

# Reproductive Health in Women with Intellectual and Developmental Disabilities in Ontario: Implications for Policy and Practice

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## Abstract

**Reproductive healthcare needs of women with intellectual and developmental disabilities (IDD) have received little attention. Using health and social services administrative data in Ontario, Canada, we comprehensively documented the reproductive health of women with IDD, including their fertility rates, pregnancy outcomes and reproductive health after pregnancy. Our findings showed high rates of adverse health outcomes for these women and their babies, supporting the development of reproductive healthcare programs tailored to their unique needs.**

## The Issue

In 2005, the World Health Organization called on member countries to include a disability component in their reproductive healthcare programming (WHO 2005). Yet, women with disabilities continue to report being underserved in reproductive healthcare settings (Gibson and Mykitiuk 2012), and women with intellectual and developmental disabilities (IDD) are even further marginalized within this group (Davis et al. 2014). IDD can result from genetic conditions (e.g., Down syndrome), perinatal exposure to trauma, viruses, bacteria or toxins (e.g., fetal alcohol syndrome) and unknown and multifactorial causes (e.g., autism spectrum disorder). These conditions impact on cognitive abilities and conceptual, practical and social skills (American Association on Intellectual and Developmental Disabilities 2010). Dubbed “the forgotten generation” (Fujiura 2003, pg. 420), many women with IDD historically were institutionalized or forced to undergo sterilization because of the prevailing societal view of persons with IDD being sexually deviant. In Canada, beginning in the 1970s, involuntary sterilization laws were repealed and institutions were closed (L’Arche Canada 2014). Over time, these systemic changes resulted in more opportunities for childbearing among women with IDD. Evidence from midwifery (Royal College of Midwives 2000) and child protective services (McConnell and Llewellyn 2002) suggests that fertility rates are indeed increasing in this group. Women with IDD are a vulnerable population, and they

disproportionately experience poverty, violence or abuse, chronic medical disease and mental illness (Cooper et al. 2006; Emerson 2007; Havercamp et al. 2004; Walter-Brice et al. 2012), all of which are risk factors for poor reproductive outcomes. Yet until recently, knowledge about the reproductive health of women with IDD has been limited.

## The Process

A major barrier to progress in knowledge – and action – regarding the reproductive health of women with IDD has been the lack of population-based data on their outcomes. Most studies relied on high-risk samples from specialized clinics or institutions (e.g., Chamberlain et al. 1984), leaving unknown the experiences of the broader population of women with IDD. We had a unique opportunity to study the reproductive health of women with IDD at the population level via a linkage of health administrative data from ICES (a non-profit, non-governmental organization that captures the healthcare encounter data of Ontario residents) with Ontario Disability Support Program data from the Ontario Ministry of Community and Social Services (Lin et al. 2014). From the Health Care Access Research and Developmental Disabilities cohort (Lin et al. 2014), which includes all Ontario adults with IDD, we identified women between 18 and 49 years of age with IDD and tracked their deliveries between 2002 and 2012 and obtained a record of 3,932 live births and stillbirths. By comparing women with IDD to those without IDD who delivered during the same period, we were able to document their respective fertility rates, pregnancy outcomes and reproductive health following a pregnancy.

## Key Findings

### Fertility rates

We found that although the overall fertility rate was lower among women with IDD than among those without IDD (20.3 vs. 43.4 live births per 1,000; age 18–49 years), fertility rates were similar among younger women with and without IDD

(34.1 vs. 38.3 live births per 1,000; age 18–24 years) (Brown et al. 2016a). In absolute numbers, there are approximately 400 live births each year among women with IDD in Ontario, a province with about 140,000 live births annually (Statistics Canada 2017). Although this figure translates to 0.3% of all births, its importance is highlighted when put in context. Women with IDD were more likely than their peers to be <20 years of age and to live in the lowest-income neighbourhoods at the time of pregnancy. They were more likely to have comorbid conditions, such as epilepsy, and were twice as likely to have mental health problems, including psychotic disorders, mood and anxiety disorders and substance use disorders. Among those eligible for Ontario's publicly funded drug plan, women with IDD had high rates of medication use in pregnancy, with 47.2% taking two or more medications and 13.2% taking two or more psychotropic medications (Brown et al. 2016a).

### **Pregnancy outcomes**

Given the social and health disparities experienced by women with IDD, it is not surprising that they had more complications around the time of pregnancy compared to women without IDD. Women with IDD had higher rates of fairly rare but serious complications than women without IDD, including preeclampsia (1.5% vs. 1.0%), eclampsia (0.2% vs. 0.1%), venous thromboembolism (1.1% vs. 0.7%) and severe obstetric morbidities such as placental abruption (2.7% vs. 1.9%) (Brown et al. 2017a). They were also more likely to have labour inductions (24.6% vs. 21.5%) and caesarean sections (28.0% vs. 27.3%) (Brown et al. 2016b). Their pregnancies were more likely to end in stillbirth (1.6% vs. 0.6%). Among live births, their infants were more likely to be born preterm (10.9% vs. 6.3%), to be small for gestational age (17.5% vs. 12.1%), to experience neonatal morbidity (5.7% vs. 2.7%) and to die in the first month of life (0.8% vs. 0.3%) (Brown et al. 2017a).

### **Reproductive health following pregnancy**

We also examined the short- and long-term reproductive health of women with IDD after pregnancy, including postpartum health, contraception, inter-pregnancy intervals and cervical cancer screening. Within six weeks of childbirth, women with IDD were more likely than those without IDD to visit an emergency department and to be hospitalized. Rates of acute psychiatric crises were especially high, with emergency department visits and hospitalizations for mental illness being six and ten times more likely, respectively, in women with IDD than in those without IDD (Brown et al. 2017b). In the first year postpartum, women with IDD used oral contraception and intrauterine devices at similar rates compared to women without IDD, but rates of injectable birth control (which has negative effects on mood, weight and bone density) (Bigrigg et al. 1999) and sterilization

procedures (which are permanent) were twice as high (Brown et al. 2018a). Despite this, women with IDD were more likely to deliver a second baby within 12 months of the first (Brown et al. 2018b), the short interpregnancy interval being a risk factor for poor subsequent maternal and infant outcomes (Conde-Agudelo et al. 2006). Finally, women with IDD with a prior pregnancy were less likely than women without IDD to receive cervical cancer screening according to practice guidelines, despite having a known history of sexual activity (Brown et al. 2016c).

**Preconception and prenatal care could include strategies to minimize the impact of comorbid chronic medical disease ... on pregnancy outcomes.**

### **Implications**

Collectively, these data are a clear call to improve reproductive healthcare for women with IDD. Because most women with IDD receive healthcare in general practice rather than in IDD-specific settings (Sullivan et al. 2011), family physicians and obstetricians will likely encounter more pregnant women with IDD as their fertility rate continues to rise. In 2018, based on our findings, the Canadian Consensus Guidelines for the Primary Care of Adults with Developmental Disabilities were updated to include recommendations for pregnancy care for women with IDD (Sullivan et al. 2018), with the rationale that changes to the content and delivery of reproductive healthcare programs for women with IDD could improve outcomes.

We believe that there are several ways by which reproductive healthcare programs for women with IDD can address their risk factors. Preconception and prenatal care could include strategies to minimize the impact of comorbid chronic medical disease, mental illness and polypharmacy on pregnancy outcomes. Such care could also include accessible education about labour and delivery to reduce distress, which increases the risk of intervention and subsequent complications (Nerum et al. 2006), as well as careful planning for the postpartum period so that supports for mother and baby are in place. In postpartum care, accessible information about contraception, including risks and benefits of different options targeted to women with IDD specifically, as well as follow-up to ensure adherence, might be beneficial. Reproductive healthcare programs can also attend to the long-term reproductive health of women with IDD by following guidelines for cervical cancer screening; resources exist for the appropriate implementation of gynaecological care for women with IDD, including performing Pap tests on women who have experienced sexual assault (Grimes et al. 1997).

Because many women with IDD have challenges related to literacy, memory and organizational skills, reproductive healthcare programs must be tailored to their learning needs (Abells et al. 2016). Accessibility guidelines should be applied to healthcare programs and education by providing information using shorter and simpler sentences and by using image-based materials. Reproductive healthcare visits might need to be longer and provided at more frequent intervals to ensure that medical advice is followed. Because many women with IDD are reluctant to disclose their disability because of fear of stigma (Potvin et al. 2016), care should be provided using a strength-based approach that respects women's autonomy and includes them in decision-making. Healthcare providers can also coordinate care with informal and formal caregivers who are able to support women between appointments.

Underlying all of these proposed changes is a need for better education for women and their healthcare providers on the unique reproductive health needs of women with IDD.

## Conclusion

Using population-based health and social services data, we observed increased risks for adverse outcomes among women with IDD across several indicators of reproductive health, supporting a call for action to improve care in this area. **HQ**

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