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# Participation at home of adults with multiple disabilities and influencing factors from their parents' perspective

**Running head:** Participation of adults with multiple disabilities

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**Implications for Rehabilitation**

- Despite the assistance required to carry out all activities at home, adults with multiple disabilities can be involved on a daily basis according to their residual abilities.
- Rehabilitation professionals should be sensitive to non-verbal communication as it has been identified by the parents as the main indicator of participation and involvement.
- Rehabilitation professionals should pay attention to gestures, sounds and facial expressions of adults with multiple disabilities.
- Rehabilitation professionals should consider context of realization (e.g. location, time) of activities as it contributes to make these meaningful and to forge stronger bonds with those interacting within these activities.

**Participation at home of adults with multiple disabilities and influencing factors from their parents' perspective**

Abstract

**Purpose:** To understand participation at home of adults with multiple disabilities and the indicators of their engagement from the parents' perspective as well as to explore the influencing environmental factors.

**Methods:** A qualitative, descriptive design was used. Participants had to be the parent of an adult presenting multiple disabilities aged between 21 and 65 with no degenerative diagnosis. Semi-structured interviews were conducted using an interview guide, anchored in the Human Development Model - Disability Creation Process and developed through an iterative process. Data were analyzed using a 6-step qualitative analysis process.

**Results:** The majority (5/8) of participating parents were aged between 56 and 61 years and were the parents of an adult with multiple disabilities aged between 21 and 41. Two themes for participation were generated: *communication to build relationships*, and *they are disabled, but not so much* whereas four themes relating to environmental factors were generated: *context as a determinant of meaningful activity*, *the effects of the caregiver's attitude on social participation*, the *importance of the relationship of trust*, and *facilitating participation through adaptations*.

**Conclusion**: Non-verbal communication and context of realization of activities of adults with multiple disabilities should be considered as they contribute to making participation meaningful.

**Key words:** Participation; Adults with multiple disabilities, Parents' perspective, Indicators of engagement, Qualitative study

## Background

It is estimated that 16% (1 in 6) of the worldwide population experience significant disability (1). However, the definition of what is meant by ‘significant disability’ is not readily available. In the context of this study, the definition of multiple disabilities used was "a severe disability with multiple expression associating motor impairment and severe or profound mental impairment" (2). Despite the presence of definitions of multiple disabilities, its prevalence in the adult population is unclear as the statistics currently available include also a variety of other diagnoses such as Down's syndrome, autism, Asperger's syndrome, intellectual disability due to lack of oxygen, etc. (3). These people will often present with a variety of medical conditions affecting different systems, making the evolution of their condition difficult to predict and resulting in constant and complex needs (4-6). People with multiple disabilities are typically dependent on their relatives to obtain stimulation, to participate in activities and to carry out their basic care (7, 8). From an outsider's perspective, people with multiple disabilities may give the impression of not being engaged in activity and appear passive(9). This can, among other things, be attributed to communication difficulties that can prevent them from naming what they want to do and naming the level of support they need at a specific time for a specific activity (7, 10).

Structural factors such as policies put in place by local governments may contribute to health inequities faced by people with disabilities (1). In Quebec, Canada, people with disabilities may attend school up to the age of 21. After that, very few options are available to families: staying at home with the person over the age of 21, enrolling the person in a day activity center or placing the person in an institution (5, 6, 11). Each of these options has disadvantages and does not fully meet the needs of adults with multiple disabilities and their families (5, 6). This transition after the age of 21 is often characterized with decreased social participation, restricted social interaction and few available specialized rehabilitation services

(11). Indeed, in specialized schools attended before the age of 21, the person with multiple disabilities is in constant interaction with other disabled young people and with typically developing adults (11). In younger age, children with multiple disabilities have easy access to rehabilitation services and to specialized schools, which is not the case from age 21 onwards (11). These changes increase the risk that the person with multiple disabilities will lose physical, cognitive and functional gains, experience loneliness, boredom and anxiety, and exhibit more challenging behaviors (11).

Few evidences on this topic are readily available. A quick review undertaken in November 2022 using the following search strategy in the Medline and Embase databases: *(((social or home or public or community) adj2 (participation or engagement or citizenship)).ab,kf,ti. OR Social Participation/) AND ((multipl# adj1 (disab* or handicap*)).ab,kf,ti.)* led to 15 results in Medline and to 28 results in Embase. The search was run again in December 2024 and although a systematic review and meta analysis was published in 2023 (12), authors conclude further research is needed. Indeed, of the articles obtained through the search strategy, several studies concerned children with multiple disabilities rather than adults with multiple disabilities (13-19). Most of the studies carried out are on a very specific topic related to multiple disabilities, such as education and pedagogy for students with multiple disabilities, social and professional integration services for adults with multiple disabilities, and the most effective practices for the development of children with multiple disabilities (5, 6, 20, 21). According to Gauthier-Boudreault and collaborators (11), the social participation and inclusion of people with multiple disabilities are topics increasingly addressed in research, which contributes to their recognition, and thus to fostering the development of assistance and support structures to meet their multiple needs.

Various federal and provincial laws and policies are in place to ensure the rights of people with disabilities to participate fully in their daily lives (22, 23). Social participation and

engagement in activities of daily living and social roles are essential to the quality of life of people with multiple disabilities (11, 23, 24). Social participation contributes to a person's development and well-being by providing varied opportunities (11). Given the severe disabilities described in the definition of multiple disabilities, the preconception that it would be impossible for an adult with multiple disabilities to have optimal participation would be understandable (11, 23). Nevertheless, through the help received and interactions with loved ones and caregivers, it is possible to have optimal participation (9, 25). Indeed, optimal participation can be achieved, even when a health condition has consequences on the person, as participation, defined as the level of activity and roles actually realised, becomes optimal when there is a perfect match between this level of realisation and the expectations (26).

Munde and collaborators (10) carried out a literature review of articles published between January 1993 and December 2007 (n=42) and found several elements allowing us to understand how the level of arousal can influence the participation of people with multiple disabilities. Firstly, the level of arousal is explained as a manifest and observable state in the person's behavior. The level of arousal is a result of the interaction between the person and their environment. Thus, disengagement from activities, especially group activities, may be influenced by the fact that multiple disabilities are different for each individual, and that multiple disabilities may prevent standard verbal communication. This diversified communication can create additional difficulties for family members and caregivers trying to optimize the person's participation. In addition to the level of arousal, several other elements are identified as barriers to the social participation of people with multiple disabilities such as the constant need for human support (23), the limited knowledge of caregivers and the fact that they prioritize their own preferences (23), the fact that the social network is mainly made up of caregivers, family members and other adults with disabilities in the same environments (11, 27) and the fact that people with multiple disabilities do not express their needs, choices and

emotions on a regular basis (11, 27-29). Thus, people with multiple disabilities would have fewer opportunities for participation in both leisure activities and activities of daily living such as personal care (9, 11, 28). Furthermore, these people, because of their communication difficulties, are more likely to be less involved in research, similarly to people with aphasia (30), which may contribute to explain the paucity of evidences concerning them. One strategy to overcome this is to give a voice to their relatives who live with them on a daily basis to share their perspective (31).

**Conceptual model**

We used the Human Development Model – Disability Creation Process (HDM-DCP) (32) as a lens to approach our research questions. According to the HDM-DCP, the level of realization of life habits (daily activities and social roles) can be influenced as much by personal factors as by environmental factors, not forgetting the possible inter-influence of life habits between them. All of these elements determine where a person is on the continuum from *social participation* to *disabling situation* (32). Thus, a person is in a *disabling* situation when their environment (social and physical) is not in line with their personal characteristics, which prevents them from carrying out their life habits as they wish, or in the same way as others. A life habit is described as a daily activity or role that is valued by the individual or by their socio-cultural context, depending on their characteristics (e.g., age, gender, socio-cultural identity), and that ensures survival (e.g., nutrition, sleep, excretory and bodily hygiene, etc.) and the individual's fulfillment in society (e.g., interpersonal relationships, community life, leisure activities, etc.). In short, according to this model, participation can be optimized through actions on the current situation targeting the individual's personal factors, environmental factors (extrinsic factors: social and physical factors) and life habits (32), or through actions on expectations (acceptable or desired way in which activities and roles are realized).

## Research question and study objectives

Thus, in the context of this study, the research question was as follows: From the parents' perspective, what is the level of engagement of adults with multiple disabilities at home, and what factors influence it? The primary objective was to understand participation at home of adults with multiple disabilities and the indicators demonstrating their engagement from the parents' perspective. The secondary objective was to explore the environmental factors that influenced this engagement.

## Methods

### *Study design*

We used a qualitative descriptive design, inspired by a constructivist paradigm to explore each participant's reality and experience (33-36). As such, our aim was to understand what participation of the adult with multiple disabilities meant for the parent's perspective assuming that although each experience may show singular characteristics, reality may also be constructed over time and shared across participants (36). Meanwhile, although using a design inspired by a constructivist paradigm, we were also influenced by a postpositivist orientation as we deliberately choose to anchor the interview guide in a conceptual model. This decision was made as the first two authors were novice in research and it was deemed relevant to use such a conceptual model to support the data collection process considering that combining complementary perspectives may be justified to enrich the understanding of a complex phenomenon (37). However, efforts were made in data analysis to move away from the terminology of this conceptual model to code the data using the words of the participants.

### *Recruitment and selection of participants*

The parents were recruited from a community organization located in Quebec, Canada that offers services to people of all ages and all types of disabilities (physical, intellectual or

autism spectrum). The purposive sampling method was chosen to recruit participants. Study participants were recruited through targeted contacts (key informants) identified by the community organization's day activity coordinator. In order to be included in the study, the parent had to: (1) be able to express themselves in either French or English and (2) have custody of an adult with multiple disabilities who was between 21 and 65 years of age (to be considered as an 'adult' and not an 'older adult' and 21 being the age where school ends where the study took place). The adult with multiple disabilities also had to present physical and intellectual disabilities, be registered or waiting for services at the collaborating community organization and not present any associated degenerative diagnosis (e.g., dementia). There were no additional exclusion criteria.

*Sample size*

The targeted sample size was between 5 and 10 participants. This choice was based on the research specification and the feasibility of the project (38).

*Collecting data*

Data were collected by means of individual interviews by the second author who is fluent in French. These interviews took place face-to-face, in French, in a conference room at the collaboration Community Centre or via videoconference on the TEAMS platform. Parents' perspectives were obtained using a semi-structured interview lasting 60 to 80 minutes, which is consistent with the type of design used (34). The interview guide (see Supplemental file) enabled a deeper understanding of the phenomenon of interest, while considering that there are individual variations (34). The content of the guide was anchored in the study's conceptual model (39). It included two main themes 1) participation (e.g., 12 categories of the conceptual model) of the adult with multiple disabilities from the perspective of the parent, with examples of probes being a typical day, in-depth description activities' realisation, challenges encountered, best and worst part of a day, communicational

strategies and 2) characteristics of the environment, with probes on the perceived influence of the physical and social environments as defined by the conceptual model or an ideal world. The interview guide was developed using an iterative process, i.e. back and forth based on discussions between members of the research team, each person's expertise (occupational therapy, multiple disabilities, qualitative design) and the literature consulted. At the end of each individual interview, socio-demographic data about adults with multiple disabilities and their parents were collected (see tables 1 and 2).

The audio content of interviews was transcribed verbatim. Notes on first impressions (in the form of on-the-spot summaries) were taken after each interview (33) by the interviewer. A logbook was kept to record the interviewer's impressions during data collection and the team's various reflections during data analysis. Data collection and analysis were conducted in French. Only the content included in the write up (themes, subthemes and excerpts) were translated in English using Deepl and further checked for its quality and accuracy by the last author who is fully bilingual.

*Data analysis*

The process of the thematic (40) qualitative analysis served to make sense of the textual data obtained from the interviews, with the aim of generating a synthesis of the phenomenon of interest (35). Data collection and analysis informed each other iteratively. Thus, transcription took place after each interview so that the analysis of the transcripts could begin, and ideas developed during the initial interviews could be incorporated into subsequent data collection (33). It was important to consider similarities in the data, i.e. recurring themes generated in the interviews, but also differences (35).

At the data analysis stage, the two first authors coded the interview data independently. The first author has expertise with the clientele of adults with multiple disabilities as she worked during her occupational therapy training at the center where data

collection took place. The second author, who was also completing her professional master's occupational therapy training at the time of the study, conducted all the interviews under the guidance of the last author who is a senior academic occupational therapist with extensive experience in qualitative research. The first and second author generated categories and themes. These results were discussed within the full team in an iterative process, through multiple meetings, until a consensus was reached. An effort was made to move away from the terminology of the conceptual model in which the interview guide was anchored to use the participants' words for coding. A six-stage thematic qualitative analysis was carried out (34, 41, 42): 1) Transcription using Amberscript with quality checked by second author; 2) Data familiarization by all the authors; 3) Coding by the first and second author using QDA miner data management software; 4) Identify categories and themes relevant to the two study objectives; 5) Identify an organizational data structure; and 6) Defining and naming themes. Steps 4 to 6 were accomplished by all the authors through multiple meetings.

*Scientific rigor*

The research methodology was built around the standards for reporting qualitative research. The COREQ (*consolidated criteria for reporting qualitative research*) (43) and SRQS (*standards for reporting qualitative research*) (43) grids were consulted in order to meet the criteria of scientific rigor. The topic was considered worthy (44) as not many studies on this topic were found. Scientific rigor was favoured through the inclusion of contextual information on the underlying conceptual model used, participants' selection and the process of data collection. Steps of data analysis was thoroughly described and multiple excerpts were included to contribute to credibility. Sincerity was addressed with a description of the research team personal characteristics and more specifically on the interviewer. The transferability of results was ensured by the detailed description of participants and subjects of interest.

*Ethical considerations*

The first contact with the families was made once approval had been received from the University of Montreal's Health and Science Research Ethics Committee (CERSES-2022-4043, approval obtained on 2023-02-01) and the collaborating Community Centre's Board of Directors. Written informed consent was obtained before data collection.

## Results

*Sample description*

The sample consisted of eight participants and seven interviews (as two parents were present for adult 2 and were interviewed together), all of whom were parents of an adult with multiple disabilities (see table 1). The majority (5/7) of adults with multiple disabilities included in the study were in their twenties (see table 1), with a variety of physical and intellectual diagnoses. The characteristics of the parents who took part in the study were relatively homogeneous (see table 2). The majority (5/8) were between 56 and 61 years of age and five (/8) were the mother. They all had French as their mother tongue and owned their own home. The level of schooling was half and half high school and college levels. Four (4/8) had full-time jobs. Three (3/8) had an employment or were retired from a job in the healthcare sector at the time of the interview. The majority (6/8) had a familial income of over $90,000 (Canadian Dollars).

(Insert table 2 and 3 about here)

*Results related to the main objective of the study*

To meet the main objective of the study, namely to understand the participation of adults with multiple disabilities at home and the indicators that demonstrate that they are engaged from the parents' perspective, two main themes were generated, namely (1) *communication to build relationships* with sub-themes (a) *communication methods,* (b)

*making one's needs understood* and (c) *non-verbal: the main indicator of engagement and participation* and (2) *disabled, but not so much* with sub-themes (a) *totally dependent* versus (b) *participates in most steps.*

**Theme 1: Communication to build relationships**

*(a) Communication methods*

Parents reported that their child's verbal communication skills were limited; 6/7 adults with multiple disabilities could verbalize certain key words (e.g., yes, no, pee, juice, etc.), but could not say complete sentences. These words may be familiar to family and friends, but difficult to understand for a new person (e.g., caretaker, home services staff). As reported by Parent 2:

> '*She says words, but they're not always understandable by people. We know her. When you know what she goes through every day, it's easier to understand her. When her caretaker started, she kept asking me 'what's she saying?', but now she doesn't ask me because she's always with her… So she ends up making herself understood to a certain extent with the people she knows […] with her ability to say a few words, gestures and then using the tablet... But sometimes we talk to her, and then we don't understand right away. Sometimes I understand the week after.*'

In addition, the type of alternative communication can vary. Not only do pictograms enable adults with multiple disabilities to point out their needs and identify their emotions, they also helped structure daily routines, which in turn encouraged their involvement at home. In fact, pictograms were perceived as encouraging the active participation of adults with multiple disabilities by providing a sequence to follow. According to parents, this tool had proved useful when it was difficult for their child to initiate a task. There were also programs on the electronic tablet that could be used to add pictures associated with

predetermined sentences to make a request, such as ‘Can you help me change my sanitary towel?’. However, the use of pictograms as a communication tool was perceived as being influenced by the person's ability to learn and understand. This was also the case for animated hands, which needed to be learned and reproduced in time to express a need. For example, Parent 3 said ‘*We tried these things* [referring to pictograms and the communication tablet], *then in the end it didn't work. He's not there, he's really not there... At some point, we went for the day-to-day. Yes and no are very important. When you want to know something, most of the time you get answers’*. And Parent 4: ‘*It didn't work* [talking about the communication tablet]... *She didn't understand the connection. She could push on something, but was that really what she wanted, we didn't know’.* This subtheme illustrates parents’ level of confidence and barriers encountered with different communication methods relying on technology.

*(b) Make one’s needs understood*

It can be difficult for parents or carers to understand the needs of adults with multiple disabilities, which may also reduce their ability to make choices in the activities they carry out. Indeed, most parents reported having to guess what their child was trying to tell them. As a result, the parent often had to interpret the needs expressed by the adults with multiple disabilities. For example, Parent 4 said ‘*To communicate that she wants to eat, she'll knock. She knocks to show us that she's hungry... If she wants to make another request, we have to guess, that's what happens... That's what's difficult, it's communication.* [Adult 4] *is not able to say what she needs*’. Whereas Parent 6 mentioned: ‘*I must confess that we've been anticipating her needs ever since she was a little girl, because she's never been able to express them*’. One strategy parents used to communicate with their children was to ask them yes/no questions. This is perceived to encourage their child to participate in daily life by making choices and interacting with their environment. Parent 3: ‘*Otherwise, you present him*

*with an object. For example, for 'Do you want a drink?' I present his bottle and if he pushes it it's because he doesn't want it'*.; Parent 7: '*Then*, *he learned to show things. Let's say he wants something, you don't understand, he'll go and show you to say he wants milk. If you're not sure, he'll go and open the fridge*'. However, this is not realized without difficulty as expressed by Parent 6: '*I would tell you that if we present her with two toys, we'll show her both toys and she can make the choice, but I don't even know how much she understands that*'. This subtheme also highlights parents' attitude and willingness to empower their child as much as possible, although communication remain a major barrier.

*(c) Non-verbal: the main indicator of engagement and participation*

Non-verbal communication was identified as one way in which adults with multiple disabilities can communicate with their social environment (e.g., parents, siblings, home care staff, caretaker, etc.). Gestures (e.g., thumbs up to say yes, thumbs down to say no), sounds and facial expressions let parents know whether the activity is appreciated or not. In the following extract, the parent explained how the tone of the sound helped them to understand what adults with multiple disabilities wanted to communicate: '*That's for sure, when we put these on* [talking about orthotics], *she's less happy. It seems so, because the sounds that come out of her mouth aren't sounds of joy, they're more like whining.'* (Parent 6). Thus, non-verbal communication was identified as a way for them to express their refusal or pleasure in the activity. This was a point made by all participating parents. For example, the mood of an adult with multiple disabilities is very much transmitted through non-verbal communication: '*On the other hand*, [Adult 3] *is also very moody. If he's not happy or if he's very happy, he'll show it a lot physically'* (Parent 3). More specifically, several indicators of engagement were raised by the parents. Despite a certain diversity in their expression, the same non-verbal signs were reported: facial expressions, smiling, gestures, sound noises (e.g., cries of joy, laughter), crying and disorganization (e.g., throwing a tantrum). Depending on the context of

the activity, these indicators of engagement can have positive or negative connotations. First of all, parents described adults with multiple disabilities as very expressive. They explained that they see it in their faces and their reaction when they are interested in engaging in the proposed activity. In the following transcript, the parent described her son's reaction to an activity he enjoyed: '*Physically, you see directly. He laughs. ... He has a smile on his face. He becomes vocal. He's really happy… It's by his reaction.*' (Parent 3) or '*She gives me a wicked smile and goes off laughing… To take a shower, she would cry with anyone; me, my husband, my two caretakers*' (Parent 4). Another indicator of engagement, more specific to meaningful activities, was that of being fully engaged in the activity to the point of ignoring their environment and forgetting the notion of time, spending hours listening to music or on the computer: '*He's really into the task, and you can see he's concentrating. Then he even forgets about everything else in the environment while he's doing these tasks*' (Parent 5). One challenge faced by parents was to detect the expression of bodily sensations (e.g., pain, fatigue, irritability) by the adults with multiple disabilities that might explain their lack of engagement or behavior: '*We don't know what's going on inside him. If he could verbalize that this morning it's not working because his head hurts or his back hurts, that would help.*' (Parent 3). Thus, the non-verbal cues are key in communicating.

**Theme 2: Disabled, but not so much**

According to parents, the participation and involvement of adults with multiple disabilities in different activities varied according to their physical and intellectual condition. For example, if the diagnosis that most influenced participation was intellectual, the adults with multiple disabilities may have residual physical ability to perform the task, but need more help with the sequence and understanding of the task: '*She doesn't wash herself, we wash her. She has too big of an intellectual delay do it. If you give her a washcloth and tell her to wash herself, she's not going to understand what it is*' (Parent 4). On the other hand,

for an adult with multiple disabilities whose most influential diagnosis was physical (e.g., presence of spasticity, reduced range of motion, fine motor difficulties), it may be more difficult to perform the movements required to complete the task. The caregiver's physical support is then needed to complete the tasks: '*The pants, I've never found the trick. He's too stiff to participate for pants and bottoms, but the sweater or when we put the coat on and when we take it off he'll participate*' (Parent 3). During the interviews, all parents reported that their child required assistance. The level of assistance required varied according to the activity realized and the limitations of adults with multiple disabilities. Parents reported that 5/7 adults with multiple disabilities received physical assistance with dressing. The other two sometimes required verbal reminders to initiate the task. Six (6/7) received physical assistance for hygiene care in the shower, while only one realized the activity without human assistance, using technical aids. The majority of parents mentioned that, in their opinion, their child was unable to wash effectively without human assistance: '*He doesn't take his bath alone... I have to run his water for him. He gets into the bath and I have to wash him… It would be useless gestures and he would do that* [father gestures to put his hands-on different parts of his body]' (Parent 5). But the level of assistance provided was different depending on the activity, on the context and the residual abilities.

*(a) Totally dependent*

In response to the question "*Can you describe me, with concrete examples, what you do to help your child with tasks he or she cannot do alone?*", parents spontaneously tended to answer that their child was totally dependent. For example, '*Look, we do a lot of everything. He doesn't do much... Yes, he lifts his arm, but he can't wash himself*' (Parent 3) or '*My partner dresses her completely.* [Adult 4] *is really severely disabled. She's not capable*' (Parent 4).

*(b) Participate in most steps*

Nonetheless, when parents were asked to deconstruct the task of dressing, they described how they used their child's residual abilities to promote participation at home. Some adults with multiple disabilities may, according to the parents, finalize the task that was started by the caregiver, while others may initiate the task that will be completed by the caregiver. For example:

'*Yes, he's cooperating. He'll lift his arms, but I have to do all the dressing. Undressing is easier. He can take off his sweater. Sometimes, if the sweater's too tight, he needs a little help, but yes, he can do that. He can pull his pants down and up, but sometimes you have to finish the job. He'll try to pull up his socks and slippers*' (Parent 1) or

'*She's able to take off her sweater, but she gets help getting her pants down. She does a push-up on the wheelchair or she holds on to our necks to get us to pull down her pants because she's not able to put any weight on her legs, but she's able to take off the rest when it's below the knee. She can take off her stockings and shoes. For dressing, she can put on her pyjama top or sweater by herself, but we help her with the bottoms. She'll put on her pants up to her knees and we'll help her with the rest*' (Parent 2) or

'*He's learned to put on his sweater. I present the sweater to him in a certain way. Of course, if I give him the sweater just like that, he doesn't know where the back is, but if I present the sweater to him in a certain way, he's able to take it and to put it on. To take it off, I just have to help him a little, but the rest is all up to him*' (Parent 3) or

'*When he puts on his shoes or boots, it's definitely not like the rest of us. In the sense that he has to sit on the ground. He won't stand up. He doesn't have the balance for that... He puts his pants on the floor or on the bed*' (Parent 5).

Interviews revealed that the majority of adults with multiple disabilities performed the activity of meal-taking with partial human assistance, except for one who was enteral fed. Several parents reported that they cut the food into small pieces beforehand, to avoid the risk of choking on large mouthfuls. Nevertheless, some adults with multiple disabilities have preserved their ability to participate in the task: '*She eats by herself, but we'll cut it into smaller pieces. If it's easy stuff, she'll start cutting her sausage, for example, but it's going to be hard, so that's why we help her most of the time*' (Parent 2) or

'*Traditional things like sandwiches, pizza and hamburgers she eats with her hands... You have to give her a few pieces at a time, because if you don't, if you put the whole toast on her plate, she'll eat the whole toast. Otherwise, she'll eat with an adapted spoon. Often, you have to go through the motions with her*' (Parent 4) or

'*His hands have become more movable. Now he can hold utensils very well. He cuts his food. Sometimes, it flies back. He doesn't have the finesse, but he has the gesture*' (Parent 7). These quotes providing thorough description of how activities are realized truly support the fact that they are participating in most steps of the task.

*Results related to the study's secondary objective*

To address the secondary objective of exploring the environmental factors that influence home participation of adults with multiple disabilities from the parents' perspective, 4 main themes were generated, namely (1) *context: a determinant of meaningful activity*, (2) *the effects of the caregiver's attitude on social participation*, (3) *the importance of the*

*relationship of trust*, with (a) *lack of staff stability* as a sub-theme, and (4) *facilitating participation through adaptations*, which comprises 5 sub-themes, namely (a) *home adaptations,* (b) *technical aids,* (c) *medication,* (d) *climate,* and (e) *music*.

**Theme 1: Context: a determinant of meaningful activity**

According to parents, meaningful activities played an important role in the daily lives of adults with multiple disabilities, and were highly varied, depending on their interests. All the parents mentioned at least one meaningful activity that gave their child a moment of pleasure. However, what made it meaningful was above all the context of the activity. For example, watching a film in the living room with family members would not have the same relaxing effect as watching it alone in the bedroom. Indeed, during our interviews, many parents reported that their child needed a moment alone to recharge batteries, especially after spending the day at the day-care center. For example,

> '*In the evening,* [Adult 4] *listens to his own films in his room. At one point, we'd take him downstairs with the rest of us to watch TV, but he likes to be in his room, in his little things, and then he listens to his movies*.' (Parent 4);

'*She has her big room where she spends a lot of time, not because we want, but she likes it. She has all her electronic devices like her television.*' (Parent 2); In the excerpt below, the parent describes how, in his opinion, it is the way in which the activity is carried out that makes it meaningful. Indeed, during the week, the people who come home to assist with hygiene don't take time to play with him, unlike his mother on weekends:

> '*So he sits down and collaborates very well. He loves water. The girls wash him. I give him a bath, often on Sundays, because he loves water. On Sundays, he's at the bottom of the bath and not on the transfer bench. That's where he plays. I let him enjoy himself. That's his pleasure.'* (Parent 1).

One of the parents explained how the use of electronic devices has a positive effect on the adults with multiple disabilities' sense of competence, helping to make this activity meaningful: '*He's someone who really likes the computer. He's developed skills with it. My phone belongs to him when he's with me. He goes for walks to takes photos. He makes albums. After that, he puts them on his tablet and his TV.*' (Parent 7). Even if the activity is greatly appreciated, parents have noted that it's important to respect their child's level of energy and endurance, otherwise it can become unpleasant:

> '*As I was telling you, before this whole thing* [talking about the temporary placement during the pandemic that led to a significant loss of physical abilities], *he could be in the pool for 2 hours. He'd get tired afterwards, but last summer, when we'd put him in the pool for 2 hours, he'd get out and he wouldn't be in a good mood. He was probably too tired. Now I leave him in for 1h-1h15 and then take him out*.' (Parent 3).

For some adults with multiple disabilities, music is also an opportunity to strengthen ties with their parents. For example, knowing that it's an activity their child enjoys, some parents will use their own passion for music to connect: '*His father was a bit of a musician to him. He plays the tam-tam with drumsticks. Tam-tam*, [Adult 1], *he loves it. He loves music*'. (Parent 1). Activities are thus meaningful mainly because of the context of their realization more than for the activity in itself.

**Theme 2: The effects of the caregiver's attitude on social participation**

The attitude of the caregiver (e.g., parent, personnel, caretaker) can affect the level of social participation of the adults with multiple disabilities at home. Indeed, the way in which the caregiver interacts with adults with multiple disabilities may influence their engagement in the task. Taking the time to explain the task to be performed would be a strategy that favors participation:

‘*When her father takes her into bed, he lifts her up, but* [Adult 4]*, if you make her understand, that you lower the bed, and ask her to sit down, she understands and she sits down. [...] It's about taking the time to do it. For my husband, it's easier to do it for her, but he doesn't take the time to let her do it. [...] I've always guided her with instructions, because she's grown up so much. I take my time to explain and then I try to make her understand. I realize that she understands more than before. I try to get her to touch things to make her understand, but you have to take your time with her. You can't rush her*.’ (Parent 4).

Furthermore, the caregiver's attitude would have an influence not only on the social participation of the adults with multiple disabilities, but also on indicators of engagement. Indeed, when the context of the task is conducive to a pleasant moment (e.g., turning the task into a game, singing, playing music), the adults with multiple disabilities would be more likely to smile, be in a good mood and display nonverbal excitement. As a result, they would be more likely to cooperate with the activity. Conversely, if the child feels rushed or pressured by the parent or caregiver, a disorganization is likely to occur. For example:

‘*Making her eat breakfast, it was difficult. Her father insisted so much on making her eat that the teacher at school said she was all unhinged. [...] She spent her time crying afterwards. I do it differently from him. I always come up with a little story, I sing with her, I hum. [...] I have fun with her’*. (Parent 4).

Here’s is a second example when the adult felt rushed during the morning routine: *‘She's screaming. She's tired. She doesn't feel like putting on her shin braces. She turns one way, then the other. It doesn't work the way my husband wants*.’ (Parent 4). Thus, the notion of time (time available) and the explanations given can influence the level of social participation.

On a different note, the parent's employment status (full-time, retired) and age can influence their availability to care for the adult with multiple disabilities, which may require the use of health care services (e.g., assistance from home care services) or the hiring of a caretaker. The following section highlights how staff turnover can affect the participation of adults with multiple disabilities at home.

**Theme 3: The importance of a relationship of trust**

As adults with multiple disabilities need a great deal of help to carry out most of their daily activities, the social environment around them is very important in enabling them to engage in the activity and participate fully according to their abilities. A relationship of trust between the adults with multiple disabilities and the caregiver was found to be a key factor in facilitating participation. For example, one parent explained that his child will agree to do activities with a particular caregiver, but will refuse to take part in the same activity if it's another person who asks him to do it: '*Like with [Name of caretaker], she works with him, she participates with him. [...] I know that with [Name of caretaker], they trust each other. They know each other, they do their own thing*.' (Parent 7).

*(a) Lack of staff stability*

The high staff turnover in homecare services was perceive as an obstacle to the adults with multiple disabilities' involvement in the home and to the development of a relationship of trust. Staff may not have the time to learn the routine, may be under considerable time pressure and may not know well the adult with multiple disabilities. The lack of familiarity may also decrease the employee's ability to manage the adult's mood effectively: '*What helps is when it's always the same person, that's clear... It means that the person knows him and isn't impressed by his mood swings*.' (Parent 3). To improve this stability, many parents opted for the governmental subsidy, which enabled them to find caretakers who can better meet their needs and those of their child. In fact, with one or two caretakes working several

hours a week, it's possible to create a bond of trust that will have a positive influence on the adult's behavior, and thus optimize their participation and commitment. For one family, these caretakes are retired people who have been recruited, and for another, it's the brother of Adult 6: '*One of our caretakers is in her forties and the other is 69 ... My daughter, she hugs her so much that sometimes she's almost getting into her sweater. She's a grandma, and she loves her a lot*'. (Parent 4);

> '*The public home care services doesn't come at all anymore. It's* [Brother's name] *who does that work with the governmental subsidy, which gives us 30 hours a week. The difference is that she loves her brother very much and that's also constant. Basically, if she has a rash somewhere, it's never the same person, whereas when it's* [Brother's name]*, he knows her well, she's his sister, so he's pretty alert to that*.' (Parent 6).

Thus, relationship with the caregiver is key and is also part of context, contributing to meaningfulness of an activity.

**Theme 4: Facilitating participation through adaptations**

*(a) Home adaptations*

An adapted physical environment was found to be a facilitator that enabled adults with multiple disabilities to use their residual abilities to the full extent, and thus to participate in various activities at home: '*Now, at 22,* [Adult 7] *is able to wash himself, but he has a bathroom adapted obviously*.' (Parent 7); '*Given that our house is adapted now, he doesn't have too many difficulties*.' (Parent 3). Home adaptations will mainly target the rooms in which the adults with multiple disabilities use to participate in daily activities. For example, the majority (6/7) of families have a bathroom that has been adapted to the needs of the adults with multiple disabilities. These adaptations included a threshold-free shower and

various technical aids (e.g., raised toilet, bath transfer bench, shower bench, grab bar and hand-held shower head):

> '*The toilet is high enough for her. It's an adapted toilet. It's at the height of her wheelchair seat. To get on, it's pretty easy for her and it's pretty safe because she's holding her wheelchair arm and then the grab bar so she's able to slide off.*' (Parent 2).

Many families (4/7) lived in a single-storey home, or have a platform lift that enabled the adults with multiple disabilities to move safely between rooms in the house without human assistance: '*We have French doors and everything is on the same level. We eliminated the stairs in the living room […] so there's no danger for her*.' (Parent 4); '*The patio door isn't flush with the floor. If one day we change it, I'll make it that way, but for now, he can't go out by himself*.' (Parent 3). Thus, widening door frames and lowering door thresholds also made moving around easier.

*(b) Technical aids*

To facilitate the full participation of adults with multiple disabilities, a number of technical aids were used on a daily basis to help with eating or dressing, for example: '*He eats his yogurt by himself. He eats with his adapted spoon because it has a big handle. [...] Because his grip is difficult. I put a little non-slip mat under his yogurt or plate*.' (Parent 1); '*When you put the coat on and take it off, he's going to participate. ... I put a key ring on the zipper when it's too small*.' (Parent 3). Other technical aids will enable the adults with multiple disabilities to adopt a better posture and thus be better able to collaborate on the task: '*He has a bath bench with a backrest. Otherwise, he goes backwards because he lacks control*.' (Parent 1). During the interviews, other technical aids were reported by parents, but they were used more to facilitate the caregiver's daily task than the adults with multiple disabilities' participation (e.g., patient lift, sit-to-stand device, electric bed and boot covers).

*(c) Medication*

Other environmental factors were also found to have an influence on the home participation of adults with multiple disabilities. Firstly, medications taken to control specific associated conditions, such as epilepsy, may come with side-effects that significantly reduced the level of arousal. Thus, they are likely to become barriers to participation and engagement in activities: '*When we give her epilepsy medication in the morning, it puts her to sleep. She often takes a little rest in the morning after taking her medication*.' (Parent 6). Other medications were perceived more as facilitators of participation, since they control conditions leading to behavioral problems, such as anxiety: '*He started having anxiety attacks. Autism also means violent attacks. It wasn't easy. It was resolved with medication*.' (Parent 7). As such, medication can both be a facilitator but also a barrier, depending on context, including time of the day.

*(d) The climate*

According to parents, it is much more difficult for an adult with multiple disabilities to participate in the task of dressing with winter clothing than with light summer clothing: '*In winter, in our case, it's clothing that's the most difficult. Dressing is catastrophic. [...] He can do it, but it takes a long time, a really long time. So we're always pushing him*.' (Parent 7). Thus, climate and temperature are also environmental factors found to influence participation.

*(e) The music*

Finally, music was identified from the interviews as a facilitator that would enable the adults with multiple disabilities to be more engaged in daily activities, and thus have better participation at home. Indeed, music would be a strategy that would make an activity considered unpleasant by the adult more tolerable, even pleasant: '*She really likes* [name of two singers]. *As long as those tapes last, that's how long she has to be on the vertical stander.*

*That's what we do, as if to change her mind*.' (Parent 6). Music can thus be an easy strategy to use in a variety of contexts.

**Discussion**

This study aimed to understand participation at home of adults with multiple disabilities and the indicators of their engagement from the parents' perspective as well as to explore the influencing environmental factors. We will discuss these objectives below, separately.

*Participation of older adults with multiple disabilities*

One of the main characteristics of adults with multiple disabilities mentioned in the scientific literature is the fact that they are totally dependent in all their daily activities (2, 7, 8, 21). In the present study, as mentioned under theme 2, *Disabled, but not so much*, this is also how parents spontaneously described their child's involvement. On the other hand, when parents were asked to elaborate, it seemed that adults with multiple disabilities would still participate at different levels, depending on their physical and comprehension abilities. That said, very few studies provide this nuance regarding the participation of adults with multiple disabilities. If a measurement tool such as the Measurement of Life Habits (LIFE-H) (45) or the Functional Autonomy Measurement System (SMAF) (46) had been used to collect the data, results similar to those found in the literature would probably have been obtained. Indeed, when scoring these tools, given the level of assistance required, adults with multiple disabilities would most likely be in a profile of mixed and severe impairments for the SMAF, or a dependent profile where activities will be scored predominantly as "performed by substitution" according to the LIFE-H scoring. Nonetheless, our results support the importance of investigating in greater depth how the activity is performed, since, a rating such as "performed by substitution" as spontaneously answered, does not allow for important

nuances of their child engagement, whereas a more accurate rating would be ‘realized with or without difficulty, and with human aid, technical aid and adaptation’.

That said, it is important to consider whether adults with multiple disabilities can achieve optimal participation at home. We must not forget that in the different models (32, 47), all arrows are bidirectional, meaning the level of participation (life fulfillment) will likely influence personal factors, including mood which our results support. The way in which the activity is carried out can be considered optimal if it meets the expectations of the adult with multiple disabilities, parents and/or society (26). Unlike personal factors (such as organic systems and capabilities), where standards of integrity and ability are expected, normality does not apply to life habits (48). Each adult with multiple disabilities has different abilities and ways of participating at home. We therefore aim for a way of doing things that matches the expectations of the adult with multiple disabilities and his social environment. Indeed, congruence between the way the activity is carried out and the pleasure it brings can contribute to a level of participation considered optimal (26).

*Indicators of their engagement*

Furthermore, given their communication difficulties, the principle of self-determination through the ability to make choices and communicate needs may be more difficult to apply with this clientele (49). While the parents in our sample were not the focus of this study, they seemed to adopt an autonomy-supportive style (50, 51), where they made efforts to empower their child to participate fully and make decisions. As described by our participating parents, it is sometimes necessary to guess about the preferences of adults with multiple disabilities, and even to anticipate their needs by responding to them before they communicate them. When parents interpret the adult's communication attempts appropriately, they help support their self-determination (52-55). Self-determination would also be an element that can make an activity meaningful and thus improve the quality of life of the

adults with multiple disabilities (21, 24, 56, 57). In the systematic review by Kuld and collaborators (49), 76 studies on self-determination or a component of self-determination in people with severe or profound intellectual disabilities were analyzed. The data extracted from these articles highlighted that the main components of self-determination in this clientele are choice and autonomy. Choices can be supported by caregivers, through an autonomous-parenting style (51, 58), who consider the abilities, history, preferences, interests and values of the person with an intellectual disability. Similarly, autonomy is defined by the motivation to achieve goals with the help of a significant other who interprets non-verbal cues. These results (49) are in line with our findings. Indeed, according to our results, the relationship between the parent and the adults with multiple disabilities was the basis for communication, interpretation of choices and participation in activities. In order to promote the principle of self-determination, non-verbal communication was identified by the parents in our study as the main indicator of engagement and participation. Thus, it is possible to rely on the gestures, sounds and facial expressions of adults with multiple disabilities to understand the choices and needs they are trying to communicate.

*Influencing environmental factors*

We also aimed to explore the environmental factors that influence home participation of adults with multiple disabilities from the parents' perspective. According to our results, the caregiver's attitude would have an influence on their social participation at home. Several parents reported having an employment relationship or being retired from a job in the healthcare field, which then provided them with the basic knowledge to care for their child. This raises the question of whether the employment of the social network (e.g., parents) can influence the participation of adults with multiple disabilities at home. Indeed, when parents hold or have previously held jobs related to the healthcare system, they may possibly value autonomy and independence more and do things *with* the person rather than *for* the person

(59). This therefore would promote better social participation at home. Nevertheless, the notion of time was identified as an unavoidable determinant in the opportunity that was given to the adults with multiple disabilities to use their residual abilities to carry out a portion of the task. Indeed, when the caregiver took the time to offer clear indications, explanations and physical guidance, the participation of the adults with multiple disabilities was described as enhanced. Conversely, if the caregiver believed that the adults with multiple disabilities was totally dependent for all activities, this could become an obstacle to their participation at home, since fewer opportunities to participate would be offered. As a result, the caregiver may be inclined to carry out the entire task, rather than involving the adult to the full extent of their abilities. The caretaker's attitude may be influenced by a lack of stability of personnel, which doesn't allow for the establishment of a relationship of trust that the parents in our study felt was essential. Apart from the caretaker's attitude, the active participation of the adults with multiple disabilities would also be facilitated by home adaptations and technical aids present in the home.

Overall, context was found to be a decisive factor in making an activity meaningful. Indeed, according to our results, a routine activity can be transformed into a meaningful activity depending on how it is carried out. One participating parent clearly illustrated the difference between performing hygiene care in the bath with the aim of being cleaned and corresponding to social norms, compared to performing this activity for pure pleasure. When the adults with multiple disabilities had the opportunity to take a bath in a playful context that offered time to play and have fun, bathing became a leisure activity. Participation in meaningful occupation is said to be an important determinant of a positive life experience, helping to maintain physical, psychological and emotional health and well-being (60). Occupational sciences also emphasize the need for all individuals to have the ability to

engage in meaningful occupations throughout life (61). This would contribute to an increased quality of life (9).

**Implications for practice**

The knowledge developed in this study can serve as a basis for rehabilitation professionals' assessments and interventions with adults with multiple disabilities and their families. Indeed, our results underline the importance of analyzing activity through free observation while carrying out various routine activities. An assessment based only on standardized questionnaires, without taking the time to describe in depth how each activity is performed, is likely to be incomplete, since adults with multiple disabilities would most likely obtain a "spontaneous" rating of the "performed by substitution" type, which does not take into consideration the subtleties of their actual participation in the task.

**Strengths and limitations**

In this study, several strengths can be highlighted, notably the use of a rigorous methodology, including a precise analysis process and independent coding by two individuals. Also, when analyzing the data, a continuous reflexive approach was applied in order to remain focused on the facts reported by the parents. Consequently, the results were written up minimizing, as far as possible, interpretations based on prior knowledge of the clientele. However, we also acknowledge that this prior knowledge could have enabled a more in-depth analysis of the data collected. In terms of the study's limitations, the sample was rather homogeneous as the participants were similar in terms of socio-demographic characteristics. In a qualitative study, it is relevant to have homogeneity within a sample since this allows a particular group to be described in depth while reducing variation (62). On the other hand, in order to fully understand the entirety of a phenomenon, it is important to have varied sources of information (35). Thus, varied sociodemographic characteristics, such as nationality or family income, can provide different perspectives on access to services,

understanding of autonomy and occupational expectations placed on adults with multiple disabilities (63). Therefore, the sample in this study only allowed to understand the point of view of parents of a single province in Canada with similar incomes, receiving services from a single health establishment and living in the same specific region of the province. We did not collect more information on the participants and this can be considered also as a limitation. In addition, the sample size was not assessed on a continuous basis to achieve data saturation, a method often used in qualitative descriptive research designs (33) but this was a matter of feasibility issues. Finally, although we acknowledge there are numerous studies in pediatrics, we decided to focus our literature search on the adult population and did not compare and contrast our results with pediatrics' samples which can be considered another limitation.

**Conclusion**

This study contributes to advancing knowledge about participation in the home by adults with multiple disabilities. This knowledge will be relevant in guiding the practice of occupational therapists, special educators and any other health professionals who work with this clientele in clinical and community settings. The results of this study will also provide guidance to parents and other caregivers (e.g., caretakers, siblings) on ways to optimize home participation for adults with multiple disabilities, despite their disabilities. The interviews revealed that, despite the assistance required to carry out all activities at home, adults with multiple disabilities can be involved on a daily basis according to their residual abilities. This involvement is influenced by multiple factors in the physical and social environment. In addition, non-verbal communication has been identified by parents as the main indicator of participation and involvement. Gestures, sounds and facial expressions enable adults with multiple disabilities to interact with their environment. Although they are varied, meaningful activities carried out at home will enable adults with multiple disabilities to experience

moments of pleasure that improve their quality of life, and to forge stronger bonds with their parents, who may be part of the context of these activities. That said, this study underlines the importance of the environment and context (e.g., location, time) in making an activity meaningful. According to the results obtained in this study, the relationship with the caregiver plays an important role in making activities meaningful and facilitating participation in the various activities. A relationship always involves at least two parties, but the main aim of the study was to understand the reality at home for adults with multiple disabilities. In future research, it would be interesting to analyze the parent's experience as their child's primary caregiver, given that the parent often occupies a central role in activities at home.

## References


1. World Health Organization. Disability 2023 [Available from: https://www.who.int/en/news-room/fact-sheets/detail/disability-and-health.
2. Collignon P. Éthique du soin et qualité de vie chez les enfants sévèrement polyhandicapés. Reliance. 2008;28(2):102-9 (page 5).
3. Public Health Agency of Canada. Developmental disabilities or disorders in Canada - Highlights from the 2017 Canadian Disability Survey 2021 [Available from: https://www.canada.ca/fr/sante-publique/services/publications/maladies-et-affections/infographie-incapacites-troubles-developpement-canada-faits-saillants-enquete-2017.html.
4. Dussiaume I. L'expérience d'être parent d'un enfant polyhandicapé hébergé Canada: Université de Montréal; 2016.
5. Hamel P, Vachon N. Une place après 21 ans pour les jeunes adultes polyhandicapés. Institut national de la recherche scientifique; 2018. p. 102.
6. Julien-Gauthier F, Corbeil T. Chapitre 67. La situation des personnes polyhandicapées au Québec. La personne polyhandicapée. Paris: Dunod; 2021. p. 1177-203.
7. Vlaskamp C, Hiemstra SJ, Wiersma LA. Becoming Aware of What You Know or Need to Know: Gathering Client and Context Characteristics in Day Services for Persons With Profound Intellectual and Multiple Disabilities. Journal of Policy and Practice in Intellectual Disabilities. 2007;4(2):97-103.
8. Petry K, Maes B, Vlaskamp C. Domains of Quality of Life of People with Profound Multiple Disabilities: the Perspective of Parents and Direct Support Staff. Journal of Applied Research in Intellectual Disabilities. 2005;18(1):35-46.
9. Beadle-Brown J, Leigh J, Whelton B, Richardson L, Beecham J, Baumker T, et al. Quality of Life and Quality of Support for People with Severe Intellectual Disability and Complex Needs. Journal of Applied Research in Intellectual Disabilities. 2016;29(5):409-21.
10. Munde VS, Vlaskamp C, Ruijssenaars AJJM, Nakken H. Alertness in individuals with profound intellectual and multiple disabilities: A literature review. Res Dev Disabil. 2009;30(3):462-80.
11. Gauthier-Boudreault C, Beaudoin AJ, Gallagher F, Couture M. Scoping review of social participation of individuals with profound intellectual disability in adulthood: What can I do once I finish school? J Intellect Dev Disabil. 2019;44(2):248-60.
12. Kuld PB, Frielink N, Zijlmans M, Schuengel C, Embregts P. Promoting self-determination of persons with severe or profound intellectual disabilities: a systematic review and meta-analysis. J Intellect Disabil Res. 2023;67(7):589-629.
13. Hoogsteen L, Woodgate RL. Can I Play? A Concept Analysis of Participation in Children with Disabilities. Physical & Occupational Therapy In Pediatrics. 2010;30(4):325-39.
14. Heah T, Case T, McGuire B, Law M. Successful Participation: The Lived Experience among Children with Disabilities. Canadian Journal of Occupational Therapy. 2007;74(1):38-47.
15. Law M, Petrenchik T, King G, Hurley P. Perceived Environmental Barriers to Recreational, Community, and School Participation for Children and Youth With Physical Disabilities. Arch Phys Med Rehabil. 2007;88(12):1636-42.
16. Noreau L, Lepage C, Boissiere L, Picard R, Fougeyrollas P, Mathieu J, et al. Measuring participation in children with disabilities using the Assessment of Life Habits. Dev Med Child Neurol. 2007;49(9):666-71.
17. Axelsson AK, Wilder J. Frequency of occurrence and child presence in family activities: a quantitative, comparative study of children with profound intellectual and multiple disabilities and children with typical development. International Journal of Developmental Disabilities. 2014;60(1):13-25.

18. Axelsson AK, Granlund M, Wilder J. Engagement in family activities: a quantitative, comparative study of children with profound intellectual and multiple disabilities and children with typical development. Child: Care, Health and Development. 2013;39(4):523-34.
19. Poon KK, Koh L, Magiati I. Parental perspectives on the importance and likelihood of adult outcomes for children with Autism Spectrum Disorders, Intellectual Disabilities or Multiple Disabilities. Res Autism Spectr Disord. 2013;7(2):382-90.
20. Ouellet S, Caya I. La pédagogie créative au service des élèves polyhandicapés : résultats d'une recherche-action. Revue francophone de la déficience intellectuelle. 2013;24:5-11.
21. Lehoux M, Gayadeen S, Tremblay C, Couture G. Rapport d'évaluation sur les interventions ayant démontré
un effet auprès des enfants et des adolescents de 0 à 21 ans présentant un polyhandicap. In: (ETMI) Édtedmdi, editor. Canada: Institut universitaire en déficience intellectuelle et en trouble du spectre de l'autisme; 2017. p. 93.
22. Government of Canada. Rights of people with disabilities CanadaDate modified: 2018-09-07 [Available from: https://www.canada.ca/en/canadian-heritage/services/rights-people-disabilities.html.
23. Talman L, Stier J, Wilder J, Gustafsson C. Participation in daily life for adults with profound intellectual (and multiple) disabilities: How high do they climb on Shier's ladder of participation? Journal of Intellectual Disabilities. 2021;25(1):98-113.
24. Mansell J, Beadle-Brown J. Active Support: Enabling and Empowering People with Intellectual Disabilities. London: Jessica Kingsley Publishers; 2012. 224 p.
25. Davis PK, Young A, Cherry H, Dahman D, Rehfeldt RA. INCREASING THE HAPPINESS OF INDIVIDUALS WITH PROFOUND MULTIPLE DISABILITIES: REPLICATION AND EXTENSION. J Appl Behav Anal. 2004;37(4):531-4.
26. Rochette A, Korner-Bitensky N, Levasseur M. 'Optimal' participation: a reflective look. Disabil Rehabil. 2006;28(19):1231-5.
27. Petry K, Maes B. Identifying expressions of pleasure and displeasure by persons with profound and multiple disabilities. J Intellect Dev Disabil. 2006;31(1):28-38.
28. Maes B, Lambrechts G, Hostyn I, Petry K. Quality‐enhancing interventions for people with profound intellectual and multiple disabilities: A review of the empirical research literature. J Intellect Dev Disabil. 2007;32(3):163-78.
29. Talman L, Gustafsson C, Stier J, Wilder J. Staffs' documentation of participation for adults with profound intellectual disability or profound intellectual and multiple disabilities. Disabil Rehabil. 2018;40(21):2527-37.
30. Charalambous M, Kountouri A, Schwyter JR, Annoni JM, Kambanaros M. The development of the People with Aphasia and Other Layperson Involvement (PAOLI) framework for guiding patient and public involvement (PPI) in aphasia research. Res Involv Engagem. 2023;9(1):74.
31. Roydhouse JK, Cohen ML, Eshoj HR, Corsini N, Yucel E, Rutherford C, et al. The use of proxies and proxy-reported measures: a report of the international society for quality of life research (ISOQOL) proxy task force. Qual Life Res. 2022;31(2):317-27.
32. Fougeyrollas P. International Classification: HUMAN DEVELOPMENT MODEL – DISABILITY CREATION PROCESS (HDM-DCP). Quebec: International Network on Disability Creation Process; 2020.
33. Hunt MR. Strengths and Challenges in the Use of Interpretive Description: Reflections Arising From a Study of the Moral Experience of Health Professionals in Humanitarian Work. Qual Health Res. 2009;19(9):1284-92.
34. Thompson Burdine J, Thorne S, Sandhu G. Interpretive description: A flexible qualitative methodology for medical education research. Med Educ. 2021;55(3):336-43.
35. Thorne S, Kirkham SR, O'Flynn-Magee K. The Analytic Challenge in Interpretive Description. International Journal of Qualitative Methods. 2004;3(1):1-11.
36. Poucher ZA, Tamminen KA, Caron JG, Sweet SN. Thinking through and designing qualitative research studies: a focused mapping review of 30 years of qualitative research in

sport psychology. International Review of Sport and Exercise Psychology. 2019;13(1):163-86.
37. Shannon-Baker P. Making Paradigms Meaningful in Mixed Methods Research. Journal of Mixed Methods Research. 2016;10(4):319-34.
38. Fortin M, Gagnon J. Fondements et étapes du processus de recherche (3e édition). Montréal (Québec) Canada: Chenelière éducation; 2016.
39. Fougeyrollas P, Boucher N, Edwards G, Grenier Y, Noreau L. The Disability Creation Process Model: A Comprehensive Explanation of Disabling Situations as a Guide to Developing Policy and Service Programs. Scand J Disabil Res. 2019;21(1):25-37.
40. Vaismoradi M, Turunen H, Bondas T. Content analysis and thematic analysis: Implications for conducting a qualitative descriptive study. Nurs Health Sci. 2013;15(3):398-405.
41. Dierckx de Casterlé B, Gastmans C, Bryon E, Denier Y. QUAGOL: A guide for qualitative data analysis. Int J Nurs Stud. 2012;49(3):360-71.
42. Colorafi KJ, Evans B. Qualitative Descriptive Methods in Health Science Research. HERD: Health Environments Research & Design Journal. 2016;9(4):16-25.
43. O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. Standards for Reporting Qualitative Research: A Synthesis of Recommendations. Acad Med. 2014;89(9):1245-51.
44. Tracy SJ. Qualitative Quality: Eight "Big-Tent" Criteria for Excellent Qualitative Research. Qualitative Inquiry. 2010;16(10):837-51.
45. Desrosiers J, Noreau L, Robichaud L, Fougeyrollas P, Rochette A, Viscogliosi C. Validity of the Assessment of Life Habits in older adults. Journal of rehabilitation medicine : official journal of the UEMS European Board of Physical and Rehabilitation Medicine. 2004;36(4):177-82.
46. Hebert R, Carrier R, Bilodeau A. The Functional Autonomy Measurement System (SMAF): description and validation of an instrument for the measurement of handicaps. Age Ageing. 1988;17(5):293-302.
47. WHO. International Classification of Functioning, Disability and Health: Geneva; 2001.
48. Egan M, Restall G. Promoting Occupational Participation: Collaborative Relationship-Focused Occupational Therapy. Canada: CAOT/ACE; 2022. 347 p.
49. Kuld PB, Frielink N, Zijlmans M, Schuengel C, Embregts PJCM. Promoting self-determination of persons with severe or profound intellectual disabilities: a systematic review and meta-analysis. J Intellect Disabil Res. 2023;67(7):589-629.
50. Deci EL, Ryan RM, Williams GC. Need satisfaction and the self-regulation of learning. Learning and Individual Differences. 1996;8(3):165-83.
51. Wei S, Teo T, Malpique A, Lausen A. Parental Autonomy Support, Parental Psychological Control and Chinese University Students' Behavior Regulation: The Mediating Role of Basic Psychological Needs. Front Psychol. 2021;12:735570.
52. Nicholson C, Finlay WML, Stagg S. Forms of resistance in people with severe and profound intellectual disabilities. Sociol Health Illn. 2021;43(3):642-59.
53. Watson J. Assumptions of Decision-Making Capacity: The Role Supporter Attitudes Play in the Realisation of Article 12 for People with Severe or Profound Intellectual Disability. Laws. 2016;5(1):6.
54. Nieuwenhuijse AM, Willems DL, Olsman E. Physicians' perceptions on Quality of Life of persons with profound intellectual and multiple disabilities: A qualitative study. J Intellect Dev Disabil. 2020;45(2):176-83.
55. Bigby C, Douglas J, Smith E, Carney T, Then S-N, Wiesel I. "I used to call him a non-decision-maker - I never do that anymore": parental reflections about training to support decision-making of their adult offspring with intellectual disabilities. Disabil Rehabil. 2022;44(21):6356-64.
56. Nota L, Ferrari L, Soresi S, Wehmeyer M. Self-determination, social abilities and the quality of life of people with intellectual disability. J Intellect Disabil Res. 2007;51(11):850-65.

57. Wehmeyer M, Schwartz M. The Relationship Between Self-Determination and Quality of Life for Adults with Mental Retardation. Education and Training in Mental Retardation and Developmental Disabilities. 1998;33(1):3-12.
58. Alonso-Stuyck P. Parenting and Healthy Teenage Lifestyles. Int J Environ Res Public Health. 2020;17(15).
59. Moyo M, Goodyear-Smith FA, Weller J, Robb G, Shulruf B. Healthcare practitioners' personal and professional values. Advances in Health Sciences Education. 2016;21(2):257-86.
60. Turcotte S, DeBroux-Leduc R, Aubry CV, Parisien M, Levasseur M, Daigle-Landry D, et al. Older adults' experience as peer educators in health promotion programs. Journal of Occupational Science. 2023;30(2):203-17.
61. Kristensen HK, Petersen KS. Occupational science: An important contributor to occupational therapists' clinical reasoning. Scandinavian Journal of Occupational Therapy. 2016;23(3):240-3.
62. Palinkas LA, Horwitz SM, Green CA, Wisdom JP, Duan N, Hoagwood K. Purposeful Sampling for Qualitative Data Collection and Analysis in Mixed Method Implementation Research. Administration and Policy in Mental Health and Mental Health Services Research. 2015;42(5):533-44.
63. Paul S. Culture and its Influence on Occupational Therapy Evaluation. Canadian Journal of Occupational Therapy. 1995;62(3):154-61.

**Table 1: Characteristics of adults with multiple disabilities (n=7) whose social participation was the focus of the study**

| Adult with multiple disabilities | Gender | Age (years) | Diagnostics | Communication type |
|---|---|---|---|---|
| Adult 1 | Man | 28 | Jacobsen syndrome leading to severe intellectual disability, pulmonary fragility and epilepsy | Facial expressions<br>Gestures<br>Pictograms<br>Some spoken words |
| Adult 2 | Woman | 41 | Cerebral palsy leading to quadriplegia and severe intellectual disability | Facial expressions<br>Gestures<br>Communication board (with photos and pictograms on the IPad)<br>Some spoken words |
| Adult 3 | Man | 29 | Encephalopathy with spastic diplegia of the lower limbs and severe intellectual disability | Facial expressions<br>Gestures |
| Adult 4 | Woman | 21 | Severe intellectual disability, Wilms' tumor, glaucoma, aniridia, epilepsy and severe scoliosis | Facial expressions<br>Gestures |
| Adult 5 | Man | 31 | Severe congenital hydrocephalus, autism spectrum disorder, moderate intellectual disability and diplegia | Oral communication |
| Adult 6 | Woman | 28 | Microcephaly and encephalopathy leading to profound intellectual disability and epilepsy | Facial expressions<br>Gestures |
| Adult 7 | Man | 22 | Unknown polymalformative orphan syndrome leading to profound deafness, moderate intellectual disability, autism spectrum disorder, anxiety and Syme amputation | Adapted Quebec Sign Language<br>Pictograms<br>Communication board<br>Technical support for communication |

**Table 2: Socio-demographic data for parents taking part in the study**

| Parent | Age (years) | Link with adult with multiple disabilities | School | Main occupation | Type of home | Gross family income |
|---|---|---|---|---|---|---|
| Parent 1 | 58 | Mother | College | Retired Caregiver | Bungalow owner | 100,000 and more |
| Parent 2a and 2b | 73 and 74 | Mother and father | High school | Retirees Caregivers | Bungalow owners | 60 000 à 69 999 |
| Parent 3 | 56 | Mother | College | Caregiver | Bungalow owner | 100,000 and over |
| Parent 4 | 57 | Mother | College | Full-time employment | Bungalow owner | 90 000 à 99 999 |
| Parent 5 | 59 | Mother | College | Full-time employment | Homeowner (two or more storeys) | 100 00 and over |
| Parent 6 | 61 | Father | High school | Full-time employment | Semi-detached owner | 90 000 à 99 999 |
| Parent 7 | 48 | Father | High school | Full-time employment | Bungalow owner | 100,000 and over |

Supplemental file: Interview guide

| Interview | |
|---|---|
| Interview objectives:<br>- Understand the home participation of adults with multiple disabilities and the indicators that show they are engaged from the perspective of the parent or legal guardian<br>- Exploring the environmental factors that influence home participation of adults with multiple disabilities from the perspective of the parent or legal guardian | Explanation of the interview process<br>- The interview should last a maximum of one hour.<br>- Remind participants of confidentiality rules and study objectives<br>- Mention that participation is free and voluntary and that the participant may stop the interview at any time<br>- Explain the need to record the discussion<br>- Signature of the information and consent form (sent in advance by the establishment's authorized representative)<br>- Request consent to start recording<br>- Explain the interview process |

**Demographic data** will be collected at the end of the interview.

**We begin with a preamble:**
As you read in the consent form, this study aims to better understand the daily life of adults with multiple disabilities at home from your perspective as a parent or legal guardian, and the environmental factors that influence this daily life. There are no right or wrong answers, no absolute truths, and the study looks at both positive elements (facilitators) and negative elements (obstacles). You may find that some of the questions are redundant, but don't worry, we're trying to approach the situation from different points of view. Finally, before we begin, I'd like to remind you that you can decide not to answer certain questions, ask me to take a break at any time, or even end the interview.

**Theme 1. Participation of adults with multiple disabilities from the perspective of parents and legal guardians -** focus on activities performed and social roles (life habits)

**Can you tell me your story and tell me about your role with your child?**
Probes:

- Describe a typical weekday. Describe a typical weekend day.
    - Tell me about your routines. What does your morning routine look like? What does your evening routine look like?
- How are things at home?
    - More specifically, how do you cope with eating, dressing, hygiene, getting around or transferring around the house, social relations or communication, leisure activities? Can you give me some concrete examples?
    - Can you give me concrete examples of the difficulties your child encounters in everyday tasks (specify according to the activities discussed during the interview).

- The HDM-DCP is used as an anchor for probing questions on life habits (12 categories).

**I'd love to hear what you find most challenging about your day.**
Probes:
- Which activities are the most difficult at home?
- What happens at those times?

**I'd love to hear what you find easiest about your day.**
Probes:
- Describe your best moment of the day.
- What do you think is your child's best moment (referring to which category of activity)?

**What would be the clues that show you that your child is enjoying the task, that they're having fun and that they're blossoming in this activity (which you think is their best moment)?**
Probes:
- Clues can be facial expressions, gestures, sounds, etc.
- What types of activities give them the most pleasure? Can you give me some concrete examples?

**What do you think is the worst part of your child's day (what type of activity)?**
Probes:
- What clues do you have to help you identify this moment as the worst?

**Can you tell me about the strategies you use to facilitate communication with your child? To make getting around easier? To make dressing easier? To make feeding easier?**
Probes:
- Can you describe for me, with concrete examples, what you do to help your child with tasks they can't do on their own?
- I'd like to hear how you adapt your language to facilitate communication?

**Theme 2. Characteristics of the environment -** the focus is on an in-depth description of the environment that influences the participation of adults with multiple disabilities in the home.

The HDM-DCP is used as an anchor for reminders of the various characteristics of the physical and social environment (see environmental categories of the model).

**Can you describe how the physical environment of the home helps or hinders your child's participation in activities?**

Probes (ask for concrete examples):
- How does the physical environment of the various rooms in your home (kitchen, living room, hallway, bedroom, bathroom, stairs, basement, etc.) help or hinder your child?

    - I'd like to hear what you have to say about obstacles in the physical environment?
    - I'd like to hear what you think is preventing your child from carrying out activities that are meaningful to them.
- I'd like to hear from you about home modifications or objects that help your child participate in daily activities.
- I'd like to hear about the technical aids your child uses on a daily basis.

**Without changing your child, what would you change about the environment? What about you? The tasks to be accomplished? Daily life?**

Probes :

- In an ideal world, what would you like to be different?

**What opportunities or resources (human, material, financial) do you feel are missing to make your daily life at home easier?**

Probes :

- I'd like to hear what you have to say about obstacles in the social environment.
- I'd like to hear about the support you receive to help you at home.

**Closing - end of interview**

Thank you so much for sharing! Is there anything else I should know, do you have anything else to add that we haven't covered?

What should I take away from our exchange today? What would be your final word?

Before I leave you, I'd like to ask you a few socio-demographic questions.

Thanks again for your time. I'll stop recording.