

SIBLINGS WITH A CAUSE

A SERIES OF RECOMMENDATIONS
FOR EMPOWERING THE ADVOCACY
OF YOUNG SIBLINGS IN ONTARIO



BACKGROUND

Youth (14-29) with siblings who have a disability often experience stigma from friends and society that greatly impacts their daily lives. Siblings often do not have a space to engage in conversations about, or share solutions to, barriers that impact their lives and the lives of their loved one who has a disability. Youth want to share their thoughts and ideas with decision-makers so that they can work together to build a collective vision and end the stigma around disability. Young siblings also want to help nurture relationships with other siblings in order to strengthen the voice of youth as advocates of inclusion.

To help attain these goals, Community Living Ontario supported the creation of a youth-led workshop by siblings for siblings called Siblings: Citizens with a Cause. The workshop was designed for young people (aged 14-29) who are a sibling of someone who has an intellectual disability. This workshop was part of the Ontario Youth United Campaign funded by Heritage Canada. There were 35 participants, from across Ontario, registered for this event. The purpose of the workshop was to connect young people to others with shared experiences, to think about how their experiences impact their lives and wellbeing, and to energize and reinforce their resiliency as young advocates.

The workshop was supported by a partnership between Community Living Ontario, The Siblings Collaborative and Family Alliance Ontario. Youth who attended the workshop were recruited to write and present key recommendations to decision-makers. These recommendations, as written by youth, are necessary to ensure the wellbeing and success of siblings as they support their loved ones to access the good things in life. This report is also an expression of a shared vision for a more inclusive Canada. The following report lists the recommendations that the youth identified.

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Our relationships with our siblings are often some of our longest-lived and strongest connections. We are companions for life. This relationship is even more fundamental when our sibling is vulnerable and marginalized, as is often the case for many people with intellectual and developmental disabilities (Orsmond, Kuo, & Seltzer, 2009; Orsmond & Seltzer, 2007).

The role a sibling plays in the life of their sibling with a disability varies, but often includes high levels of involvement and strong emotional ties over their lifetime (Leane, 2019, p. 264). This role can include being an advocate, friend, caregiver, helper, trustee, guardian and much more.

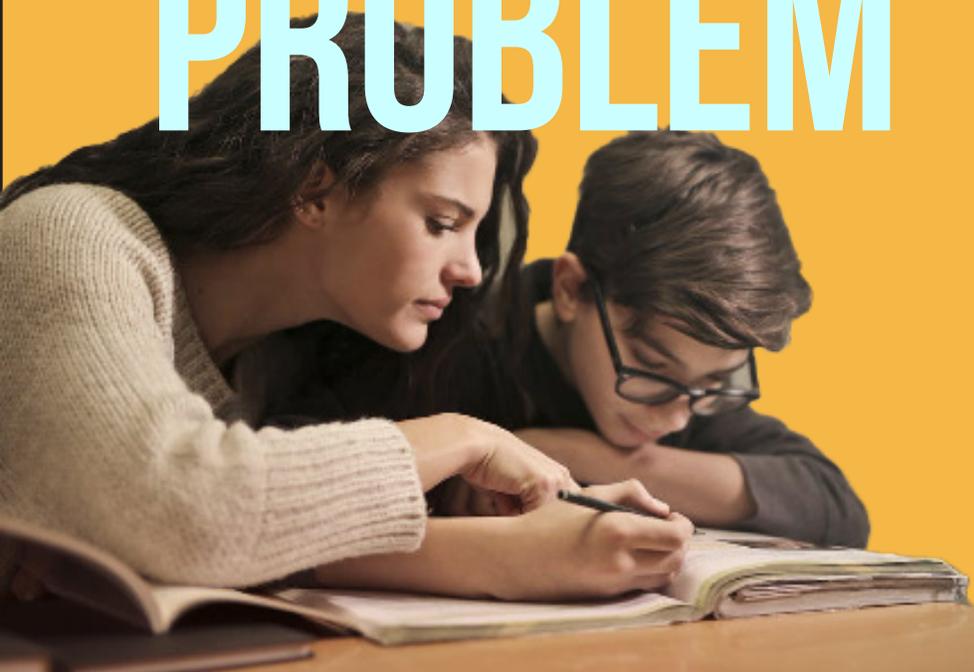
Despite having this deep connection with and understanding of their family members, siblings are

often overlooked as critical stakeholders. Instead, they are excluded from conversations related to their siblings with disabilities, not only within their own families, but also more broadly in organizations and among policy and decision makers. Exclusion from these crucial conversations can ultimately result in little to no agency over their current and anticipated roles.

For such a long-lasting, critical and diverse role, very little exists in the way of support for siblings of people with an intellectual and developmental disabilities (IDD). From a very young age until their senior years, research has shown that siblings consistently report a need for support. When siblings are better supported, it can translate into being better able to contribute to the lives of their siblings with IDD (Holl & Morano, 2014). The support siblings want includes resources relevant to them, participation in decision-making and most of all, a chance to connect with other siblings who understand what they are going through and can offer peer support.

Helping siblings understand and navigate their experiences can contribute to their strength and resilience, which in turn can better support the well-being of their brothers and sisters with disabilities over a lifetime.

THE PROBLEM



A SERIES OF RECOMMENDATIONS

1.0 Leadership and Impact

- 1.1: Siblings want to strengthen their role as advocates to navigate discussions with family on particular life events or transitions that may affect the care of their siblings with a disability.
- 1.2: Siblings want 'meet-ups' and spaces for conversations to connect with other siblings with the same reality. These services could help them learn and exchange ideas for their siblings with a disability to have similar experiences as everyone else.
- 1.3: Siblings want youth-friendly resources (online and offline) that support their role in navigating family dynamics, decisions and responsibilities to prepare for future transitions and unforeseen life events.
- 1.4: Siblings want youth-driven resources that support youth-to-youth knowledge exchange as well as the ability to create such resources/events that cater to specific youth needs.

2.0 Health and Wellness

- 2.1: Siblings want access to mental health services that help them openly share about the stress and anxiety that affects them as siblings.
- 2.2: Siblings want intentional education about emotional wellbeing so they can maintain their own mental health and that of their sibling who has an intellectual disability. These services are also important for connecting youth with other siblings who share similar experiences.
- 2.3: Siblings want to increase awareness about the social stigma of disability, genuine inclusion and ableism for people across Canada. Services that enhance knowledge of the above topics will also better equip people to help one another and eventually break the stigma.

3.0 Innovation, Skills and Learning

- 3.1: Siblings want intentional education and skill building around the role and responsibilities of caretaking that will empower them to plan their future with confidence.
- 3.2: Siblings need a variety of free, youth-focused learning opportunities and easy access to practical information that will set them up for when their sibling comes to live with them.
- 3.3: Siblings want digital, plain language resources on government funding sources, budgeting, advocacy and life skills written specifically for siblings.
- 3.4: Siblings want decision-makers to ensure that both siblings and youth who have a disability are given access to a quality education and opportunities to develop solid employability skills. This is essential to our ability to take care of our siblings and for our siblings to enjoy the good things in life.

4.0 Truth and De-institutionalization

- 4.1: Siblings want their communities to understand that the history of institutionalization and the effects of ableism need to be better recognized and acknowledged by all Canadians, and that their siblings who have a disability need to be part of the reconciliation process.
- 4.2: Siblings want the process of deinstitutionalization to involve listening to whole truths, acknowledging past and current injustices and ongoing action to dismantle discrimination. The process should focus on the contributions and possibilities for youth who have a disability rather than on disability itself.
- 4.3: Siblings want these efforts to reflect the principles of the United Nations Convention on the Rights of Persons with Disabilities that was ratified 11 years ago.
- 4.4: Siblings want institutionalization to be part of the school curriculum alongside curriculum on residential schools, slavery, and the evolution of women's rights.
- 4.5: Siblings want more guest speakers and in-school learning events that focus on the experiences of people who have a disability so that conversations about language, ableism and misconceptions about disability are part of mainstream conversations.
- 4.6: Siblings want ongoing, intentional opportunities to connect with one another and with decision-makers to support the process of de-institutionalization in Canada.