

## **Passports to Adulthood, Strong Families and Good Mothers: A Summary of Robyn Saaltink's Dissertation**

**Context:** Policy, journalism, advocacy and research about adults diagnosed with intellectual or developmental disabilities often refer not only to adults with disabilities but to their families as well. In Ontario, for example, the developmental services sector is often described as unresponsive to the needs of both adults with developmental disabilities and their families.

**What I researched:** In my dissertation, I aimed to describe common ways that the categories “adult with a developmental disability”, “family” and “motherhood” are understood to investigate why family and disability are frequently discussed as though they are naturally and inextricably linked. I also examined some of the effects these understandings have on the experiences of mothers of adults diagnosed with developmental disabilities.

**How I did this research:** With the support of MAPS funding, I conducted interviews with members from eight families seeking services under the Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act (SSPSIPDDA) 2008 in Ontario. I analyzed interview transcripts, SSPSIPDDA policy and related documents and Legislative Assembly of Ontario Select Committee on Developmental Services transcripts. As I reviewed these materials, I paid attention to the meanings associated with disability, family and motherhood within each document.

**What I found:** In Ontario, there are many different ideas about who adults with developmental disabilities are. Adults with developmental disabilities are often discussed as being

- different than normal adults;
- deserving of normative outcomes and experiences;
- unique individuals who can and should make choices and strive to reach their personal potential to achieve desirable outcomes.

In many ways, these understandings represent a progressive shift away from ideas that justified institutionalization. It is also important to note, however, that these ways of thinking and talking about adults with developmental disabilities frequently rely upon and strengthen pervasive ideas about mothers: specifically, that mothers are responsible for their children's outcomes and that “good” mothers can and should provide intensive care for their children. Accordingly, these understandings can justify or contribute to the intense work often performed by mothers of adults diagnosed with developmental disabilities. For example

- Emphasis on choice and the unique individuality of adults with developmental disabilities justify reliance on family and mothers for care because mothers, dominantly deemed to know their children best and to care about their children the most, are often described as the people best suited to helping their children make choices.

- Likewise, ideas that adults with disabilities are different than normal adults, and thus require specialized, attentive care, interact with ideas that mothers care the most about their children to make family-provided care appear as the most desirable or sensible option.
- In interaction with prevalent notions that mothers should put their children's needs before their own, focus on potential and choice encourages parents to put considerable efforts into enhancing their children's development and supporting the choices their children make, often at the expense of their own choices and well-being.
- A focus on normative outcomes and experiences, and on choice and potential as the preferred routes to achieve these outcomes, justifies a lack of services and enhances the work parents must do to achieve these outcomes.

At the same time as the meanings given to disability, family and motherhood interact to promote and intensify family-provided care, the meanings given to these categories also allow mothers to state that they are not the best providers of care and to make demands of the province. For example, some mothers referred to the importance of normative outcomes and independence to support arguments that their adult children should reside or be supported somewhere other than in the family and by someone other than a parent.

**Take-away messages:** Meanings currently associated with disability, family and motherhood can contribute to sentiments that family is the best and most natural place for care and that "good" mothers can and will do everything for their adult children. Thus, these meanings legitimize a lack of publicly provided services and can enhance the work required or expected of parents generally and mothers specifically.

For policy makers and service providers, it is important to consider the surface level and underlying meanings of disability and family that are included in policy and practices, and to consider possible consequences of these meanings.

Robyn's full thesis is available from the Queen's University library system:

<https://gspace.library.queensu.ca/handle/1974/24250>.