

Young Adults with Developmental Disabilities & Inclusive Research: Why does it matter?

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Young Adults with Developmental Disabilities: Exclusion and Discrimination

People with developmental disabilities (DDs) live in conditions of socioeconomic disadvantage. They experience inequality because they have fewer opportunities to achieve education and employment opportunities. They are also excluded because of stigma, and face obstacles to fully participate in their communities. In Canada people with disabilities between 15 and 64 years old have an employment rate of about 22%, the rate for people without disabilities is more than 73% (Statistics Canada, 2015). Discrimination, exclusion and stigma significantly impact on people with disabilities' mental health and wellbeing.

The challenges individuals with DDs face may become acute when young individuals move from adolescence to early adulthood, which entails choices regarding further education, employment, residential transition. This transition is difficult for adolescents with disabilities, particularly in light of the limited opportunities youth have to thrive in society. In this Information Sheet we discuss the relevance of including the ideas and voices of young adults with DDs in studies or projects that aim at addressing and provide recommendation in relation to their issues. As researchers have highlighted, young adults with DDs are the experts on their own problems so researchers should do a better job in accommodating young adults in research. Our aim as researchers should be to make efforts to include youth's views and recommendations.



The YADD Study

This Information Sheet is part of a larger project that looked at the issues young adults with DDs and their families face in securing access to financial support. Information Sheet #10 provides detailed information about the study. We conducted in-depth interviews with young adults with DDs, caregivers and service providers. We wanted to know about:

- Types of funding young adults with DDs have access to.
- The problems they face in getting access to direct funding.

In this Information Sheet we discuss the importance of including young adults with DDs in studies. We present ideas on how to better accommodate youth with DDs so they can participate in research studies and provide ideas about their needs and how to better address them (Vazquez et al., 2018).

- ✓ 1 in 5 Canadians, or 6.2 million aged 15 years and older had a disability (22%) (Statistics Canada, 2017).
- ✓ Youths aged 15 to 24 years (13%) had one or more disabilities. Women were more likely to have a disability than men across all age groups (Statistics Canada, 2017).
- ✓ 1% of this population reported to have a developmental disability (Statistics Canada, 2017). The main developmental conditions reported in 2012 were Autism, Cerebral Palsy and Down Syndrome (Statistics Canada, 2012).

Why do we need to promote the participation of young adults with DDs in research studies?

Initiatives and policies that aim at addressing people with disabilities’ social and economic exclusion and discrimination, and to promote needed services, must take into account people’s own views on their problems and their recommendations. “Nothing about us without us” (Scotch, 2009) promotes the idea of putting at the forefront the voice of people with disabilities in decision-making processes and interventions. The inclusion of people with disabilities is a fundamental human right recognized in the United Nations Convention on the Rights of Persons with Disabilities.

United Nations Convention on the Rights of Persons with Disabilities (UN, 2006)

The Article 21 refers to the “freedom of expression and opinion, and access to information” and highlights the need to take “measures to ensure that persons with disabilities can exercise the right to freedom of expression and opinion” including:

- ✓ provision of information in accessible formats
- ✓ facilitation and use of alternative communication, modes and formats

How can we promote a meaningful inclusion of young adults with DDs in research?

The promotion of inclusive research implies that researchers need to improve their research practices, such as the implementation of innovative ways of recruitment and conducting interviews, as well as the creation of materials and procedures that are accessible for people with DDs (Kidney & McDonald, 2014). The following are the strategies we applied to promote the inclusion of young adults with DDs in our study.

Flexible Research Strategies to Accommodate young adults with DDs

Recruitment

- Flyer with easy to read and clear information about the project, with short key messages
- Honorarium of \$30 for participation: economic incentives to cover basic expenses (e.g. lunch, transportation)

Interviews Location & Format

Individualized to young adults and caregiver’s needs and preferences:

- Phone
- Face-to-face
- Alone or accompanied by family member or service provider
- Location where participants feel comfortable (e.g. community center)

Interviews

- Adaptation of the interview guide for young adults (e.g. change wording and complex questions to short and clear ideas and language).
- Support from family caregiver or service provider in helping young adults to understand questions.
- Provision of breaks during the interview. Variety of Formats (e.g. allowing participants to interact with a dog while conducting interview).

Another strategy we applied was the inclusion of young adults, caregivers and service providers in the study's Advisory Committee. This Committee met with the research team to discuss initial research findings, provided feedback on the project's activities, and participated in the community event.

What did we learn from the inclusion of young adults with DDs in our research?

The inclusion of young adults with DDs in studies was of fundamental relevance because some young adults with DDs...

- ❖ Have few opportunities to be asked about what they think about their lives
- ❖ Are often not asked to provide their opinion about the services they are receiving or about the issues they face
- ❖ Have few opportunities to interact with researchers (other than from the helping professions) and share their opinions about their life

From our interviews we learned that including young adults with DDs, especially young adults with more support needs, is of fundamental relevance if we aim at designing meaningful changes to their lives. It is important to also highlight that researchers that may only focus on including in their studies "high functioning" individuals with DDs, could represent an excluding strategy that may discriminate "low functioning" persons who may want to be part of studies, and whose participation is key if we want youth to be empowered and have a say about their issues.

In the interviews young adults expressed their positive views about being asked about the issues they face:

I think it's just really great to have studies like this where we could just come and try to answer some questions and try to help other people... (P47, female young adult) (Vazquez et al., 2018, p. 11).

Young adults highlighted their rights to be included and to promote equity among people with and without developmental disabilities:

I guess to have a voice and that we can stand up for ourselves and our rights and for people to treat people the same as people that don't have a disability to treat them the same. And for people to be accepting of us too (P77, female young adult).

They spoke about the importance of being communicated with respect:

I haven't met too many service providers but I find that sometimes like when we as people with disabilities try to talk to them, they kind of talk to us as people with disabilities and not really as like people, so then they might like talk down to us maybe or just like talk to us and kind of a more childish way, which makes us feel like crap and it makes us feel like we can't always do things on ourselves when that is not true. It's hard! (P47, female young adult).

Implications

- ✓ Understanding the relevance of the inclusion of young adults with DDs in research is key to initiate changes in the way traditional studies are implemented.
- ✓ By including young adults' voices, they are supported to feel empowered in shaping the world around them.
- ✓ Efforts to apply inclusive research should include strategies to promote the participation of persons with disabilities in project design and knowledge transfer.
- ✓ Other strategies to promote inclusion can be the involvement of persons with disabilities in research advisory committees.

- ✓ Flexibility, taking into account people with disabilities' accommodation needs, and improving recruitment strategies, are some of the changes that need to take place in order to promote inclusion.
- ✓ It is important that researchers include in their studies people with different types and degrees of disabilities, as well as from different gender, age, ethnic and racial backgrounds.

Selected References:

- Scotch, R.K. (2009). "Nothing about us without us": Disability rights in America. *OAH Magazine of History*, 23 (3): 17-22.
- Vazquez LM, Khanlou N, Davidson D & Aidarus, F. (2018). Strategies to promote the inclusion of young adults with developmental disabilities in community-based health studies. *Qualitative Health Research*, 1-14.

ABOUT THE INFORMATION SHEET

This information sheet is part of a series of information sheets produced at our Office and in relation to the Intersectional Approach to Immigration Status, Gender and Disability Research Program. It provides some of the key findings from our qualitative study titled *Impact of Gender and Migration Status on Accessing Direct/flexible/self-directed Social Funding for Developmental Services in Ontario* (the YADD project).

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