

Disability Funding for Young Adults with Developmental Disabilities

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Young adults with developmental disabilities

Young adults with developmental disabilities (DDs) experience social and economic exclusion and barriers, specifically related to their education, career opportunities and employment options –e.g. underemployment or unemployment- which impacts on their health and wellbeing. Developmental disabilities may include, but are not limited to, Intellectual Disability, Autism, Down Syndrome, Fragile X, and other disabilities that affect development and optimal functioning. DDs may be present at birth or develop before 18 years of age (DSO, 2016). Young adults with DDs are individuals between 18 and 29 years of age, who are at a critical transition in their health as they move from adolescence into adulthood. This transition has been characterized as challenging for youth and their families. Young adults with DDs may have higher rates of preventable health problems, more complex health issues, and a greater frequency of co-occurring medical or psychiatric illnesses than typically developing young people. It is in the context of these challenges that access and optimal utilization of disability funding is strategic for a successful transition.

In this Information Sheet we present findings related to the issue of access to disability funding. We analyze the barriers caregivers of young adults with DDs face when they apply for direct funding, and once they get the funding, the challenges they face to manage it.



Our study

This Information Sheet reports on some of the findings from our study that looked at the issues young adults with DDs and their families face in trying to access direct funding. We wanted to know:

- What type of funding do young adults with DDs have access to?
- What are the problems they face in getting access to direct funding?
- Are there any advantages or disadvantages in getting direct funding versus agency-based funding?

Qualitative in-depth interviews were conducted with 86 individuals: 21 young adults with DDs (8 males and 13 females YADD), 45 caregivers of young adults with DDs (8 males and 37 females; 26 Canadian-born and 19 immigrants) and 20 service providers (4 males and 16 females). Study participants shared important insights related to economic constraints, employment, education, health and mental health, discrimination and stigma, and service and institutional support needs.

Disability funding

Funding for disability is directed through direct and indirect funding. Direct Funding is characterized as:

- ✓ Self-directed payments, cash for care, consumer-directed care or individualized funding, and involves payment provided directly to the individual with disabilities.
- ✓ Funding that provides payments, and can take the form of either a monthly allocation of funds to the person with a disability, to purchase required supports (Laragy & Ottmann, 2011).

What do we know about disability and disability funding in Canada?

- ❖ 1 in 5 Canadians (6.2 million) aged 15 years and older had a disability (Statistics Canada, 2017). 1% of this population reported to have a developmental disability (Statistics Canada, 2017). Youths aged 15-24 years (13%) had one or more disabilities (Ibid).
- ❖ Changes in rates of disability and delivery of funding support for individuals with developmental disabilities are currently challenging existing public policy.
- ❖ Very little is known about factors that may hinder or facilitate access to, and utilization of disability funding among young adults with developmental disability who are at an important transition in their life.

What did participants say about the application process?

Caregivers shared their concerns about the application process for direct funding, specifically related to bureaucracy, paper work and time constraints:

The majority of the caregivers thought that the application process is very complex:

Now when we went through the process with our son, and we're talking two university educated parents, it was a difficult process. We had to seek clarification throughout the process and it's eight hours. So that could present a barrier to families I'd suspect, immigrant families (P7, father).

It's the time. The time it takes to get the appointment, to get the paperwork completed, to have a five hour meeting, to go to the doctor and get forms filled out and then submitting everything....It's the time constraint that you call and then you have to wait for somebody to call you back. And they are going to send you the forms and then you have to wait for the forms and then you fill out the forms. You have to take out a portion of that to your doctor or somebody to sign off that says, yes my son is like this or that. And then you submit it again and then you wait and you call and you leave a voicemail and you don't hear and you don't know if you crossed all your T's and dotted your I's... (P26, mother).

Planning, administrating and budgeting

Family caregivers talked about the difficulties of planning, managing and budgeting the direct funding they receive for their young adults with DDs. The direct funding system requires from families to have specific knowledge and skills in selecting and managing the services, and administering payments to providers.

It was a lot of work to put together, you have to put together a plan. We want him to do this or that or the other thing, how much would it cost, put a budget together, how much the transportation costs, how many days, and then you would get a fraction of that back and you would have to adjust to things like that (P30, mother).

So finding whether it's [program] going to suit, where it is, what time of day it is, so you could say 'oh that's really great but it's only in the afternoons'. It's in [location] so there's no way to get there realistically. So all of these factors you have to take into account, you have to run down a checklist, fall in love with the program but it has a waitlist. You hear really good things about a program and it's 45 minutes away in the wrong direction. Or it conflicts with times he [YADD] is doing something else that he really likes. It's this whole huge case management, you become a case manager. So that's the barrier, it takes a lot of time. I've invested a really ridiculous amount of time and set up my own database (P10, mother).

Satisfaction with direct funding

Despite many challenges described by caregivers of young adults with DDs, such as inadequate levels of funding in relation to need, limited types of available and accessible services (e.g., residential, employment training and support), and the planning and budgeting challenges, caregivers also had positive views on the direct funding system.

Well, direct payment has been really good. It works out, I take care of it. I manage, I keep track of the hours, I hire the workers, I use it for what benefits my daughter...I have had no problems, there's a lot of paperwork and long meetings and conversations... if you have the funding then you can hire the right workers for them [young adults with DDs] or you can find programs that are suitable for them, but you do it not an agency that doesn't know her [her young adult with DDs] (P18, mother).

As recognized by caregivers, direct funding is a good system for some families, but it requires certain skills that not all the families have:

So direct works for me well because I feel that I am capable and I know what my son needs best and I like to be in control and know who I am hiring and why, that I train them to do everything. But for me that works better. That's the pro for me and having the funding to do it, great... So I like that I have the control, but on the other hand, someone who is not comfortable with that and doesn't know where to start...or have issues themselves, emotional or mental...I pray that they would allow an agency to help them implement these things (P13, mother).

Conclusion

- Although many caregivers expressed satisfaction with the increase in choice and control that the direct funding provides them, many also signaled a concern regarding the time and skills required to administer it.
- Challenges to manage direct funding for young adults and their families include: looking for and selecting a service; financial decisions (e.g., best price, best distribution of resources; managing, scheduling, training workers; and, remitting invoices to the funder for financial reimbursements. This is a complex process and a source of anxiety and stress for families.
- Intersections of English as a second language, new immigrant status and not knowing multiple service systems intensifies challenges.
- The complexity of the direct funding system and the skills required to navigate it sets up an inequity system. Only those families who have certain key skills (i.e. knowledge of the system, network of others who are "in the know", and good English / French language skills) have better access to the direct funding. Those who do not have the skills (e.g. immigrants who do not have the language skills or know the system) have less access, simply because they do not know how to navigate the system.
- Lack of information about available services and the complexity about how the funding system works, were among some of the concerns participants shared with us.

Selected References:

Developmental Service Ontario (DSO). (2016). <http://www.dsontario.ca/whats-a-developmental-disability>

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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