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Barriers and inequalities faced by caregivers of children and young adults with developmental disabilities in accessing and managing direct payment funding: Key recommendations

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Abstract: *Background:* People with developmental disabilities experience systemic barriers in accessing and utilizing disability funding. Direct funding aims at enhancing the quality of life of persons with developmental disabilities. It relocates the choice and control over services from agencies and service providers to individuals with developmental disabilities or their families. We explore the impacts of this shift on the family caregivers of persons with developmental disabilities in relation to access, management and utilization. *Methods:* The paper draws on a larger qualitative community-based research project with 86 participants that explored the impacts of direct payment for young adults with developmental disabilities in Ontario, Canada, and their caregivers. Specifically, we report findings from 45 family caregivers. *Results:* Direct funding allows individuals to select what services they wish to receive, and to maximize the degree of control they have on service delivery. However, extensive inclusion and exclusion requirements of what constitutes acceptable expenditures, lengthy paperwork and record keeping, and time limitations for use, can be challenging for caregivers. Direct funding requires human capital, knowledge, resourcefulness, time, skills and experience of the caregivers to navigate across systems and communicate with multiple stakeholders. Caregivers report stress and anxiety in their (new) role as the administrators of complex choices and decision-making processes. *Discussion and Conclusion*: The success of direct funding is contingent on human capital attributes of its users and/or caregivers managing the funds, and flexibility in administration expectations that applies a person-centred lens. Families with developmental disabilities who experience the greatest burden and inequalities in care are often those with the least time and resources to manage and administer direct funding in light of extensive contractual and complex funding requirements.

Keywords: Direct payment, personal budgets, person-centred, developmental disabilities, caregivers.

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Introduction

In this article we analyze the experiences of families with children and youth with developmental disabilities with the direct payment system in Canada. Funding for disability in Canada is implemented through direct and indirect funding. Direct funding involves payment provided directly to the individual with disabilities and is characterized as self-directed payments, cash for care, consumer-directed care or individualized funding (Findlay & Damji, 2013). Direct payments can take the form of monthly allocation of funds to the person with a disability, or lump sum payments paid in advance or retrospectively, to purchase required supports and services (Community Living Ontario, 2021; Laragy & Ottmann, 2011).

According to Carey and colleagues (2021), personalized direct funding is guided by two strategic agendas: efficiency in government spending and services, and the human rights agenda promoted by the disability community. Furthermore, disability policy and practice promote the rights of people with disabilities to exercise choice and control and to enhance their quality of life (Araten-Bergman, 2023). The use of direct funding approaches for those with disabilities is driven by a desire to improve the system in three key ways: enhancing responsiveness, flexibility, and choice. Over the last decades, there has been research on how well such funding approaches achieve those goals (Crozier et al., 2012; Crozier et al., 2013; Friedman, 2025; Glasby, 2014; Graham, 2015; Harkes et al., 2014; Jones et al., 2012; Jones et al., 2014; Manthorpe et al., 2015; Pattyn et al., 2021; Sims & Gulyurtlu, 2014; Turnpenny et al., 2021; Welch et al., 2012). Studies have examined a wide variety of approaches including young people in transition from child to adult services and the use of family members as paid carers (Manthorpe et al., 2011; Mitchell, 2015).

Individualized funding models are rooted in person-centred care approaches. Person-centred care includes a variety of strategies that have been designed to individualize the delivery of care. Person-centred care situates individuals with disabilities "at the centre of decision-making about their lives, recognising their strengths, preferences and personal goals" (Araten-Bergman, 2023, p. 183). It is a type of care that aims at personalizing "care plans to reflect individual needs, preferences and goals through active participation and direction from the person-supported" (Idrees et al., 2025, p. 2). Individualized funding is also embedded in the Independent Living Movement (ILM) (Fleming et al., 2019), a global movement that emerged in the 1970s to advocate for rights of people with disabilities to make their own choices, live independently, and to fully participate in society (Barnes & Mercer, 2010; Independent Living, 2025). ILM surfaced in the area of supports and services for individuals with disabilities (Barnes, 2007; Glasby, 2026; Spandler, 2004) and integrated ideas from civil rights, social justice, consumerism, self-help, de-medicalization and de-institutionalization movements (DeJong, 1978, 1983; Stainton, 2002). ILM established a template for empowerment and autonomy calling for a shift toward social services and supports that were consumer-oriented and non-paternalistic (Lachat, 1988). The goals of ILM are two-fold: individualized, consumer directed services and, secondly, an advocacy thrust to promote the collective opportunities and social well-being of those facing a disabling condition (Lachat, 1988).

In this paper we adopt a critical approach to the understanding of direct funding program design and implementation. We argue that under direct funding systems, work is downloaded to families; caregivers become "co-workers" (Turnpenny et al., 2021), performing "invisible work" (Katzman et al., 2022) seemingly unrecognized and unpaid labour that impacts them and their family's wellbeing. Direct funding increases the workload of families with children and youth with developmental disabilities, adding complexity to their already challenging caregiving experiences, and requiring a structural support system.

Under direct funding, public funding is transferred to service users (or their caregivers) to recruit, hire, train, and manage support staff (Katzman et al., 2022). Direct payment involves individualized funding through which families identify the needs of their children and youth with developmental disabilities, search and hire the needed services they think their children need, monitor service provision, and pay for these services directly to the providers. Direct payment represents a shift in the way families receive services: it relocates choice and

control over services from service providers to people with disabilities (Findlay & Damji, 2013; Fleming et al., 2019).

The introduction of direct payment systems has led to the evolution of how services are provided in an attempt to increase choice for service users/family caregivers (Zhang & Forder, 2025). The policy goal of such transformation is autonomy: allowing individuals to not only (i) select what services they wish to receive, but to (ii) further maximize the degree of control they have on service delivery (Direct Funding Ontario, 2026; Fleming et al., 2019; Kröger & Chou, 2025). However, critical to this goal is the recognition that direct payment requires families to perform tasks, activities and actions and not just make choices – including how to use the disability funding, the selection of services as per the needs of their children and youth with developmental disabilities (Pattyn et al., 2021). Tasks and activities that were under the previous service system, typically performed by service providers and the administrative structure of an agency, are now under the direct payment system, transferred to the caregiver. Such tasks, activities and actions can be multiple and on-going and impact the wellbeing of families of children and youth with developmental disabilities.

Our analysis draws on a larger community-based qualitative study that looked at the barriers, families with young adults with developmental disabilities face in accessing and managing direct funding (Khanlou et al., 2015). The study included the views and perspectives of 86 research participants: young adults with developmental disabilities (n=21), their family caregivers (n=45) and service providers (n=20). In this article we analyze the specific experiences of family caregivers. We asked participants about the potential barriers and positive solutions for accessing direct funding; we wanted to understand caregivers' awareness and perceptions of direct funding versus indirect or agency-based funding; and to explore the advantages and disadvantages in accessing direct social funding versus indirect or agency-based funding. The study's research question was: What are the potential barriers and positive solutions for accessing direct social funding for young adults with developmental disabilities and their family caregivers by gender and migration status? Very little is known about factors that may hinder or facilitate access to and utilization of disability direct funding among young adults with developmental disabilities who are at an important transition in their life; this paper aims at filling in the gap.

Methods

Our study was conducted in Ontario, and we received approval from York University's Office of Research Ethics prior to data gathering. Qualitative in-depth interviews were conducted with 45 family caregivers of young adults with developmental disabilities (8 males and 37 females; 26 Canadian-born and 19 immigrants). In this article we report research findings from the family caregiver participants only.

Participants

Participants were recruited from the Greater Toronto Area through community partners and networks. Family caregivers were eligible if they were a parent or primary caregiver with at least one child between the ages of 19-29 years with developmental disabilities, and available to participate in a 1 to 1.5 hours long interview.

Procedure

Written consent was obtained from the research participants before the interviews. We asked the participants to read the consent form and to ask any questions that they had about its content. Data were collected through in-depth interviews with demographic items as well as a series of semi-structured and open-ended questions. All interviews were conducted by 4 trained interviewers. We asked family caregivers questions about their experiences of being caregivers of young adults with developmental disabilities; we asked them to describe the types of social support and funding they had come across for their children with developmental disabilities including, for example, Ontario Works, Ontario Disability Support Program, and Passport Funding; we also asked them whether funding for developmental services/agencies was easily accessible and how they managed it.

Data Analysis

Audiotapes were transcribed verbatim. Analysis included inductive coding to generate theory (Strauss & Corbin, 1998; Mills et al., 2006). Four researchers read the

transcripts and completed the coding process (Mills et al., 2006). Data coding and analysis were then conducted through a three-step process for our study: (1) development of a preliminary coding scheme for an initial set of interviews; (2) sub-coding and coding on all remaining interviews; and (3) identification and analysis of broader emergent themes according to funding type, migration status and gender.

Trustworthiness

Triangulation between research team members was employed by having them review, code, and interpret the same transcripts and then collectively discuss and decide on emerging sub-codes, codes, and themes. To support confirmability, member checking with our project's Advisory Committee and with key stakeholders was conducted (Creswell & Creswell, 2017). For example, we presented preliminary research findings with research participants and other key stakeholders in a community event and incorporated their input into the analysis of findings.

Results

In Table 1 we provide the demographic characteristics of the caregiver participants. In this section we discuss findings from our community-based study on the transformations and impacts that caregivers with children and youth with developmental disabilities experienced as a result of their use of direct payment system.

Table 1: Characteristics of Family Caregiver Participants

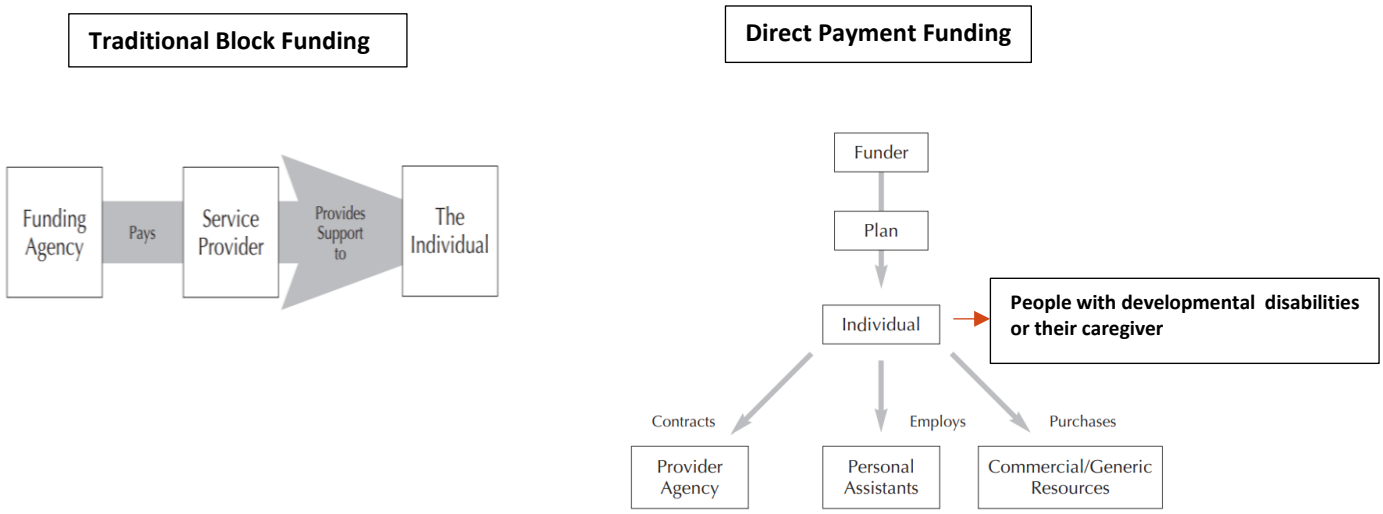
Total Participants N=45	Immigrant n= 19	Canadian-born n= 26
Gender		
Male	5	3
Female	14	23
Age Group		
41-50	6	8
>50	13	18
Highest Level of Education		
High School	2	3
College	1	5
University	7	12
Graduate	6	4
Missing data	3	2
Continent/Country of Origin		
North America (Canada)	0	26
Africa	1	0
South America & Caribbean	2	0
Europe	4	0
Asia	9	0
Missing data*	3	0

Caregivers' Roles and Responsibilities under Direct Payment Systems

Direct payment systems represent a shift in roles and relationships with the transfer of responsibilities from the agencies providing disability related service, to the people with disabilities or their caregivers (Direct Funding Ontario, 2026). Direct funding for developmental services is defined as funding "where people who need personal and health-related supports manage their own funds and pay for supports directly" (Community Living Ontario, 2021, p. 6). Figure 1 illustrates the direct payment flow system compared to the traditional systems of funding allocation.

In this section we discuss four system elements: 1) Transfer of responsibilities from agencies to caregivers; 2) Defining and assessing the needs of children and youth with developmental disabilities; 3) Creation of a personalized service plan; and 4) Financial decisions. We provide some recommendations that emerged from the literature and the community-based study about needed supports for caregivers in the context of the direct funding system (Table 2).

Figure 1. Type of Disability Funding



Source: Adapted from Findlay, I. M., & Damji, A. (2013).

Table 2. Elements of support in system elements

System element	Supports
1. Transfer of Responsibilities Transition from a traditional co-producer of caring to an administrative co-producer, with intensive and complex administrative functions	✓ Adapt and re-contextualized book-keeping courses for direct payment management ✓ Easy to use software ✓ Sources of on-going support and mentoring recognizing the diversity of caregivers' differential capacities and resources ✓ A single point of contact and a person to answer questions. ✓ Clear guidelines and communication on the use of direct funding
2. Defining Need The assessment of needs and abilities to determine the required level of services and supports	✓ System of learning and support ✓ An appeal system related to funding decisions ✓ A family-centred approach to the assessment of need
3. Creation of Personalized Service Plan The process of translating abstract measures of need and budget allocation into a personalized service and support plan	✓ A visible, accessible hub of information ✓ Tools and techniques to find and interpret information ✓ Community supports for families with language barriers/newcomers
4. Financial Decisions The task of aligning a personalized service and support plan into a budget that fits the funding allocation	✓ Financial literacy ✓ Peer mentoring ✓ Recognition of unpaid labour in managing direct funding

1. Transfer of Responsibilities

Direct payment represents the marketization and the consumer decision of buy-don't buy disability related services and incorporates the 'de-professionalization' (Kröger & Chou, 2025) of what were once coordination and management activities (e.g., bookkeeping, human resource management) by professional staff, with a transfer of responsibilities and tasks to caregivers. The administration of direct payment includes tasks and activities such as following funding eligibility rules, tracking hours, and remitting invoices. These management tasks are complex, requiring time, knowledge and skills from the individuals performing them. Coordination and management of staff and services were previously administered by individuals paid to perform the necessary functions; such performance was conducted by individuals with the needed education, skills and experience (Van der Veen, 2025).

Caregivers under the direct payment system face uncertainty when dealing with difficult administrative and employee management activities for which they may have little to no experience and education, or time (Turnpenny et al., 2021). Researchers have found that caregivers with prior administrative and managerial experience, and with higher education, report an increased capacity to cope with the demands of direct payment (Brookes et al., 2015; Grootegoed et al., 2010; Owens et al., 2017). Increased coping and satisfaction with the direct payment system then appears to reflect individual capacity in terms of human, financial and social capital, as well as time to perform the tasks required by the system.

The administration of direct funding appears to represent a focal point of carer dissatisfaction and stress, of "substantial mental and emotional load" (Turnpenny et al., 2021, p. 59), as caregiver participants in our own study also explained. It is also an issue recognized by agencies serving the disability community that state direct funding in developmental services (for caregivers and people with disabilities) "can be stressful and sometimes exhausting to be an employer and manage your own workers" (Community Living Ontario, 2021, p. 6).

Recommendations

The elements of a supportive system for caregivers under direct payment are:

(i) Adapting and re-contextualizing bookkeeping courses for direct payment management (Turnpenny et al., 2021);

(ii) Easy to use software designed to manage direct payment budgets (e.g., in Ontario, My Direct Plan, an on-line direct funding management software is available for carers) (Community Living Toronto, 2026) and;

(iii) Sources of on-going support and mentoring in recognition of differential capacities of carers (including a third-party organization offering administrative services) (Duerksen et al., 2025).

(iv) A single point of contact and a person to answer questions.

(v) Clear guidelines and communication on the use of direct funding (Turnpenny et al., 2021).

2. Defining the Need in Funding Application

As direct payment systems involve a distribution of public funds, the assessment of the needs of children and youth with developmental disabilities is rigorously controlled and managed by government agencies. Defining what the individuals with developmental disabilities need is the foundation for all decisions, choices and processes that follow. Caregivers provide information on the individual with developmental disabilities, but the focus on level of need is within control of the government assessor guided by the protocol of the assessment tool (e.g. Supports Intensity Scale) (AAIDD, 2026; Developmental Services Ontario, 2026). However, such assessments can be complex and time consuming. In our study, caregivers discussed the process as a significant source of anxiety and stress for them, with little independent assistance from government agencies. For example, a caregiver explained:

I just filled out a form and sent it in. Passport [direct funding program], there is a whole assessment process through the DSO [Developmental Services Ontario] where they spend 3 or 4 hours getting you

> through this incredibly cumbersome assessment...I did not find it a family friendly assessment (P11 Family Caregiver).

Elsewhere we have reported on the vast amounts of complex paper-work to be completed as well was an intense, invasive investigation of the intellectual and functional status of children with developmental disabilities (Khanlou et al., 2019; Khanlou et al., 2017; Khanlou et al., 2015a, 2015b). Relatively unexplored in the literature is the issue of what sources and types of information and support are available to the caregiver in preparation for completing the assessments forms and participating in the assessment process that is required to access the direct payment system.

The next step is the translation of the measured need to a funding allocation, a process that again renders the caregiver as a passive entity. Researchers have highlighted unequal power relations in resource allocation assessments, and the need to increase the role of individuals in assessing their own needs (Stevens et al., 2011). Overall, this phase of direct payment is a "black box". Turnpenny and colleagues (2021) describe it as a stage of "'operational ambiguity' and frontline discretion" (p. 59). For example, caregivers in our study described the lack of "transparency" in the process:

> The process… should be more transparent… I think that is like, like it's not maybe simple; it needs to be simplified (P5 Family Caregiver).

> … it wasn't very clear on how we got it [Passport direct funding program] because it sort of happened behind the scenes (P10 Family Caregiver).

Caregivers reported problems with the amount of the monetary allocation as being insufficient to meet the required needs of their children with developmental disabilities:

> Now we've had quite a significant increase but it's still not covering 7 or 8 hours of 1 on 1 care of [my] son, 5 days a week while we are working. I think it's probably covering about 5 hours (P11 Family Caregiver).

> He gets Passport funding every year, the minimal amount that is never enough to cover his expenses for day programs and support staff because he does require 1-to-1 staffing – so paying for day programs, paying for support workers, paying for day to day for his transportation… Passport [program] runs out before the fiscal year is finished (P18 Family Caregiver).

> I wish that there's one kind of funding that's going to be life-long and that's going to be secure and enough to fulfill the needs of a person with a disability (P14 Family Caregiver).

Generally, caregivers have no direct input to the allocation decision, which has fundamental impacts on the type of decisions the caregivers need to take (i.e., type of services they can afford to pay). Even less investigated is the presence of formal appeal mechanisms or available supports for individual advocacy related to a funding decision. We heard frequent stories of individual caregiver advocacy, such as regular calls to the assessment centre and engagement of local politicians. Success in advocacy is dependent on time, resourcefulness, human capital and social capital, but further research is needed.

Recommendations

The elements of a supportive system for caregivers under direct payment are:

> (i) An independent system of learning and support to assist new entrants to a direct payment system with the process of assessment (Fleming et al., 2019); and

> (ii) An appeal system including the availability of an independent advocate to support the carer in the appeal process.

> (iii) A family-centred approach to the assessment of need.

3. Creation of a Personalized Service Plan

In this stage, caregivers of children with developmental disabilities engage in the process of constructing a personalized service plan (based on the available funded allocated) and search for information on programs and facilities that fulfil the desired actions in the service plan. Caregivers do not simply select a program or personal support worker from a list. Here, the caregivers are structurally dependent on the availability, accessibility, and quality of comparative information on what exists, what it does, fit with eligibility rules, hours of operation and, critically, cost (Turnpenny et al., 2021). Alternatively, in the selection of a personal support worker, caregivers also depend on the availability of

workers, their rates, qualifications and experience and area of coverage.

Most studies, including ours, report on the difficulties of caregivers in finding information on available services, as an immigrant caregiver explained:

> There is a really big lack of communication and awareness of communicating what is out there and what's available to families… I think they should have linguist. They should have multi- language of the newsletter, what is it called… advertising in the newspaper (P8 Family Caregiver).

Uncertainty can be reduced by improving the availability, accessibility and quality of information (Findlay & Damji, 2013; Rodrigues & Glendinning, 2015). From research, it is known that written information, such as leaflets, are considered helpful as is verbal information, particularly when provided by certain professionals or experiential information from other caregivers (Baxter et al., 2011). How information is presented can improve understanding and interpretation (Khanlou et al., 2015a), especially if we consider communities with large immigrant population as is the case of the Greater Toronto Area in Canada.

Recommendations

The elements of a supportive system for caregivers under direct payment are:

> (i) A visible, accessible hub of information providing 'real time', comprehensive information on all current service options including available capacity, linguistic/cultural orientation and cost (Carey et al., 2021; Khanlou et al., 2019; Khanlou et al., 2017; Khanlou et al., 2015a);
>
> (ii) Continued applied research and testing of learning environments, tools and techniques that enable individuals to find and interpret information (e.g., classroom instruction, digital communication) for a broad diversity of caregivers (Fleming et al., 2019; Araten-Bergman, 2023).
>
> (iii) Community supports for families with language barriers/newcomers.

4. Financial Decisions

Financial decisions taken by the caregivers are key elements of a direct payment system. Assuming the desired options are available and accessible, there remains the complex task of aligning the personalized service plan into a budget that fits the funding allocation. Caregivers shared their views about the complexity of the decision-making process:

> Maybe parents might need some support on helping them decide, and some parents might need some support on helping them work out what's best for their kids, maybe that would be helpful. But I think we know what our kids need (P12 Family Caregiver).
>
> I'm not sure whether all the families that have people with disabilities can really understand how to utilize that Passport [program] money at the end of the day… It takes an effort from caregivers to decide how that money is going to be spent and utilized (P14 Family Caregiver).

Caregivers voice their concerns about financial literacy (Khanlou et al., 2019; 2017), an important skill that researchers have tied to people's well-being (Finlayson, 2009). Financial literacy is defined as a "person's capacity for managing money" (Remund, 2010). Zait and Bertea (2014) suggest the definition of financial literacy is complex and multiple with the term implying facets of knowledge, education, ability, competence and responsibility.

The relevance of financial literacy and related knowledge and skills have long been recognized in the field of disability as an essential concept (Kang et al., 2025; Thohari & Rizky, 2021). However, from this perspective, the focus on financial literacy is the individual with a developmental disability, evolving in relation to de-institutionalization and the potential for supported living and employment over several decades. Accordingly, there has grown over time a research agenda that explores the types of knowledge and decision making for household management, for example, (a) using a chequing account (Puli et al., 2024), (b) using an ATM (Scott et al., 2013), or (c) purchasing skills (Xin et al., 2005).

What has not fully emerged in the literature is a robust definition of the 'literacy' required by caregivers to achieve autonomy in choice or control in direct payment, nor research on how to organize and communicate such

learnings to a population of diverse caregivers with large variances in financial knowledge and decision-making. There is research on financial literacy in terms of caregivers making long term plans for the economic future of their family member (e.g., trusts), but 'financial literacy' as a concept in the context of direct payment and the structural requirements for autonomy in direct payment systems requires further exploration.

Recommendations

The elements of a supportive system for caregivers under direct payment are:

(i) Re-contextualizing financial literacy for caregivers that aligns with direct payment knowledge to enhance their deliberative capacity in developing budgets and making purchase decisions (Kang et al., 2025; Thohari & Rizky, 2021);

(ii) Accessible independent support by way of peer mentoring and education/training using a variety of materials and modes (e.g., classroom instruction, computer simulations, on-line communication) which are appropriate and sensitive to the level of financial literacy and characteristics of the caregivers (Pallisera et al., 2021; Rowe & Test, 2012).

(iii) Recognition of unpaid labour of caregivers in managing direct funding and coordination of access for services.

Discussion

Under direct payment systems caregivers are viewed as "co-workers", as "resources" for the system (Turnpenny et al., 2021), responding to neoliberal agendas that aim at prioritizing efficiency in spending (Carey et al., 2021). This has equity implications. We argue that direct payment systems download the work from agencies and service providers to the families, without the necessary support system to help them navigate and manage the process. The system strongly emphasizes individual skills and advocacy, and assumes families have this human capital. There is a lack of recognition that families vary in status (migration, socioeconomic, types and severity of disabilities), and therefore, in their personal resources (e.g. literacy, advocacy). To address inequalities in access and utilization of funding, and individualized family-centred approach is needed.

Direct funding approaches have the potential to strengthen independence and choice with evidence of improvements in satisfaction (individual and family) and well-being (Manthorpe et al., 2015; Turnpenny et al., 2021). However, such positive findings are counter-balanced by less positive factors such as the issues discussed in this article, including complexity of navigating the service system and heavy paperwork load. The evidence indicates implementation success is highly contingent; that local context and system design are crucial determinants in relation to uptake, utilization and outcomes.

Moreover, the context and characteristics of the individual and family mean that the design and implementation of such funding approaches should be flexible and adaptive – one size does not fit all. A 'one size *does not* fill all' approach in direct funding design is critical in relation to a range of personal, socio-economic and other demographic factors. Our research findings show that the direct payment system requires a varied range of knowledge and skills from caregivers, necessitating different aspects of human capital. Autonomy is dependent on the human capital, knowledge, resourcefulness, time, skills and experience of the caregiver.

We found that caregivers need supports to manage their new roles. We argue that in the absence of supports, autonomy is dependent on the human capital attributes of individual caregivers risking substantial inequity in experiences and outcomes. We echo research that highlights how policy reforms that aim at promoting empowerment, through increasing individual's choice and control, may fail if administrative systems do not take into account the existence of structural inequities (Malbon et al., 2019). By failing to do so, systems may reproduce social inequalities. We argue that current applications of direct funding may be creating a two-tier system with such payments being disproportionately utilized by families with high literacy and resources to access and manage direct funding. Furthermore, and in light of the proportion of immigrants to Canada, from non-English and diverse ethno-cultural backgrounds, it is important to understand barriers to developmental disabilities services uptake, utilization and access to direct funding at the intersection of migration status.

It would be inaccurate to suggest that direct payment systems do not provide some information and support

for caregivers to assist in the process of adaptation and learning. Yet, consistent research findings of stress, anxiety, and individuals (as our qualitative interviews demonstrated) who are dissatisfied with the direct payment system, provides evidence of needed accommodation to foster caregivers' autonomy. Furthermore, we echo research findings that highlight caregivers' "need for substantial resilience and determination in navigating the system" when managing direct funding (Turnpenny et al., 2021, p. 59). Findings point at the need for a supportive structure embedded across sectors, to enable caregivers with diverse backgrounds (including socioeconomic status, migration status, gender) and varying levels of human capital to develop and evolve their capacity for autonomy. In the absence of such a support system, direct payments might be reinforcing inequalities in using funding and accessing strategic (and in some cases vital) services for children and youth with developmental disabilities.

Limitations

Our community-based study benefited from a diverse and large sample size of research participants. However, the participants were recruited from a large urban centre in Canada, and we recognize that individuals with developmental disabilities' requirements may differ across settings (e.g., rural areas). There is the need to incorporate individuals with diverse socioeconomic status to further understand the specific barriers faced by marginalized populations. Finally, exploring system solutions is contingent on an understanding of the regulatory and disability funding systems, which differ across provinces in Canada. Our study focused only on the challenges faced by families in Ontario and the Greater Toronto Area. Our findings are specific to this context and cannot be generalized to other regulatory context in other parts of the country. However, we hope the research findings point to solutions to improve family-centred approaches to direct funding for families with children with developmental disabilities.

Conclusion

We conceptualized the critical elements of 'autonomy' within a system of direct payment, and identified the key supports required to support and enable caregivers of people with developmental disabilities. Caregivers in our study call for an approach aligned with supporting an individual with a developmental disability, and also the caregiver who constitutes the essential decision maker for many of these individuals. An individual (with developmental disabilities) is not independent of the collective (caregiver, family, extended networks).

In this paper we provided four categories of recommendations namely: i) transfer of responsibilities, ii) defining need, iii) creation of a personalized service plan, and iv) financial decisions. An individualized family-centred supportive structure, including direct contact persons and support centres to offer information and activities such as service brokerage, peer support, peer mentoring and education and training, is needed to enable caregivers with diverse backgrounds and with varying levels of human capital, to develop and exercise their autonomy. Solutions to accommodate diverse immigrant populations may include funding for culturally sensitive advocacy services to advocate on behalf of people from marginalized groups; support for small community organizations providing workers who can deliver culturally suitable care; peer mentors who can inform other people in their community about their experiences of holding a personal budget; and, for families with language barriers and newcomers ethnoculturally-sensitive community support is needed.

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