

The Right
to **Decide.**

Intellectual Disability and the Right to Decide

Resource #7: Youth, Self-Determination,
and Legal Capacity

This document offers a look at the negative role that substitute decision-making can play in the lives of youth in the developmental service system, and discusses alternatives that can lead to better outcomes and a higher quality of life.



The Right to Decide Project – Overview

‘Legal capacity’ refers to people’s experience of being recognized as persons before the law, exercising rights, accessing the civil and judicial system, entering into contracts, making decisions about their own life and property, and communicating on their own behalf.

In many situations (for example, in the case of guardianship) substitute decision-making removes people’s legal capacity, i.e., the right to direct their own lives, including managing their money, making health-related decisions, and deciding where and with whom they live.

From 2018 to 2023, Community Living Ontario worked with five front line service organizations to understand how people who have an intellectual disability exercise their right to legal capacity – that is, how they make choices and decisions, and the barriers they face in doing so.

Our collaborative work uncovered many enablers of legal capacity, as well as many barriers. This resource is part of a series of documents that address this important issue.

Our local partners in the project were Community Living Dryden & Sioux Lookout, Brockville & District Association for Community Involvement, Durham Family Resources, and Community Living Windsor in partnership with Windsor Essex Brokerage for Personal Supports.

Special thanks to the Institute for Research and Development on Inclusion and Society (IRIS), PooranLaw, and Inclusion Canada.

For more information and resources related to this project, please visit our Right to Decide resource page.



Youth, Self-Determination, and Legal Capacity

1. Introduction

It is very difficult to get access to significant funding to pay for developmental services and supports in Ontario. Currently, about 25,000 adults with intellectual disabilities receive funding on top of their Passport allocation.¹ With more than 100,000 adults with an intellectual disability in the province, clearly the majority are not accessing significant support funding. Tens of thousands are living with parents and other family members, in boarding houses (sometimes called domiciliary hostels or 'housing with support'), in hospitals, long-term care homes, forensic facilities, jails, and other institutional settings.²

Generally speaking, a person on the waiting list for developmental services funding will move off of that list in two situations: (1) if they suddenly lose a primary caregiver, or a caregiver becomes unable to provide adequate support, or (2) if they are a youth transitioning out of the child welfare system.

The Government of Ontario does not publish detailed information about people supported with developmental services funding. However, service organizations consistently report that a large number of new entrants to the system are transition-aged youth, and that a significant number of these youth are Indigenous. For some organizations, transition-age youth make up the majority of new entrants to their services.

2. New population, new challenges

Supporting transition-age youth has become a significant challenge for the sector, and one that is likely to continue for the foreseeable future. In any given month, there are more than 8,000

youth in care in Ontario, and almost 60% are 16 years of age or older.³

Ontario's child welfare system has been studied extensively and covered widely in the media. It is large, diverse, and complex. As with any sector, there is a significant range of approaches and quality among service providers. Unfortunately, evidence suggests that children and youth are often put in situations where they experience a pervasive lack of control over their lives, which is often combined with neglect and abuse.

In the spring and summer of 2022, Global News and APTN published a series of investigative articles on unhealthy and dangerous conditions inside Ontario's group homes for children in the care of children's aid societies. The series found that "the child welfare system mistreats some children, lacks qualified staff, and has little oversight or accountability." While private group homes were of particular concern, the series brought attention to problems in the entire system.⁴

The findings of this investigative series are unfortunately not surprising. A 2016 government-sponsored report, *Because Young People Matter*, reported that "in many ways, the experience of living in a residential setting erodes the very skills needed for healthy and successful independence." Further, the report stated that "young people identified as having complex special needs are particularly voiceless and clearly vulnerable in Ontario's residential services system."⁵

In his 2019 book, *A Hard Place to Call Home*, Kiaras Gharabaghi offers a detailed examination of how institutions in the sector are actively causing harm to children and youth:

- “What youth have said consistently and repeatedly is they don’t feel they matter much.”
- “Their stories reflect themes of isolation, neglect, imposed power and control, and very often even undernourishment, unreasonable punishment, and a loss of identity and sense of self-worth.”
- “Frequently, the nuances of abuse within past relationships have featured demands for compliance and conformity... yet residential care and treatment is structured in a manner that promotes relationships based on the imposition of control over young people.”
- “... we need to take seriously the complaint of young people that they do not feel they have any control whatsoever over the things that happen to them.”
- “Some young people have likened their experience in residential care and treatment to a prison experience.”
- “They can plainly see that the setting hires large male staff mostly to provide a deterrent against aggression on the part of youth.”

- “... young people who identify as LGBTQ2s++ often question their safety, and are threatened by their peers, staff, and the community around the residential setting. Black youth find their identity largely dismissed, and they typically know that their actions will be interpreted differently than the actions of white peers... Indigenous youth know full well that their heritage is not desired in residential care and treatment.”
- “... the absence of hard debate and specifically the presence of a form of emotional detachment... has allowed some very bad things to fester within residential care and treatment settings around the country.”

The neglect, abuse, and loss of control experienced by children and youth in care is often combined with histories of alcohol and substance use, other risky behaviours, and interaction with the criminal justice system. For example, nearly 40% of youth living in group residential settings in Ontario report using substances. Youth with Fetal Alcohol Syndrome in particular are at high risk of using substances, and have much greater involvement with the justice and corrections systems than the general population. They also experience mental health issues at very high rates.⁷

Youth in care report pervasive issues with obtaining support and treatment for mental health issues and substance use. Despite increased attention to the effects of childhood trauma, there is a pronounced shortage of trauma-informed services and supports.

Too often, children and youth in care experience additional traumatic situations, rather than getting access to supports that help them deal with past trauma.

3. The limits of protection and care

Ontario's developmental service sector leans heavily toward protection and care of those who are accessing it, and this can be a mismatch for youth entering the system.

Many transition-age youth supported within developmental services do not have physical disabilities, and many have been diagnosed with mild intellectual disabilities or limited cognitive impairments, including those related to Fetal Alcohol Syndrome. Often, they do not require broad or intensive support services. Nevertheless, due to the nature of the system, they are often offered places in congregated residential settings with around-the-clock staffing. According to agency staff, this can lead to culture shock and a strong desire for more freedom and independence.

Given their histories of abuse, neglect, lack of control, and (often) substance use and mental illness, it is little wonder that transition-age youth are challenged by the developmental service system. In turn, support agencies report that, in more highly-regulated settings, youth can develop worsening mental health, substance use, aggression and violence against staff, and are prone to leaving residential settings for extended periods.

In response to these challenges, a group of Ontario developmental service organizations came together to create *The Shift: Holistic and Intersectional Harm Reduction Services for People with Developmental Disabilities*.

The harm reduction approach outlined in *The Shift* represents a move away from the traditionally controlling nature of developmental services, toward supporting people to make their own decisions and direct their own lives, even when those decisions may have negative implications for their well-being. The Shift delves into the realities of alcohol and substance use, gender and sexuality, and trauma. It makes a direct connection between harm reduction, control, and decision-making:

- “The goal of harm reduction is to help people with developmental disabilities build the skills necessary to achieve various degrees of independence, in a way that fosters their self-reliance and self-sufficiency, while also realistically preventing any further harm.”
- “More than anything, The Shift is about seeing a situation and a person through a common lens and fully understanding not only what they need to survive and thrive, but also, what they don't need.
- “What they don't need is judgment; authority-imposed restrictions from a power they do not feel is considerate of their life and value. A person with developmental disabilities does not need to lose their own power — the power to make decisions, to choose how they will engage with risk, and to determine the course of their own life.”
- “Neurotypical people often assume that those with a developmental disability need protection. And, while that is true, they don't need the paternalistic restriction that the system currently provides.”



Youth entering the developmental service system are demanding, whether they realize it or not, the same right to choice, control and legal capacity that disability advocates have been calling for over many decades. The system – including developmental services, the health care sector, financial institutions, legal stakeholders, and beyond – is overly focused on protection and control, without sufficient attention to dignity (including the dignity of risk) and human rights. The changes that organizations have put in place to address the needs of transition-age youth – i.e., changes informed by a respectful supported decision-making model – are the same changes that will support the exercise of legal capacity among all people with disabilities.

For more information, including our recommendations for change, please visit our Right to Decide resource page.

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Notes

1. Auditor General of Ontario (2018). Office of the Public Guardian and Trustee. https://www.auditor.on.ca/en/content/annualreports/arreports/en18/v1_309en18.pdf.
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3. See also: A. Durbin et. al (2018). Intellectual disability and homelessness: A synthesis of the literature and discussion of how supportive housing can support wellness for people with intellectual disability. Current Developmental Disorders Reports, 5, 125-131.
4. Ontario Association of Children's Aid Societies (2022). Facts and figures. <https://www.oacas.org/childrens-aid-child-protection/facts-and-figures>.
5. A. Russell et. al (2022). Inside Ontario's 'scary' child welfare system where kids are 'commodities.' Global News. <https://globalnews.ca/news/8874449/ontario-child-welfare-system-serious-occurrence-reports>.
6. Ministry of Children, Community and Social Services, Residential Services Review Panel (2016). Because young people matter. <https://www.ontario.ca/document/because-young-people-matter-report-residential-services-review-panel/executive-summary>.
7. O.O. Aderibigbe et. al (2022). Substance use among youth in community and residential mental health care facilities in Ontario, Canada. <https://ir.lib.uwo.ca/cgi/viewcontent.cgi?article=3555&context=paedpub>.
8. S. Popova et. al (2021). Health, social and legal outcomes of individuals with diagnosed or at risk for fetal alcohol spectrum disorder: Canadian example. Drug and alcohol dependence, 219(1).
9. The Shift can be accessed at https://communitylivingontario.ca/wp-content/uploads/2022/08/The-SHIFT-final-high-rez_17Aug21.pdf



Community Living Ontario is a non-profit provincial association that has been advocating with people who have an intellectual disability and their families for 70 years. We proudly work alongside more than 115 local agencies and advocate on behalf of more than 100,000 people across Ontario.

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