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"*Lots of trial and error*": Direct Support Professionals' Perspectives on Supporting the Participation of Adults with Intellectual and Developmental Disabilities

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Abstract

Background: *Participation in everyday life is central to the health and well-being of adults with intellectual and developmental disabilities (IDD). For many adults with IDD, opportunities for participation are shaped by the availability and quality of supports. Direct Support Professionals (DSPs), a key source of formal support, work closely with adults with IDD and play an integral role in supporting their participation in meaningful activities.*

Aim: *The objective of this study was to understand the experiences of DSPs who provide participation support to adults with IDD at one developmental service agency in Ontario, Canada.*

Methods: *Five virtual and in-person focus groups were conducted with 16 DSPs between December 2021 and May 2022. Data were analyzed using thematic analysis.*

Results: *Three main themes were identified that reflect staff experiences, challenges, and needs: (1) "the how of it"—the process of identifying individuals' goals and aspirations; (2) practical challenges in supporting participation; and (3) needs moving forward.*

Impact: *Findings highlight key practice-based insights, including opportunities, challenges, and needs related to DSPs' work in supporting the participation of adults with IDD in everyday life.*

Introduction

People with intellectual and developmental disabilities (IDD) experience lower levels of participation than people without IDD, often spending substantial portions of their day disengaged or in sedentary, home-based, or solitary activities that are limited in scope or dependent on staff support (Verdonschot et al., 2009). Participation in life situations is a core dimension of human health and functioning (World Health Organization [WHO], 2001) and can be further conceptualized as engagement in occupations that are personally meaningful, culturally relevant, and supportive of identity and well-being (Hammell et al., 2008). Importantly, opportunities for participation are shaped not only by personal factors, such as individual abilities and preferences, but also by environmental factors (WHO, 2001). For many adults with IDD, participation is further influenced by the availability and quality of supports (Beadle-Brown et al., 2015; Friedman, 2022), introducing an additional and critical dimension shaping everyday participation.

Participation is often a core outcome for organizations that support adults with IDD (Dean et al., 2016), and staff practices play a pivotal role in enabling—or constraining—everyday participation (Bigby & Beadle-Brown, 2018). Direct Support Professionals (DSPs) work closely with adults with IDD; they assist in identifying preferences and aspirations, translating person-centred plans into action, supporting communication and choice-making, and creating opportunities for involvement in everyday activities and life events (Friedman, 2022,2025).

Despite this important work, DSPs routinely face barriers to supporting participation. Community-level barriers include inaccessible transportation, stigma, and limited availability of inclusive community services (Souto et al., 2024). In response, many DSPs take on advocacy roles when discrimination, exclusion, or systemic barriers limit participation, actively working to facilitate meaningful activities and social inclusion for adults with IDD (Friedman, 2018; Wille et al., 2025). They also navigate diverse relationships and often act as intermediaries between individuals, families, and interdisciplinary teams (Kelley et al., 2024). While these roles can support participation, they may also create tensions related to the autonomy and self-determination of adults with IDD. These tensions contribute to staff uncertainty about professional boundaries and hesitation to initiate or support participation despite its importance (Overwijk et al., 2021). DSPs additionally face workplace barriers, including limited time, competing demands, staffing instability and organizational contexts that do not consistently prioritize participation-focused practices (Friedman, 2018; Wille et al., 2025). Furthermore, Wille and colleagues (2025) suggested that DSPs can feel constrained by limited guidance on how to enact participation-focused support in everyday contexts.

Understanding DSPs' work through a participation lens positions them as a key mechanism for advancing the quality of life and inclusion of adults with IDD (Leser et al., 2018). This perspective shifts attention away from individual, deficit-based explanations of limited participation and toward practice- and systems-level factors (Vincente et al., 2023), framing participation as a shared responsibility of individuals with IDD, staff, organizations, and broader systems (Friedman, 2022). Building the capacity of DSPs to support participation is essential, and much can be learned from those embedded in the daily work of support. Accordingly, the aims of this paper are to: (1) describe the experiences of DSPs supporting the participation of adults with IDD, and (2) identify the opportunities and challenges DSPs encounter in this work.

Methods

Five focus groups were conducted with staff (n = 16) from one Developmental Service Agency in Ontario between December 2021 and May 2022. Focus groups followed a semi-structured interview guide and lasted between 60 and 90 minutes. Discussions were audio-recorded, transcribed verbatim, de-identified, and stored on a secure, password-protected server.

Data were analyzed using reflexive thematic analysis (Braun & Clarke, 2022) and began with repeated reading of all transcripts to support immersion in the data. Two authors (NB, VR) independently conducted inductive coding, focusing on identifying codes relevant to staff experiences of supporting participation in everyday practice. Regular meetings were held to compare coding, identify patterns and refine the analytic focus. Codes were iteratively grouped into preliminary themes, reviewed to ensure coherence and relevance to the study aims and subsequently discussed with co-authors to clarify meaning and strengthen practice relevance. This iterative process resulted in a final set of themes and sub-themes reflecting key experiences, tensions and needs when staff support participation.

Reflexivity was attended to throughout analysis. Authors (NB, SL, LJ, AH) had current or prior professional experience within the participating organization, providing insider knowledge of the service context and supporting a further contextualized interpretation of participants' accounts. Authors (BB, AF, VR, GR) were involved in data collection and analytic discussions, contributing alternative expertise and perspectives (e.g., international alternative and augmentative communication expertise).

Results

Three central themes were identified: 1) *"the how of it*" - the process of determining individuals' goals and aspirations, 2) practical challenges in supporting participation, and 3) needs moving forward.

Table 1: *Themes and Sub-themes*

Themes	**Sub-themes**
1. *"The how of it*" - the process of determining individuals' goals and aspirations	Formal opportunities –Person-centered planning Natural opportunities – Exploring interests in everyday life
2. Practical challenges in supporting participation	"It's a lot of trial and error" – Communication challenges

	"It's my best guess" – Knowing the person Environmental Barriers -Built and Attitudinal
3. Needs moving forward	Continuing to refine the person-centered planning process More staff and more staffing consistency Appropriate funding

Theme 1: *"The how of it"* - The Process of Determining Individual Goals and Aspirations

The first theme focused on the opportunities to help adults with IDD determine and articulate their goals and aspirations. Staff spoke to the formal processes, such as person-centered planning, and also natural, unstructured opportunities where staff and people with IDD explored interests together. Participants identified that the primary formal process at this organization was person-centered planning. Staff noted: "It's annual for every person, but anybody can call a meeting in-between" (SP-3). Participants also emphasized that planning brings together family, people with IDD and staff to build a shared understanding of interests, preferences and supports. Conversations were guided by questions such as "What is working well for you? What isn't working well for you? What things do you like? What things need work?" (SP-7). From a staff perspective, they focused on "What can we do to help them live their best life? What does a good life look like?" (SP-7). Staff stressed that meaningful planning depends on having staff that know the person well, otherwise "it is a total guessing game" (SP-11).

Beyond formal planning, staff described an ongoing responsibility to support everyday choices through more informal or natural opportunities in interactions and activities. This involved exploring interests and engaging in critical self-reflection to ensure that goals reflected what mattered to the person, not staff assumptions: "It's not what's important to me, it's what's important to them" (SP-9). Staff also shared that "everybody is different and learns differently. You need to just have that approach. Just learning about them and what works best with them. I think that is something you should always have in mind" (SP-1).

Theme 2: Practical Challenges in Supporting Participation

The second theme captured challenges related to communication, knowing the person, as well as attitudinal and environmental barriers. Participants shared when they supported people with minimal verbal communication it became a matter of their "*best guess*" whether the person liked participating or not and it was a lot of "*trial and error*". Despite working through communication challenges, there was a strong commitment among staff to try to understand individual communication preferences.

> I'll see what type of communication they have. Whether it's a PECS board, or if they can make choices or pictures, to get an idea of how to communicate

> with them. It all boils down to making sure that they have choice, that they have variety and that they're included. It really is a guessing game and a heavy reliance on staff knowing them so well. It's like a puzzle. It's a mystery picking out what we think is important to them and looking at their reactions. (SP-14)

Another participant noted,

> lots of trial and error. This one time I took him on a ferry, and he sat behind me on the boat the entire time saying, "Bad [Staff]" His file should say 'dislikes ferries'. How in my wildest dreams would I have ever figured that he has never been on a ferry before? What am I going to do? Take him off it? I'm already on it. (SP-7)

DSPs also described environmental barriers and negative public attitudes that limited participation and contributed to feelings of exclusion:

> Environmental barriers… exist out there …and a lot of the people we support need really extensive personal care. Should they need to be changed while we are out, that is often impossible, not just difficult. So that's something of a barrier for us sometimes. You can't always go where you want to go because there's not always facilities to accommodate us. (SP-14)

Beyond built environmental barriers, staff spoke about attitudinal barriers and not feeling accepted in the community, "sometimes people are not very kind. I've been in the grocery store and heard people say, "why do they have those people here?" that kind of thing and they stare." (SP-1)

Theme 3: Needs Moving Forward

The final theme identified priorities to strengthen support for participation. First, staff emphasized the need to refine person-centered planning processes to see "goals that are structured differently … [with] clear guidelines, indicators and benchmarks for what a good life looks like" (SP-3). Also, a clear commitment to centering what is meaningful and feasible to the person with IDD versus externally imposed ideas. Staff reported

> We've been told from our audits that our goals aren't feasible. What is the expectation? …I think comfort goals, getting outside, having things that are important to them are meaningful. But then we'll have the government come and say that's not meaningful, you need to have time, you need to have an expectation of duration, you need to have all these things that are again putting people in boxes and our people are not in that box. (SP-3)

Furthermore, participants shared that to make informed decisions in planning meetings, people with IDD needed opportunities to explore various activities, to understand the available options and programs, to have their communication needs met and to practice decision-making. Staff also indicated a need for "more help in terms of exploring some other areas of potential interest [with people supported] that they maybe aren't thinking of." (SP-6)

Participants also highlighted the need for more staff and more staffing consistency. They reported that quality of care can be improved with more staff, "so that people can have more

individualized care, which would also increase their means of [participation] and communication because their support would be one-on-one" (SP-1). Knowing what people like, what they are interested in, and how they can participate takes time, and a lot of *trial and error.* While increased staffing would support individualized care, consistency was also viewed as essential for relationship-building, communication, and understanding preferences—especially for individuals with complex physical and communication needs. As one participant noted:

> We have 500 staff or more out there, providing care to a range of individuals and it just makes it hard when we need to have different types of qualified staff in different areas. If we could limit that I think it would be better... so that they're not getting someone who is casual who came because somebody called in sick and they haven't worked with them in six months. I can't remember over six months what flavor toothpaste somebody likes or what's really important. It just makes it difficult. (SP-15)

Finally, participants linked staffing challenges to systemic underfunding. This was raised as a critical need to ensure that both staffing and consistent staffing were possible to support participation. DSPs also noted the need for

> Way more… money, … we do what we can within our scope of financial advantage to make them more comfortable in their beds, in their chairs, in the way they can move their bodies. (SP-2)

Participants suggested that more money would help to "have some extra money to do things in the community. With [Disability Support], after paying your rent, they're not left with a lot of money afterwards" (SP-11) in which to access activities and opportunities.

Discussion

This paper explored the experiences of DSPs supporting the participation of adults with IDD, and identified the opportunities and challenges encountered in this work. Consistent with prior research, DSPs described involvement in a wide range of activities aimed at supporting participation aligned with individuals' interests and aspirations (Friedman, 2018). Participation support occurred through both formal mechanisms, such as person-centred planning, and informal, natural opportunities embedded within daily activities. This finding reinforces evidence that participation is shaped not only by formal plans, but by how support is enacted in everyday contexts (Beadle-Brown et al., 2015; Verdonschot et al., 2009).

Importantly, this study extends existing literature by demonstrating that participation support is relational, interpretive, and context-dependent work. Prior research has established that staff practices are among the strongest predictors of engagement and quality-of-life outcomes (Bigby & Beadle-Brown, 2018; van Herwaarden et al., 2025). Our findings illuminate how DSPs operationalize these practices in real time. DSPs described participation as continually negotiated through trial and error, especially when supporting individuals with limited verbal communication. These accounts align with Wille's (2025) work highlighting DSPs' reliance on tacit knowledge and experiential learning. Wille et al. (2025), similarly describes participation-support as relational, practice-dependent, and shaped by organizational conditions. This study extends that work by illustrating how DSPs navigate constraints in real time through advocacy,

"doing with" strategies, and ongoing negotiation across interpersonal and organizational contexts. Participation emerges not as an individual responsibility, but as a shared accomplishment shaped by DSP practices within enabling—or constraining—systems of support.

This interpretive dimension of participation-support remains under-recognised in dominant service and policy frameworks, which often assume that preferences and goals can be clearly articulated, documented, and monitored. In contrast, the Quality of Life Supports Model conceptualizes participation as a supported outcome produced through systems of support enacted at the microsystem level (Gómez et al., 2021). Our findings provide empirical support for this model by illustrating how DSPs translate values, plans, and aspirations into participation through moment-to-moment relational work. Viewed in this way, participation is not a static outcome, but an emergent process shaped through interaction.

The frequent reliance on trial-and-error approaches to understanding interests and preferences underscores the need for stronger support for DSPs, particularly in training on communication and participation support. As McNaughton and colleagues note, "communication provides the foundation for participation in society," (2025, p.259) and access to communication supports (e.g., alternative and augmentative communication [AAC]) "is a critical first step to increased self-determination and community participation." (2025, p. 256) It is therefore essential that staff, as communication partners, have knowledge of AAC systems and skills to be able to provide appropriate communication supports and reduce the need for "best guesses". Related to building capacity around participation-support, integrated approaches such as active support, a support model focused on increasing engagement in meaningful activities and relationships, provide a useful example of how participation can be embedded into everyday practice by shifting staff roles from task completion to graded assistance and shared engagement (Bigby & Beadle-Brown, 2018; van Herwaarden, 2025). Similarly, occupation-based health promotion frameworks such as Do-Live-Well emphasize the importance of everyday activities and activity patterns on overall health and well-being (Moll et al., 2015). More intentional integration of these models into training and practice may help DSPs navigate uncertainty by providing shared principles, a common language and guidance for supporting participation in daily life.

Participants also raised concerns that participation-supportive practices were substantially constrained by organizational and systemic conditions. They identified staffing shortages, scheduling/workforce instability and chronic underfunding as barriers to supporting participation. These findings align with national data in the United States documenting high turnover, limited benefits, and low wages for DSPs (Laws et al., 2024; National Core Indicators, 2024). Importantly, participants emphasized that consistency, not staffing numbers alone, was foundational for participation as it enabled relationship-building, trust, and the development of experiential knowledge required to interpret preferences over time, particularly for individuals with complex communication needs. This supports Friedman's (2025) findings that a stable DSP work force delivered more individualized and person-centered supports; consistent staff knew more about personal needs and wants and were more responsive to those needs.

Organizational models that prioritize efficiency, compliance, and basic care are frequently described as misaligned with participation-focused practice (Bigby, Beadle-Brown & Mansell, 2014). Similar critiques have been identified in work highlighting the influence of environmental context and organizational priorities on DSPs' ability to support engagement in healthy lifestyles (Overwijk et al., 2021). Our findings extend this work by demonstrating how staffing and scheduling challenges are experienced in everyday practice; these challenges limit DSP

discretion and reinforce basic task-oriented routines at the expense of individualized participation. As noted by Johnson and Bagatell (2017), when support is primarily custodial or driven by compliance or efficiency, opportunities for participation are narrowed, reinforcing patterns of passivity and limited choice.

Person-centred planning was identified as the key formal mechanism to support choice-making about participation. DSPs valued the planning processes that centered individuals' goals and aspirations yet raised concerns about externally imposed definitions of what constitutes "meaningful" or "feasible". These tensions reflect critiques that regulatory and audit frameworks often privilege measurable outputs over lived experience and quality of life (Friedman, 2022; Gómez et al., 2021). Without alignment between policy expectations and relational practice, planning processes may inadvertently constrain participation by narrowing what is possible and subsequently, the range of goals that are considered legitimate.

This study focused on DSP perspectives within a single developmental service agency in Ontario and allowed for an in-depth exploration of DSP experiences within a specific geographical and organizational context. The perspectives of people with IDD and family members were not included and would provide important additional insight into participation as a relational and shared process. Future research should examine DSP experiences across diverse service models, regions, and funding contexts, and incorporate the perspectives of people with IDD and families to inform the co-development of participation-focused supports grounded in lived experience.

Overall, this study underscores the important role DSPs play in creating the conditions for meaningful participation in everyday life. The findings highlight participation-supportive work as skilled, relational, and essential, and point to the need for sustained investment in workforce capacity, staffing stability, training, and organizational prioritization of participation. Strengthening these conditions are central to advancing opportunities for meaningful participation for adults with IDD.

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