

RESEARCH

Environmental, Personal, and Relational Barriers and Facilitators to Self-Determination among Adults with Intellectual Disabilities

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For people with intellectual disabilities, the potential for self-determination depends on both personal characteristics and factors related to the social environment. This study examines barriers and facilitators to self-determination among residents at facilities for people with intellectual disabilities. We held 13 focus group discussions to explore the opinions and experiences of 10 people with mild to moderate intellectual disabilities and 10 social care professionals at three residential facilities in Western Switzerland. We identified environmental, personal, and relational barriers and facilitators to self-determination associated with attitudes, representations, and institutional settings. Within the social environment of people with intellectual disabilities, relationships based on trust, partnership, and collaboration appear to promote self-determined behaviours. Ideally, strategies for promoting self-determination among people with intellectual disabilities should take both personal characteristics and the social environment into account.

Keywords: intellectual disabilities; self-determination; barriers; facilitators; special education; social care relationship

Background

In recent decades, the self-advocacy and empowerment movements have highlighted the importance of promoting self-determination among people with intellectual disabilities (Soresi, Nota, & Wehmeyer 2011). Intellectual disabilities can be defined as a diagnosis based on three criteria, namely substantial limitations in intellectual functioning, limitations in adaptive behaviour relating to conceptual, social and practical skills, and the fact that those limitations must appear before the age of eighteen (AAIDD 2010).

Existing studies point to a positive association between high levels of self-determination and social participation in areas such as access to employment and education (Wehmeyer & Palmer 2003), community inclusion (Wehmeyer & Schwartz 1998), academic achievement (Gaumer Erickson, Noonan, Zheng, & Brussow 2015), and quality of life (Lachapelle, Wehmeyer, Haelewyck, Courbois, Keith et al. 2005). Other studies stress the importance of self-determination among people with intellectual disabilities in the fields of health care (McPherson, Ware, Carrington, & Lennox 2016), special education (Carter, Lane, Cooney, Weir, Moss et al. 2013), and higher education (Thoma & Getzel 2005).

Relationships between people with intellectual disabilities and members of their social network appear to foster self-determination (Cudré-Mauroux, Piérart & Vaucher, under review). Several existing studies suggest that levels of self-determination are governed by personal and environmental factors, as well as by strategies for promoting self-determined behaviours among people with intellectual disabilities. Self-determination therefore depends not only on individual abilities, but also on the availability of both choice-making opportunities and support for achieving goals (Sarrazin 2013).

On the one hand, research shows how self-determination can be hindered by certain features of intellectual disabilities, including interpersonal difficulties, lack of emotional regulation (Peterson 2004), and poor decision-making skills (Sands & Kozleski 1994). Likewise, intellectual disabilities can be a barrier to self-regulation (Haelewyck & Nader-Grosbois 2004). On the other hand, research also shows how various factors related to the social environment can promote or hinder self-determination among people with intellectual disabilities. For instance, environmental factors can increase or restrict opportunities for making choices or expressing preferences (Wehmeyer & Metzler 1995). Meanwhile, institutional variables such as scheduling practices and group sizes can affect the level of personal control enjoyed by people with intellectual disabilities (Stancliffe 1997; Stancliffe, Abery, & Smith 2000).

By identifying factors that promote or hinder self-determination, researchers can support the development of new strategies that better promote self-determination among people with intellectual disabilities and that adequate the practice of social care professionals to disabled people's needs. Specifically, this paper discusses barriers and facilitators to self-determination in an institutional setting, with a focus on relationships between residents and staff at facilities for people with intellectual disabilities. Our research project used a bottom-up approach, with the goal to develop and share solutions inspired by the participants themselves. Bottom-up approaches move from facts to theory (instead of from theory to facts) and tend to focus on the experiences and practices of participants (instead of relying on external experts or policy-makers). Our study therefore addresses the needs of both groups of participants (people with intellectual disabilities and professionals), by reflecting on the development and implementation of meaningful strategies and tools based on the target population's experiences, needs, and ideas. This approach also empowers participants by making them responsible for implementing new practices and adopting new representations (Bergstrom 2008).

In Switzerland, people with intellectual disabilities generally still live in specialized facilities offering protected accommodation and employment programs for residents, and thus challenges regarding social participation mostly take place in this specific context. Therefore, the staff members who accompany and support the residents on a daily basis play an important part in their social and professional lives. Indeed, it has been shown that, in contexts of institutionalization, the social environment of people with intellectual disabilities is mainly formed by social work professionals (Marquis & Jackson 2000). The fact that practices for the promotion of self-determination generally take place within the interactions between people with intellectual disabilities and staff members convinced us that this specific relationship would be a privileged context for the study of the emergence and maintenance of self-determined practices of people with intellectual disabilities living in specialized facilities. The fact that their interactions occurred in this specific context made it necessary to take into account the inscription of the socio-pedagogical relationship within our study setting.

Methods

Study Setting

Our participatory research project used qualitative methods to explore self-determination in the context of everyday relationships. Over a period of ten months (September 2015 to June 2016), we collected data from 13 focus group discussions held in three distinct facilities. Each residential institution was located in a different political region of French-speaking Switzerland, one in the center of a city, one in the suburbs of another city, and one in a village. The three institutions included accommodation and catering services, and two of those also included employment and day-program options. The other institution collaborated with a day-program and employment service of the same city.

We first contacted the direction services of several pre-selected facilities which openly showed an interest in the topic of self-determination, and asked them if they would be interested to participate in our study. Two criteria were important in the first selection of facilities: the presence of self-determination in their institutional guidelines, and offering an accommodation service for adults with intellectual disabilities, regardless of the form of the residential structure (protected apartments, supervised private households, etc.). Three facilities answered positively to our invitation and were thus selected as the three participating facilities. As a result, we had no impact on the localisation of each residential institution, and the localisation variable was not comprised in our analysis. We began by sending an introductory document, prepared according to established accessibility standards for French-language text (UNAPEI 2009), to facilities that expressed an interest in the study. We then gave on-site presentations to interested staff and residents, using simplified language and visual supports. After this presentation, 20 people accepted to participate in the study, and the individuals who chose to participate were asked to complete an adapted consent form (Détraux 2014). Before data collection began, we held a meeting to address the special needs of participants with intellectual disabilities in terms of scheduling, procedures, and supports.

Participants

The participation of people with intellectual disabilities in a research project raises important ethical issues related to free and informed consent. Indeed, this population is especially vulnerable during the recruitment process (Giard & Morin 2010). We therefore ensured that participants received sufficient information to make an autonomous decision and that they were not subjected to external pressure. We also addressed the specific needs of people with intellectual disabilities during the recruitment process.

A total of 20 participants were assigned to 10 dyads at three different facilities (see **Table 1**).

Each dyad was composed of an adult resident with mild to moderate intellectual disabilities and a social care professional. The person with intellectual disabilities had to be capable of participating in a group discussion and received daily support from the professional in an institutional setting. The members of each dyad were asked to maintain their relationships for at least one year.

Except for those who spontaneously mentioned it during the focus group discussions in relation to their approaching birthdays, we did not have access to the age of the participants in our study. However, based on some information they shared with us about their life trajectories, we can assume that a majority of participants—residents and staff members—were aged between 30 and 50 years old.

Table 1: Distribution of participants and dyads by residential institution.

	Residential institution 1 (village)		Residential institution 2 (city center)		Residential institution 3 (city – suburb)	
	Residents	Staff members	Residents	Staff members	Residents	Staff members
<i>Dyad 1</i>	Rebecca (F)	Françoise (F)	Caroline (F)	Julie (F)	Celia (F)	Alexandre (H)
<i>Dyad 2</i>	Pablo (H)	Marc (H)	Philippe (H)	Louis (H)	Anaïs (F)	Samantha (F)
<i>Dyad 3</i>	Jean (H)	William (H)	Joël (H)	Brice (H)		
<i>Dyad 4</i>	Sarah (F)	Geraldine (F)	Samuel (H)	Maxime (H)		
Total	4	4	4	4	2	2

Ethics approval and consent to participate

All participants consented to participate in the research study through a written agreement and all data was processed in strict confidentiality. In relation to the specific Swiss context regarding researches conducted in the field of social science and qualitative studies in general, an ethics approval request to the regional Ethics Committees on research involving humans was not required for this study.

Study Design

We organized focus group discussions to explore the everyday perceptions, attitudes, and experiences of project participants regarding self-determination. Focus groups have been recognized as an appropriate method for studies involving people with intellectual disabilities (Fraser & Fraser 2001; Gates & Waight 2007). They are accessible to this population (Muir & Gibbs 2006), in part because participants do not need to know how to read or write. The format is also less intimidating than one-on-one interviews. Furthermore, the presence of familiar staff, as well as peers with similar experiences and personal characteristics, helps encourage active participation in group discussions (Barbour & Kitlinger 1999), making it possible to examine a variety of factors related to self-determination. We paid special attention to the needs of people with intellectual disabilities, adapting our language to their level of comprehension, requesting the support of participating professionals as facilitators, and adjusting the pace of discussions in response to fatigue or inattention.

Each focus group (one per institution) met at three-month intervals, and each round of discussions dealt with specific topics and objectives. These included each participant's definition and understanding of self-determination, the importance of self-determination in their everyday lives, examples of self-determination among participants with intellectual disabilities, and requests made by residents to staff. Following established guidelines for qualitative research involving focus groups (Barbour & Kitlinger 1999), each 70- to 110-minute discussion involved between four and eight participants. Each focus group met at the institution where its members lived or worked, and discussions were led by a trained moderator with assistance from two co-moderators. Transcripts were prepared based on audio recordings and field notes taken by the co-moderators. All focus groups were held in French. The excerpts presented in this article were first translated from French to English by one of the researchers, and then the manuscript, including the translated abstracts, was reviewed by a professional translator. All the names used in this article are pseudonyms.

Between each round of focus group discussions, we asked the members of each dyad to jointly reflect on their experiences through writing, videos, pictures, or any other medium. In particular, we invited them to discuss situations where the participant with intellectual disabilities expressed self-determination (as seen from both the resident's and the professional's points of view). Participants received simplified oral and written instructions for these weekly meetings. They were free to choose the time, duration, and location.

We have had only partial and indirect access to the material developed during the moments that the participants shared within their dyad meetings, through the experiences reported by the participants during the focus group discussions. During those discussions, participants were sometimes asked to review some of the situations discussed during their dyad meetings or to share the strategies deployed to keep track of these meetings throughout the research process. Therefore, the material built and used within the dyad encounters was not systematically reviewed and analyzed by the research team.

Data Analysis

Our comprehensive approach to data analysis consisted of three parallel phases:

1. A longitudinal analysis of how definitions and understandings of self-determination evolved within each dyad.
2. A cross-sectional comparative analysis of the conditions that fostered or hindered self-determination in the context of social care relationships across all dyads.
3. A practical analysis focused on finding concrete strategies.

Each phase involved inductive qualitative content analysis (Miles & Huberman 2003). After familiarizing ourselves with the data, we independently coded the discussion transcripts for key themes and reviewed our findings at regular meetings.

All participants were included in the research process, from the discussion of the study setting, until the data analysis. Considering restitution as a process and not as an end in itself, the avenues for analysis were presented to the participants approximately six months after the end of the field phase, through an oral presentation, combined with a written document including illustrations. The participants could ask questions, react or make suggestions after the presentation, in an informal setting. Many discussions between the participants and the research team resulted from this presentation. Several participants with an intellectual disability reacted to the data, mainly to claim that they identified with the results presented. Staff members mainly reacted to share their expectations about the openings of the research, which helped us define its possible applications.

Results

Environmental Barriers

Environmental barriers to self-determination identified by participants reflected practical considerations, such as financial constraints, limited choices, and the range of parameters to be considered. These obstacles were often associated with the shortcomings of an institutional setting, such as the limited number of social care professionals, turnover on social care teams, and the lack of time and space available for meetings between residents and staff. Furthermore, the slow pace of new initiatives and resistance to change, as well as rigid frameworks and hierarchies were seen as standing in the way of innovative practices designed to promote self-determination. For example, one resident expressed frustration when no one seemed to follow up on her proposal for a weekly medication plan: "We wanted the medications to manage or to prepare the weekly medication plans. Now, all we can do is wait. I hope it happens before I'm in my grave". (Anaïs, resident, residential institution 3). These considerations highlight the importance of considering the resources necessary to promote the self-determination of people with intellectual disabilities. These resources can relate to material, financial, political or organizational aspects.

Participants also identified institutional constraints associated with communal living, such as rigid schedules, the need to keep quiet at night, and restricted food choices. Meanwhile, the relative status of residents and staff was seen as creating asymmetric relationships that can hinder self-determination among participants with intellectual disabilities. One participant therefore lamented the fact she and her fellow residents were prohibited from using mobile phones during the day, whereas professionals at her institution were not bound by the same rule: "Maybe we should have the same rule for everybody. Sometimes, it might be better if we said: 'No one is allowed to do this.'" (Rebecca, resident, residential institution 1). The preceding materials seem to indicate that the rules which govern the facilities are likely to slow down or suppress the self-determined initiatives of the persons assisted.

Participants also described how social prejudices and negative representations of disabilities can be barriers to self-determination. For instance, people with intellectual disabilities have very limited job opportunities. One resident also explained how difficult it can be to find an apartment, given the discrimination he faced because of his disability: "You call a property manager or even a landlord, and you say: 'Hello sir, I'm interested in renting an apartment.' But as soon as you say, 'I receive a disability pension,' they immediately start treating you differently. And sometimes it hurts a little. And I was starting to get fed up because, you see, other people in a normal situation can manage to find an apartment, but people who receive a disability pension aren't so lucky. Just the words 'disability pension' seem to scare them a little." (Pablo, resident, residential institution 1). Still too often negative representations of disability seem to represent an important barrier to people's self-determination.

Environmental Facilitators

Aside from the financial support available for activities and residents' ability to manage their own money, participants identified very few aspects of the institutional environment that could foster self-determination. But although it was generally portrayed as restrictive, the institutional setting was also sometimes described as a source of protection, something that sheltered people with intellectual disabilities from negative outside influences. These aspects reflect the positive and protective part played by the hosting facilities and by the professionals. For example, the staff at one residential institution supported a resident in protecting her privacy from controlling family members: 'And then this year, in consultation with our manager, we developed a strategy for keeping Caroline's parents out of her room. We told them it was her space and that they couldn't go in whenever they wanted. So we established a rule: They could only enter the room when she was there. Otherwise, they had to keep out' (Julie, staff, residential institution 2). It was indeed difficult for Caroline to set limits to her parents about her private space, when it was an important need for her: 'I wanted some freedom, and also it was my room, it's mine and I can live my own life. So I don't need anybody entering my room like that. So now I feel like a delivery, because they [her parents] are far and rarely come.' (Caroline, resident, residential institution 2). Caroline was thus able to rely on institutional resources to uphold her self-determination.

Personal Barriers

Both professionals and residents noted how the attitudes and perspectives of people with intellectual disabilities could prevent the latter from expressing self-determination. Indeed, participants described a wide range of fears expressed

by residents: the fear of expressing themselves, of destroying relationships, of violating environmental constraints, of doing activities on their own, of deceiving others, of change, of taking initiative, of giving an opinion, of being wrong, of taking responsibility for a mistake, etc. As one professional explained: 'I now think these boundaries are more deeply embedded, I would say, in the minds of people with intellectual disabilities. And it can really confuse them, in the sense that ... sometimes they only dare go so far in terms of getting involved, making choices, expressing desires, or believing someone will help them achieve a goal' (Marc, staff, residential institution 1). Emotions of fear can thus represent significant obstacles to self-determined initiatives, all the more so for people with intellectual disabilities who cannot yet rely on positive experiences of mastery. Some participants in our study, however, were fully aware of their emotions, such as Rebecca who once confessed her fear of leaving her residential institution to move to another city and thus of losing contact with her friends, as follows: 'I'm afraid, I'm telling you. I'm bloody afraid, the day something happens to me... But I believe that people who have known me for nine years will understand that it is not because I don't love them anymore, but because I need novelty. If my friends understand and remain after I am gone, that will be because they are real friends' (Rebecca, resident, residential institution 1).

When discussing personal barriers to self-determination, participants also referred to difficulties encountered in the course of pursuing or achieving a goal, or while evaluating risks and assessing possibilities. Examples include problems communicating or understanding, as well as trouble taking sides, saying no, making choices, reading and writing, and managing money. For instance, one resident described a situation where he wanted to buy sports gear but lacked the money to pay for it: 'No, I don't know, no. I don't know if I have enough money' (Jean, resident, residential institution 1). While not having enough money or not, being allowed to manage one's own money is more of an environmental barrier, and this excerpt also shows that in this situation, managing his budget or understanding the costs of sports equipment also represented personal challenges for Jean. Other personal barriers described by participants involved cases where residents wanted things to happen too quickly, needed to obtain validation for their choices, or faced a clash between personal desires and practical realities. The lack of skills related to problem-solving, self-regulation or even understanding one's environment appeared to be able to prevent any initiative on the part of the participants with intellectual disabilities. These elements are often intimately linked to some of the functional specificities of intellectual disabilities (AAIDD 2010) and are identified as important barriers to self-determination in the literature (Haelewyck & Nader-Grosbois 2004).

Furthermore, staff observed various embedded behaviours, tied to individual life courses, that hindered self-determination. In particular, some people with intellectual disabilities are accustomed to having a passive attitude, to being docile, and having others take responsibility for their decisions and actions. Staff associated these behaviours with a lack of self-confidence, which can trigger withdrawal in residents when their ideas are not accepted. This is how a professional explained the problem: 'And I think it depends on each person's life course. Some people arrive here feeling the weight of the past. They are not used to taking the lead, they don't dare give an opinion. And this, to me, represents a boundary that they have to learn to actively and consciously cross if they are going to thrive a little and express some self-determination' (Maxime, staff, residential institution 2). This passive trend, which has often taken place in people with intellectual disabilities due to the lack of developmental opportunities in many areas of their lives, seems to be a powerful barrier to self-determination, according to our results. When important, this lack of confidence is likely to prevent any self-determined initiative.

Personal Facilitators

Conversely, staff and residents agreed that the latter can best achieve self-determination when they are self-confident, have high self-esteem, are capable of appreciating their own abilities, and can establish priorities. Other personal facilitators to self-determination identified by participants include the ability of people with intellectual disabilities to show initiative, to develop projects, to question themselves, to make decisions, to take action, to work autonomously, to express opinions, to be assertive, to show flexibility, and to ask for advice. For example, a staff member explained how one particular resident usually makes decisions: 'This has always surprised me about him. He is capable of making a lot of decisions very quickly. Usually, he can't explain why he made a particular choice; he just knows what he wants' (Maxime, staff, residential institution 2). Finally, participants noted the ability of residents to leverage available resources, to keep some things to themselves, and to maintain a private space. Skills present in residents have proved to be real levers for support for self-determination; some professionals have indeed mentioned the importance of being aware of this and of relying on these existing resources in their support practices. So that these resources can be fully expressed, it is however a question of allowing the accompanied persons to mobilize them in autonomous learnings which make sense for them. For example, Rebecca tells us that she needs to make her own experiences to grow: 'We have to experience it for ourselves. If they tell me, "Go on, experience things for yourself," if I fall over, at least I will not turn to them, I will tell myself, "It's your fault, you wanted to go too fast." We also need to fall over to learn' (Rebecca, resident, residential institution 2).

Relational Barriers and Facilitators

Our study identified a large number of relational barriers and facilitators that reflect the key role of relationships in promoting self-determination. And given our methodology, most of these factors concern relationships between residents and staff. However, participants also mentioned other kinds of relationships, including those with relatives, friends, and romantic partners.

Relational Barriers Associated With Staff

Some relational barriers to self-determination, such as a tendency to overprotect people with intellectual disabilities, were associated with both social care professionals and family members. As a professional explained: 'We need to hold back because, deep down, we may also have certain fears or feel the need to protect the person' (Geraldine, staff, residential institution 1).

Such fears and urges can hinder self-determination insofar as they prevent people with intellectual disabilities from controlling their own lives. Indeed, both staff and family members recognized their tendency to take too much responsibility for residents; to think, to make decisions, to act on their behalf, and to anticipate their choices. The emotions of the professionals who support people with intellectual disabilities therefore appear in our data as barriers to supporting their self-determination; by taking part in the relationship, these fears prevent the professionals from offering the space needed by the persons to experiment through actions based on their own initiatives.

Social care professionals who lack the time and energy to fully develop their relationships with residents, or who are reluctant to change, were seen as barriers to self-determination among people with intellectual disabilities. Staff reported a tendency to impose their own wishes and schedules on residents or to think they knew what was best for people with intellectual disabilities. Furthermore, when transitions occur, staff often blindly adopt their colleagues' approaches to working with particular residents, rather than reassessing individual needs and specific circumstances. This can perpetuate prejudices, including the idea that residents lack the confidence or motivation necessary for self-determination: 'You might be on the same team for eight years, and when a transition happens, you're told, "Look, you should act this way with her because she is an anxious person. We've always done things this way. It works well.' So I just take their advice and I eventually stop questioning myself. You end up always following the same routine and, after eight years, you notice that the person has stopped growing.' (Françoise, staff, residential institution 1). The routine that can be revealed in the accompaniment of people with intellectual disabilities can become an important barrier to the promotion of self-determination, preventing the person from opening up to new horizons and developing new skills. Changes related to the self-determination of people with intellectual disabilities consequently generate changes in the whole system surrounding them. According to our results, it seems important to consider the various resistances that may occur in this context.

Staff also recognized that they often wrongly equate self-determination with total freedom, and therefore avoid promoting it. Professionals can indeed stand in the way of self-determination among people with intellectual disabilities when they fear losing control over the residential institution and when they see residents' choices and goals as too abstract. This is how one staff member described the issue: 'When I bring it up behind the scenes, I find that there are still some people, including those responsible for implementing the self-determination program, who think that staff would lose some of their power if [residents] took more control over their lives. This way of thinking can pose a major barrier to self-determination' (Samantha, staff, residential institution 3). The understanding and representations that professionals have of self-determination seem to be important elements to consider if we want to encourage them to promote it in their support practices. We noted that during our research, the professionals' representations of self-determination have shifted from a theoretical representation, derived from their professional training, to an embodied and experiential understanding, anchored in daily life and relationships (Vaucher, Cudré-Mauroux & Piérart 2019).

Finally, staff can also hinder self-determination out of fear of self-exposure or a desire to protect themselves—for example, by trying to keep their private and professional lives separate. Participants with intellectual disabilities noted, however, that genuine sharing with professionals could be a source of learning, as Rebecca explained: 'I like spending time with staff members, doing several activities, laughing, talking about how it goes at their place, knowing that life is not always simple, knowing that their life is not easy either' (Rebecca, resident, residential institution 2).

Relational Facilitators Associated with Staff

Participants saw the social care relationship as a key context for promoting self-determination among people with intellectual disabilities. Indeed, residents considered the presence, support, and encouragement of social care professionals to be key resources. For instance, staff might encourage residents to be more assertive and develop their decision-making abilities, or support them in the achievement of a goal once they had made a choice. While searching for an apartment and in order not to be discouraged by negative perceptions of people with intellectual disabilities, Pablo needed motivational support. He explained: 'I also had a little help. Marc was like, "Go, go! Don't lose faith!" And I was starting to get fed up. I was saying, "I am tired of it, I want to stop it all and I will look next year. But sometimes Marc was telling me, "No, Pablo, you will find it!" [an apartment]. (...) It was nice of him to encourage me. Sometimes he came to my workplace and asked me about the procedure, and he was like, "No Pablo, you shall find!"' (Pablo, resident, residential institution 1). Based on our data, professionals can also facilitate self-determination among people with intellectual disabilities by listening to them, trusting them, valuing their actions and decisions, and refraining from expressing judgments or attempting to influence choices. Staff explained how, before offering to support residents achieve a goal, it was important to proactively create a space where requests and goals could take shape. Such a space could also help residents analyze the situation and address questions on their own. Social care professionals could subsequently support people with intellectual disabilities evaluate the feasibility of their choices and consider

alternatives. Self-determination appeared to be further promoted by support that adapts to individual abilities and limitations, that remains in place over the long term, and that helps residents understand the broader context of their decisions.

Meanwhile, residents emphasized the importance of communication for promoting self-determination. Thus, people with intellectual disabilities need to be able to express themselves and their desires through words or actions, to discuss their goals and how to achieve them, and to have someone who will listen attentively. Likewise, a willingness to seek out support and advice, an ability to formulate requests and express disagreement, and a readiness to express preferences and opinions were all identified as facilitators to self-determination.

Staff described being able to co-construct relationships based on partnership when they abandoned their need for control, when they reassessed existing approaches, when they revealed themselves, and when they shared their own life experiences with residents. These co-constructed relationships were considered crucial to promoting self-determination among people with intellectual disabilities: 'When all is said and done, we're in a relationship. And in a relationship, you need to do your part. Because I trust him, I can also contribute. I think this is an essential part of building a partnership. Without it, we'll never really have a real partnership. We won't be able to talk about self-determination because that can only be achieved when you can reveal yourself and you can count on the other person's respect' (William, staff, residential institution 1). A relationship based on partnership requires symmetrical interactions, by taking power off the professionals and by considering the relational needs of the people supported (Cudré-Mauroux, Piérart et Vaucher 2019).

Finally, staff reported being better able to support self-determination among people with intellectual disabilities when residents felt responsible for their own choices and actions, and when they were given an opportunity to influence decisions made at their residential institution.

Relational Barriers Associated with Family

In terms of barriers to self-determination, residents mentioned a tendency among their relatives to infantilize them by providing too much assistance with daily tasks and by limiting opportunities for decision-making. As with professionals, the tendency to overprotect people with intellectual disabilities also affects families. In particular, residents described how their parents wanted to know everything and ended up invading their privacy. As one participant with intellectual disabilities reported: 'I explained to my mother that she's always bringing up my disability. I told her that I don't want her interfering in my business' (Anaïs, resident, residential institution 3).

Professionals confirmed these observations, mentioning how some parents asked for detailed accounts of residents' daily lives at the residential institution. Paradoxically, parents reportedly expressed fears that their children with intellectual disabilities would become either too independent or submissive. Indeed, family members' inability to listen and their lack of confidence in residents were seen as hindering self-determination. Some residents reported that their relatives were too demanding, gave too much advice, or sometimes tried to influence their decisions. Finally, residents cited the idea that they do not have the same rights as others, especially where romantic relationships are concerned, as a barrier to self-determination. This is how one resident explained the situation: 'At the same time, like anyone else, whether or not they have an intellectual disability, I have the right to have a boyfriend, I have the right to want to find love, I have the right to dream. And sometimes it's hard to make my parents understand that' (Rebecca, resident, residential institution 1). The impact that the extended environment of supported persons can have on the results related to support to self-determination should not be overlooked.

Relational Facilitators Associated with Family

Relatives were seen as supporting self-determination in people with intellectual disabilities when they expressed trust in residents, supported the latter's autonomy, and respected their privacy. Participants also stressed the importance of close family ties. Indeed, relatives were seen by the professionals as being better able to promote self-determination among residents when both parties knew each other well. However, our research setting provided very little data regarding this aspect.

Discussion

Our study challenges the idea that individuals make choices free of any external influence. Our results show that the self-determination of people with intellectual disabilities is subject to many systemic influences. Indeed, whether they face an everyday choice or an important decision, people with intellectual disabilities tend to seek out support from professionals, thereby expressing a need for emotional and practical support. Their environment reacts to their requests and self-determined actions, in particular according to the influence of these on its organization. Existing studies recognize that a range of factors, including personal characteristics and environmental variables, shape self-determination among people with intellectual disabilities (Shogren 2013; Stancliffe 2001). In particular, the social-ecological model of self-determination emphasizes the interplay between individuals and their environment (Shogren 2013). Our results concur with this model in terms of how individual, family, and public considerations impact self-determination among people with intellectual disabilities.

Our study also highlights how social representations—and not just social behaviours—can hinder self-determination among people with intellectual disabilities. Indeed, other researchers have noted how individuals need to have positive beliefs about themselves and their future to achieve self-determination (Palmer & Wehmeyer 1998). Disability labels have also been cited as a potential barrier to self-determination among people with intellectual disabilities (Shogren, Wehmeyer, Palmer, Soukup, Little et al. 2007).

With regard to family, residents reported being infantilized by close relatives who provide too much assistance with daily tasks and leave little room for independent decision-making. By imposing their view of what is best for people with intellectual disabilities and of how the latter should behave, family members can usurp their autonomy. Residents also expressed a need for privacy and complained of frequent intrusive behaviour on the part of relatives (Barr, McConkey & McConaghie 2003). Likewise, other studies have identified overprotective parents as potential barriers to self-determination among adults with intellectual disabilities (Jahoda & Markova 2004; Shogren & Broussard 2011). Barr et al. (2003) suggest a possible link between a lack of privacy and a tendency to infantilize people with intellectual disabilities. However, whereas they focus on the fact that staff has keys to residents' rooms, our results highlight the threat to privacy posed by family members. We found that staff tends to serve as mediators when residents complain of intrusive family members. Another study that addresses the challenges faced by parents of children with intellectual disabilities confirms a tendency among family members to cast themselves in the role of decision-maker or instructor (Bianco, Garrison-Wade, Tobin, & Lehmann 2009).

Meanwhile, social care professionals find themselves torn between the desire to encourage self-determination and empowerment among people with intellectual disabilities, and the need to follow institutional procedures and daily routines. For example, they may be required to organize activities and complete tasks on a group basis, while engaging all residents simultaneously (Finlay, Antaki, & Walton 2008). Existing studies also reveal a tendency among social care professionals to interrupt the decision-making cycle of people with intellectual disabilities, resulting in disempowerment (Antaki, Finlay, Walton, & Pate 2008). This echoes our findings on the excessive control that relatives and staff sometimes exert over the lives of residents.

Our study confirms the results of others (McConkey & Collins 2010; Wehmeyer 1996) that highlight the crucial role played by the interpersonal relationship between residents and professionals in promoting, supporting, and maintaining self-determination among people with intellectual disabilities. However, the relationship with professionals is not the only relevant context for promoting self-determination. In particular, we found that residents recognized the importance of having strong trusting relationships with not only staff but also family members who could provide emotional support, practical assistance, and advice in the context of decision-making.

Reflexivity and Limitations

The results presented in this article were based on the study of self-determined practices in the context of relationships between adults with intellectual disabilities and social work professionals, themselves embedded in the context of facilities intended for the support of people with intellectual disabilities. Therefore, and all the more given dominant models that have demoted people with disabilities in subaltern positions, in society as in research, it is important to reflect on how our study design may have influenced our results. Indeed, the perceptions of barriers and facilitators to self-determination which were suggested by our study participants were co-created in the context of their daily relationships as well as in the context of our study setting. While we considered the presence of staff members who shared a previous privileged relationship with the residents as very useful in the expression and understanding of the residents' point of views, it cannot be completely excluded that their presence and participation may have influenced the participants' statements or attitudes. Our methodological choices were embedded in our interest in the construction and maintenance of self-determined practices in the context of a socio-pedagogical relationship. Therefore, the results may have been different if we had decided to use peer groups of people with intellectual disabilities instead of dyads with social care professionals.

However, we considered it important to investigate the positive part that the relationship between people with intellectual disabilities and social care professionals may play on the self-determination of people with intellectual disabilities. A recent study suggested that people with intellectual disabilities who had shared training on self-determination with social work professionals showed a greater degree of learning regarding self-regulation skills than their peers who followed the same training in a group of people with intellectual disabilities only (Fontana et al. 2016). Similarly, the impacts of our study setting in terms of mutual enrichment brought us to consider that reflective spaces regarding self-determination would benefit from being mixed (residents and staff members), to potentiate inter-influences in the learning process and to generate and maintain an inclusive effect.

In relation to the inductive, exploratory and qualitative nature of our research study, and to the restricted number of participants, we do not aim at generalizing its results. Indeed, being aware that the actual Swiss context regarding the support offered to people with intellectual disabilities is quite different from other European and international contexts—namely in terms of residential settings or inclusion policies—we consider that our results have to be taken with precaution.

While we didn't consider age as a relevant feature for analyzing the perceptions and practices of both professionals and people with intellectual disabilities during the research process, we now realize that knowing the age of the

participants could have enriched our analysis. Indeed, by crossing the participants' age with their statements regarding self-determination, it may have been possible to investigate how age itself or life trajectories may have influenced the barriers and facilitators experienced by the participants, and how they may have managed to overcome some barriers over time.

Finally, the restricted size of the population under study did not allow for compared analyses underscoring how gender or localization of the residential institution may have influenced the barriers and facilitators encountered by the participants regarding the self-determination of people with intellectual disabilities.

Conclusion and Implications for Practice

Our research results suggest that the potential for self-determination among people with intellectual disabilities is defined by the constant interplay between individuals and their environment (society, institutional setting, education, family, friends, partners, etc.). It is therefore important for people with intellectual disabilities to develop trusting relationships with individuals who can provide support, advice, and active listening in the context of decision-making.

Our findings and those of other researchers (Wong & Wong 2008) underscore the importance of optimizing conditions for self-determination among residents of facilities for people with intellectual disabilities. It is therefore crucial to implement strategies that are adapted not only to the personal characteristics of each resident, but also to the specific environment where that individual develops daily. A first step would be to recognize the importance of self-determination for people with intellectual disabilities who live in an institutional setting and to help professionals overcome their fear of giving up some control. Indeed, our study shows that providing residents with more opportunities for social participation and decision-making in no way threatens relationships based on respect and trust.

Our research results indicate the importance of considering the various systemic factors acting on the self-determination of people with intellectual disabilities in the organization of hosting facilities, as well as in support and training. At the level of organization of hosting facilities, our results highlight the need for adjustment between institutional features and the desire to promote the self-determination of the people hosted. The socio-ecological approach to self-determination takes into account the repercussions that the environment can have on the development of self-determination (Shogren 2013); thus, the promotion of self-determination *de facto* initiates a change at the organizational level. It is first a question of considering the material, financial and legal resource needs related to the promotion of self-determination. To allow adequate and individualized support, facilities should not only provide the means necessary but also clarify their role in terms of responsibility, to guarantee a security basis on which the actions of professionals and the development of people can rely on. Facilities must remain places that offer security and protection to the people they host while helping them to grow. In order to promote the self-determination of people by relying on innovative and inclusive practices, it would also be about reviewing rigid and hierarchical managerial trends, by becoming aware and by accepting the effects that the emancipation of people with intellectual disabilities will have on organizational functioning.

In terms of support, we believe the aim would be developing a partnership relationship within which different elements would be addressed in the course of the occurring life experiences. It would thus be a question of considering the various barriers likely to appear on the path to self-determination, of developing the necessary skills for its implementation, and of relying on existing individual resources. In this context, it seems important to take into account the negative representations of intellectual disability people may have and to prepare people to face them. The emotions of fear that may appear in people with intellectual disability, as well as the learned passivity which they often experience, could also be approached relationally, helping them to become aware of the progress they are making based on concrete experiences of mastery.

Concerning training, we believe it is important to help professionals build a positive and realistic representation of the self-determination of the people they support. The aim would be to encourage them to learn based on life experiences, by daring to question theoretical models which are sometimes difficult to relate with realities in the field. In relation to these representations, it would be important to help professionals become aware of their resistances and to understand how their actions and attitudes can represent resources or barriers to the self-determination of the people they support. Finally, to help them set up support practices based on partnership, it would be beneficial to discuss the necessary evolution of some of their practices.

Competing Interests

The authors have no competing interests to declare.

References

- American Association on Intellectual and Developmental Disabilities (AAIDD). 2010. *Intellectual Disability: Definition, Classification and Systems of Supports* (11th Edition). Washington, DC: American Association on Intellectual and Developmental Disabilities.
- Antaki, C., Finlay, W., Walton, C., and Pate, L. 2008. "Offering Choices to People with Intellectual Disabilities: An Interactional Study." *J Intellect Disabil Res* 52(12): 1165–1175. DOI: <https://doi.org/10.1111/j.1365-2788.2008.01101.x>

- Barbour, R., and Kitzinger, J. 1999. *Developing Focus Group Research: Politics, Theory and Practice*. London: Sage Publications. DOI: <https://doi.org/10.4135/9781849208857>
- Barr, O., McConkey, R., and McConaghie, J. 2003. "Views of People with Learning Difficulties about Current and Future Accommodation: The Use of Focus Groups to Promote Discussion." *Disability & Society* 18(5): 577–597. DOI: <https://doi.org/10.1080/0968759032000097834>
- Bergstrom, N. 2008. "The Gap Between Discovery and Practice Implementation in Evidence-based Practice: Is Practice-based Evidence a Solution?" *Int J Evid Based Healthc* 6(2): 135–136. DOI: <https://doi.org/10.1111/j.1744-1609.2008.00102.x>
- Bianco, M., Garrison-Wade, D. F., Tobin, R., and Lehmann, J. P. 2009. "Parents' Perceptions of Postschool Years for Young Adults with Developmental Disabilities." *Intellect Dev Disabil* 47(3): 186–196. DOI: <https://doi.org/10.1352/1934-9556-47.3.186>
- Carter, E. W., Lane, K. L., Cooney, M., Weir, K., Moss, C. K., and Machalicek, W. 2013. "Parent Assessments of Self-determination Importance and Performance for Students with Autism or Intellectual Disability." *Am J Intellect Dev Disabil* 118(1): 16–31. DOI: <https://doi.org/10.1352/1944-7558-118.1.16>
- Cudré-Mauroux A., Piérart G., and Vaucher C. 2019. "The Importance of the Relational Needs of People with Learning Disabilities in the Promotion of Self-determination." *British Journal of Learning Disabilities* 1–7. DOI: <https://doi.org/10.1111/bld.12268>
- Cudré-Mauroux, A., Piérart, G., and Vaucher, C. Under review. "Partnership with Social Care Professionals as a Context for Promoting Self-determination Among People with Intellectual Disabilities."
- Détraux, J.-J. 2014. "La Place de la Personne en Situation de Handicap Dans la Recherche: Quels Principes Éthiques ?" In *Méthodes de Recherche Dans le Champ de la Déficience Intellectuelle*, edited by G. Petitpierre & B.-M. Martini-Willemin 187–221. Berne: Peter Lang.
- Finlay, W. M., Antaki, C., and Walton, C. 2008. "Saying No to the Staff: An Analysis of Refusals in a Home for People With Severe Communication Difficulties." *Sociol Health Illn* 30(1): 55–75. DOI: <https://doi.org/10.1111/j.1467-9566.2007.01028.x>
- Fontana-Lana, B., Angéloz Brügger, P., Gobet, L. and Hauenstein, I. 2016. "Des Outils Pour Soutenir L'implémentation de Pratiques D'autodétermination et de Participation Citoyenne en Milieu Socio-éducatif." *Revue Suisse de Pédagogie Spécialisée* 1: 18–25.
- Fraser, M., and Fraser, A. 2001. "Are People with Learning Disabilities Able to Contribute to Focus Groups on Health Promotion?" *J Adv Nurs* 33(2): 225–233. DOI: <https://doi.org/10.1046/j.1365-2648.2001.01657.x>
- Gates, B., and Waight, M. 2007. "Reflections on Conducting Focus Groups with People with Learning Disabilities." *Journal of Research in Nursing* 12(2): 111–126. DOI: <https://doi.org/10.1177/1744987106075617>
- Gaumer Erickson, A. S., Noonan, P. M., Zheng, C., and Brussow, J. A. 2015. "The Relationship Between Self-determination and Academic Achievement for Adolescents with Intellectual Disabilities." *Res Dev Disabil* 36: 45–54. DOI: <https://doi.org/10.1016/j.ridd.2014.09.008>
- Giard, M.-F., and Morin, D. 2010. «Le Consentement à la Recherche en Déficience Intellectuelle: Situation Québécoise.» *Revue Francophone de la Déficience Intellectuelle* 21: 40–53.
- Haelewyck, M. C., and Nader-Grosbois, N. 2004. «L'autorégulation: Porte D'entrée Vers L'autodétermination des Personnes Avec Retard Mental?» *Revue Francophone de la Déficience Intellectuelle* 15: 173–186.
- Jahoda, A., and Markova, I. 2004. "Coping with Social Stigma: People with Intellectual Disabilities Moving from Institutions and Family Home." *J Intellect Disabil Res* 48(Pt 8): 719–729. DOI: <https://doi.org/10.1111/j.1365-2788.2003.00561.x>
- Lachapelle, Y., Wehmeyer, M. L., Haelewyck, M. C., Courbois, Y., Keith, K. D., Schalock, R., et al. 2005. "The Relationship Between Quality of Life and Self-determination: An International Study." *J Intellect Disabil Res* 49(Pt 10): 740–744. DOI: <https://doi.org/10.1111/j.1365-2788.2005.00743.x>
- Marquis, R. and Jackson, R. 2000. "Quality of Life and Quality of Service Relationships: Experiences of People with Disabilities." *Disability & Society* 15: 411–425. DOI: <https://doi.org/10.1080/713661967>
- McConkey, R., and Collins, S. 2010. "The Role of Support Staff in Promoting the Social Inclusion of Persons with an Intellectual Disability." *J Intellect Disabil Res* 54(8): 691–700. DOI: <https://doi.org/10.1111/j.1365-2788.2010.01295.x>
- McPherson, L., Ware, R. S., Carrington, S., and Lennox, N. 2016. "Enhancing Self-Determination in Health: Results of an RCT of the Ask Project, a School-Based Intervention for Adolescents with Intellectual Disability." *J Appl Res Intellect Disabil*. DOI: <https://doi.org/10.1111/jar.12247>
- Miles, M. B., and Huberman, A. M. 2003. *Analyse des Données Qualitatives*. Bruxelles: De Boeck.
- Muir, W. J., and Gibbs, S. M. 2006. "Research in the Psychiatry of Learning Disability." In *Research Methods in Psychiatry*, edited by C. Freeman & P. J. Tyrer, 252–291. London: Gaskell.
- Palmer, S. B., and Wehmeyer, M. L. 1998. "Students' Expectations of the Future: Hopelessness as a Barrier to Self-determination." *Ment Retard* 36(2): 128–136. DOI: [https://doi.org/10.1352/0047-6765\(1998\)036<0128:SEOTFH>2.0.CO;2](https://doi.org/10.1352/0047-6765(1998)036<0128:SEOTFH>2.0.CO;2)
- Peterson, C. 2004. *Looking forward through the lifespan*. Frenchs Forest, NSW: Pearson.

- Sands, D. J., and Kozleski, E. B. 1994. "Quality of Life Differences Between Adults With and Without Disabilities." *Education and Training in Developmental Disabilities* 29: 90–101.
- Sarrazin, C. 2013. *Autodétermination et Déficience Intellectuelle. L'expérience D'une Institution Suisse: Le Village d'Aigues-Vertes*. Saint-Denis: Edilivre.
- Shogren, K. A. 2013. "A Social-ecological Analysis of the Self-determination Literature." *Intellect Dev Disabil* 51(6): 496–511. DOI: <https://doi.org/10.1352/1934-9556-51.6.496>
- Shogren, K. A., and Broussard, R. 2011. "Exploring the Perceptions of Self-Determination of Individuals with Intellectual Disability." *Intellect Dev Disabil* 49(2): 86–102. DOI: <https://doi.org/10.1352/1934-9556-49.2.86>
- Shogren, K. A., Wehmeyer, M. L., Palmer, S. B., Soukup, J. H., Little, T. D., Garner, N., et al. 2007. "Examining Individual and Ecological Predictors of the Self-determination of Students with Disabilities." *Except Child* 73: 488–509. DOI: <https://doi.org/10.1177/001440290707300406>
- Soresi, S., Nota, L., and Wehmeyer, M. L. 2011. "Community Involvement in Promoting Inclusion, Participation and Self-determination." *International Journal of Inclusive Education* 15(1): 15–28. DOI: <https://doi.org/10.1080/13603116.2010.496189>
- Stancliffe, R. J. 1997. "Community Living-unit Size, Staff Presence, and Residents' Choice-making." *Ment Retard* 35(1): 1–9. DOI: [https://doi.org/10.1352/0047-6765\(1997\)035<0001:CLSSPA>2.0.CO;2](https://doi.org/10.1352/0047-6765(1997)035<0001:CLSSPA>2.0.CO;2)
- Stancliffe, R. J. 2001. "Living With Support in the Community: Predictors of Choice and Self-determination." *Ment Retard Dev Disabil Res Rev* 7(2): 91–98. DOI: <https://doi.org/10.1002/mrdd.1013>
- Stancliffe, R. J., Abery, B. H., and Smith, J. 2000. "Personal Control and the Ecology of Community Living Settings: Beyond Living-unit Size and Type." *American Journal of Mental Retardation* 105: 431–454. DOI: [https://doi.org/10.1352/0895-8017\(2000\)105<0431:PCATEO>2.0.CO;2](https://doi.org/10.1352/0895-8017(2000)105<0431:PCATEO>2.0.CO;2)
- Thoma, C. A., and Getzel, E. E. 2005. "'Self-determination Is What It's All About': What Post-secondary Students With Disabilities Tell Us Are Important Considerations for Success." *Education and Training in Developmental Disabilities* 40: 217–233.
- UNAPEI. 2009. «L'information Pour Tous. Règles Européennes Pour une Information Facile à Lire et à Comprendre.» http://www.unapei.org/IMG/pdf/Guide_ReglesFacileAlire.pdf
- Vaucher C., Cudré-Mauroux A., and Piérart G. 2019 "Perceptions and Understandings of Self-determination in the Context of Relationships Between People With Intellectual Disabilities and Social Care Professionals." *International Journal of Developmental Disabilities*, 1–10. DOI: <https://doi.org/10.1080/20473869.2019.1623595>
- Wehmeyer, M. L. 1996. "Self-determination as an Educational Outcome: Why Is It Important to Children, Youth and Adults With Disabilities?" In *Self-determination across the life span: independence and choice for people with disabilities*, edited by D. J. Sands & M. L. Wehmeyer, 15–34. Baltimore: Paul H. Brookes.
- Wehmeyer, M. L., and Metzler, C. A. 1995. "How Self-determined are People With Mental Retardation? The National Consumer Survey." *Ment Retard* 33(2): 111–119.
- Wehmeyer, M. L., and Palmer, S. B. 2003. "Adult Outcomes for Students with Cognitive Disabilities Three-Years After High School: The Impact of Self-Determination." *Education and Training in Developmental Disabilities* 38(2): 131–144.
- Wehmeyer, M. L., and Schwartz, M. 1998. "The Relationship Between Self-determination, Quality of Life, and Life Satisfaction for Adults With Mental Retardation." *Education and Training in Mental Retardation and Developmental Disabilities* 33: 3–12.
- Wong, P. K., and Wong, D. F. 2008. "Enhancing Staff Attitudes, Knowledge and Skills in Supporting the Self-determination of Adults With Intellectual Disability in Residential Settings in Hong Kong: A Pretest-posttest Comparison Group Design." *J Intellect Disabil Res* 52(Pt 3): 230–243. DOI: <https://doi.org/10.1111/j.1365-2788.2007.01014.x>

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