 4 hours of care per** week.[19] The most commonly reported helping activities provided by young carers include cooking, cleaning, providing transportation, and home maintenance.[19] The emotional, mental, and physical impacts of young caregiving are more severe for those children providing more than 10 hours of care per week. **Education and work commitments are reported most often as areas of difficulty, as well as feelings of worry and** anxiety.[19]

However, caring for a parent with disabilities can also be a **uniquely positive and beneficial experience for young carers**. In a number of studies, mothers with disabilities have shared that their children learn to be independent and mature, are more tolerant of differences, and express a unique sense of empathy and compassion towards others.[5,26] Young carers have also reported that caring for a family member or friend can be very rewarding and can strengthen their relationships.[19]

The needs of young carers and their families can be met with adequate supports.[25] Instead of pathologizing these families, more efforts need to be made to identify and support their needs, as well as acknowledge their unique strengths.

Parenting Supports

Mothers with disabilities have unique parenting needs, including adapted cribs and change tables for mothers with physical limitations and flashing baby monitors for mothers with hearing impairments. Research has shown that adaptive baby equipment has a positive effect on parent-child interactions and relationships, and also reduces the pain, fatigue, and difficulties associated with unassisted or inaccessible infant care.[21] However, appropriate and **adaptive baby care equipment is hard to find and not currently funded by the Canadian government**.

Mothers with disabilities have sparse access to funded assistance in caring for their children. Currently, personal care attendants are prohibited from assisting parents with disabilities with childcare tasks.[11] Parents or mothers

with disabilities in need of parenting supports must apply for and arrange these services individually.

In Ontario, this parenting assistance is delivered through the **Nurturing Assistance** service. Nurturing Assistance began in 1988 to provide physical assistance to parents with disabilities with young children so that they have the opportunity to care for their children like any other parent.[27]

Nurturing assistants assist disabled parents with activities such as bathing, diapering, preparing meals, lifting, carrying, nursing, cuddling, and playing with children. Disabled parents who are able to arrange for this service are funded for a limited number of hours per week – up to six hours per day – through the Direct Funding Program administered by Independent Living Centres and funded through the Ontario Ministry of Health and Long-Term Care.[27]

The Nurturing Assistance program is not well known and is largely discovered through word of mouth.[27] Mothers who are able to receive this service have to find and advocate for it alone.

Currently, Nurturing Assistance is available only to parents who require attendant care themselves and meet the eligibility requirements for the Direct Funding Program. Parents without physical disabilities or those who can care for themselves unassisted but require help in order to care for their children are not eligible for the program.[27] Long waitlists, partial or inadequate funding, and limits to the length of services are common grievances Canadian mothers with disabilities report.[28]

As a result of the challenges these mothers face in finding and receiving adequate parenting assistance, many mothers with disabilities report "doing without" home care support of any kind, or are forced to rely on informal supports such as family members and friends.[10,28] In extreme cases, when no informal supports are available, some mothers are forced to relinquish their children into the care of Children's Aid.[10]

Resources for Parents with Disabilities

The **DisAbled Women's Network of Canada (DAWN)** works towards the advancement and inclusion of women and girls living with disabilities in Canada. DAWN's website (http://www.dawncanada.net/en/) provides information and resources for women – including mothers – with disabilities.

Centres for Independent Living are nation-wide, community-based resource organizations that support the optimum independent living of individuals with disabilities. The Toronto chapter (CILT; http://www.cilt.ca/parenting.aspx) is home to the **Parenting with a Disability Network (PDN),** which offers support and resources to parents with disabilities, including workshops and seminars, information about **Nurturing Assistance**, and as parenting guides such as **The Parenting Book for Persons with a Disability**.

Mothers with disabilities can parent as well as any others. With adequate supports in place, these families can flourish and participate equally and actively in Canadian society. Efforts must be made to raise awareness and provide services to mothers with disabilities that can improve their lives and the lives of their families.

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