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Perceptions and understandings of self-determination in the context of relationships between people with intellectual disabilities and social care professionals

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This study examines perceptions and understandings of self-determination in the context of relationships between people with intellectual disabilities and social care professionals. We held focus group discussions to explore the views and experiences of 10 residents and 10 professionals at three facilities for people with intellectual disabilities located in Western Switzerland. Participants perceived and understood self-determination in terms of decision-making, social skills, procedures, identity, self-consciousness, autonomy, freedom, barriers, and facilitators. The research process highlighted the shifting and situational nature of the concept, as well as the importance of self-determination for people with intellectual disabilities. The findings also highlight the importance of discussion and reflection on the concept of self-determination and its benefits for people with intellectual disabilities.

Keywords: Intellectual disabilities, self-determination, educational relationships, special education, perceptions

Background

In recent decades, the self-advocacy and empowerment movements have highlighted the efforts and importance of promoting self-determination among people with intellectual disabilities (Carter *et al*. 2008, Soresi *et al*. 2011). 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 and Palmer 2003, Palmer *et al*. 2004), academic achievement (Zheng *et al*. 2014, Gaumer Erickson *et al*. 2015), and quality of life (Wehmeyer and Schwartz 1998, Lachapelle *et al*. 2005). Other studies stress the importance of self-determination among people with intellectual disabilities in the fields of health care (Deci and Ryan 2012, Bastien *et al*. 2015, McPherson *et al*. 2016); education, especially during the transition from school to adulthood (Carter *et al*. 2013, Gragoudas 2014); and physical activity (Springer 2013). Furthermore, several studies have contributed to highlight the impact of efforts to promote self-determination on self-determination itself among people with intellectual disabilities (Bambera

and Gomez 2001, Field and Hoffman 2002, Powers *et al*. 2004). Other studies have focused on the impact of self-determination training on school and adult outcomes (Eisenman and Chamberlin 2001, Carter *et al*. 2008), notably in terms of student involvement (Allen *et al*. 2001, Arndt *et al*. 2006) and task performance (Copeland and Hughes 2002).

In the field of intellectual disabilities, self-determination refers to people's right and ability to control their own lives. The notion of causal agent is key to the idea of a person who acts deliberately and with purpose (Wehmeyer 2005). The most common model of self-determination focuses on four personal characteristics: autonomy, self-regulation, empowerment, and self-realization (Wehmeyer 1996). Although educational strategies have been developed to promote self-determination among people with intellectual disabilities, little is known about how these individuals subjectively perceive and understand the concept. Furthermore, people with intellectual disabilities remain under-represented in social sciences research (McDonald *et al*. 2008).

Perceptions of self-determination among people with intellectual disabilities have mainly been studied in the context of the transition to adulthood and educational

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outcomes (Trainor 2005, Trainor 2007). Studies show that young people with intellectual disabilities tend to understand self-determination in terms of an ability to plan for future, to achieve goals, and to set new objectives. These individuals therefore consider self-determination to be very important in an educational context. They also see it as an evolving process (Madson Ankeny and Lehmann 2011) that requires the development of problem-solving skills and self-awareness (Getzel and Thoma 2008).

We wish to emphasis three projects which have explored the perceptions and understanding of self-determination among people with intellectual disabilities, by eliciting their opinion and making their voices heard, which is also one of our goals in this article. First, Shogren and Broussard's qualitative study (2011) has explored everyday perceptions and understandings of self-determination among adults with intellectual disabilities. Their study found that perceptions of self-determination were structured around three main themes: (a) the meaning of self-determination in everyday life, including people's ability to choose, to set goals, and to defend their rights; (b) the different ways that people can learn to become more self-determined; and (c) hopes for the future, including the desire to be included and to participate in society. Secondly, the National gateway to self-determination (2011) interviewed people with intellectual disabilities about their understanding of self-determination. The participants in this video project mainly perceived self-determination in terms of self-consciousness, choice-making, well-being, and the ability to do things on one's own. Thirdly, a recent research by Suk-Hyang *et al.* (2019) explored perceptions and experiences of self-determination among children and young adults with intellectual disability and distributed their findings into four main themes: (a) participants awareness both of the term self-determination and of its meaning; (b) practices of self-determined behaviors, among which were decision-making and conflict situations involving the participants' desires; (c) goals for transition to adulthood, notably in terms of self-improvement, employment, housing and marriage; and (d) plans for achieving transition goals, mainly studying.

Although existing studies highlight the importance of promoting self-determination, self-management and social inclusion among people with intellectual disabilities, as well as the important role of staff in this effort (McConkey and Collins 2010, Sandjojo *et al.* 2018), very few researchers have explored perceptions and understandings of self-determination in the context of relationships between people with intellectual disabilities and social care professionals. Yet the perceptions observed among the participants in our study can help develop better professional strategies for promoting self-determination, as well as new insights on the

perceptions and understandings of self-determination from the perspective of people with intellectual disabilities. "Perceptions" refers to how participants defined and understood self-determination, as well as to how they subjectively experienced it—in other words, how self-determination manifested itself in their everyday lives. This article therefore addresses participants' prior knowledge of self-determination, as well as how their perceptions and understandings evolved over the course of the research project. More precisely, it aims at exploring their embodied perceptions of self-determination, by relating them to the people's lived experience, taking into account the phenomenological, relational and situational nature of the concept.

Methods
Study setting
Our participatory research project used qualitative methods to explore the views and experiences of people with intellectual disabilities, as well as those of professionals. It investigated the processes that support everyday expressions of self-determination in the context of professional support relationships. Existing studies show both the potential and the pitfalls of qualitative research involving people with intellectual disabilities (Kiernan 1999, Gilbert 2004, Lennox *et al.* 2005). Among the documented stakes-known by researchers as well as by social care professionals-appear the greater vulnerability of this population, in particular during the recruitment process, difficulties regarding their freedom of consent, and the importance of ensuring that the people have well understood the implications of their participation in the research. Finally, when the data collection phase occurs over an extended period, it can be difficult to ensure the attendance of participants with intellectual disabilities, and withdrawals can occur. Our awareness of these challenges—through an extended literature review and our professional experience—informed our methodological choices, among which the choice to hold various discussions with the participants before the study was initiated, as will be detailed hereafter.

Over a period of ten months (September 2015 to June 2016), we collected data from 13 focus group discussions involving residents and staff at three residential facilities for people with intellectual disabilities located in the cantons of Geneva, Vaud, and Fribourg (Western Switzerland).

We initially approached several facilities that (a) offer residential services to people with intellectual disabilities and (b) address the question of self-determination in their institutional guidelines. We began by sending an introductory document, prepared according to established accessibility guidelines for French-language text (UNAPEI 2009), to facilities that expressed an interest in the project. We then gave on-site

Table 1   Participants

	Facility 1		Facility 2		Facility 3	
	Residents	Staff	Residents	Staff	Residents	Staff
Dyad 1	Pablo (M)	Mark (M)	Sam (M)	Max (M)	Anaïs (F)	Samantha (F)
Dyad 2	Sarah (F)	Geraldine (F)	Layla (F)	Julie (F)	Celia (F)	Alex (M)
Dyad 3	Rebecca (F)	Françoise (F)	Julian (M)	Louis (M)		
Dyad 4	John (M)	Bill (M)	Joe (M)	Bob (M)		
Total	4	4	4	4	2	2

presentations to interested professionals and residents, using simplified language and visual supports. During this whole recruitment process, we began to address the specific needs of people with intellectual disabilities by adjusting the pace of our presentations to their signs of fatigue or inattention, by using visual supports, by adapting our language to their level of comprehension, and by requesting the help of the social care professionals who were present to ensure the clearest understanding possible on the part of the people with intellectual disabilities. Finally, we ensured that everyone had enough time to make a decision, and encouraged the potential participants with intellectual disabilities to talk about the research project and the implications of their possible participation with the staff members.

The participation of people with intellectual disabilities in a research project raises important ethical issues related to free and informed consent. Indeed, people with intellectual disabilities are especially vulnerable during the recruitment process (Giard and Morin 2010). On this basis and in relation to what was mentioned here above regarding the different stages of the presentation of the project to the participants with intellectual disabilities, we did the best we could to ensure that the participants with intellectual disabilities received sufficient information to make the most informed and autonomous decision possible regarding their participation in our research project. However, as our findings will show, decision-making is often a situation in which people with intellectual disabilities seek for support from staff. Therefore, we cannot exclude that their decision to participate in our study was partly encouraged by the social care professionals who accompanied them at the time.

Individuals who finally chose to participate in the project were asked to complete an adapted consent form (Détraux 2014). Before data collection began, we held a meeting including the future research participants (people with intellectual disabilities and social care professionals) as well as two of the three researchers (the third one joined the team at the stage of data collection) to address the special needs of participants with intellectual disabilities in terms of scheduling, procedures, and supports.

Participants
A total of 20 participants were assigned to 10 dyads at three different facilities. Each dyad was composed of a middle-age adult resident with mild to moderate intellectual disabilities and a special educator. The person with intellectual disabilities had to be capable of participating in a group discussion and received daily support from the special educator in an institutional setting. The members of each dyad were asked to maintain their relationships for at least one year. With one exception, the dyads were composed of participants of the same gender (F-F or M-M). All names used in the manuscript and listed in Table 1 are pseudonyms.

Study design
Focus groups
We organized focus group discussions to explore everyday perceptions, attitudes, and experiences related to self-determination. The group dynamic encouraged participants to share opinions, anecdotes, and feelings. Indeed, focus groups have been recognized as an appropriate method for studying the perceptions, attitudes, and experiences of people with intellectual disabilities (Fraser and Fraser 2001, Barr *et al.* 2003, Gates and Waight 2007, Boyden *et al.* 2009). They are accessible to this population (Muir and 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 professionals as well as peers with similar experiences and personal characteristics helps encourage active participation in group discussions (Barbour and Kitzinger 1999).

Thanks to the meeting we held with the participants before the beginning of the data collection process, we were able to pay special attention to the needs of participants with intellectual disabilities during the focus groups, adapting our language to their level of comprehension and requesting the help of participating professionals as facilitators. Researchers addressed participants by their first names, focused on practical situations, and adjusted the pace of discussions in response to fatigue or inattention.

Each focus groups (one per facility) met four times at three-month intervals, and each round of discussions dealt with specific topics, which are presented in Table 2.

In accordance with established guidelines for qualitative research involving focus groups (Puchta and Potter 2004, Markova *et al.* 2007), each 70- to 110-minute

Table 2 Topics addressed in each focus group

		Topics
First focus groups	a.	how each participant perceived, understood and defined self-determination (use of photo-language)
	b.	the importance of self-determination in their everyday lives
	c.	examples of self-determined behavior they had observed
	d.	supports and strategies for promoting self-determination among people with intellectual disabilities
Second & Third focus groups	a.	everyday expressions of self-determination, as recorded at weekly dyad meetings
	b.	how participants changed and adapted their perceptions based on shared experiences
	c.	how residents made requests related to self-determination in the context of professional support relationships
	d.	how staff responded to these requests
	e.	how the relational needs of people with ID encouraged self-determination
	f.	suggestions for support based on group discussions
Fourth focus groups	a.	how participants changed and adapted their perceptions based on shared experiences
	b.	how the study helped participants reflect on self-determination
	c.	how suggestions regarding support strategies had evolved
	d.	suggestions for support strategies based on group discussions

discussion involved between four and eight participants. Each focus group met at the facility 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.

Photo-language

The focus groups used a photo-language to articulate each participant's perceptions and understandings of self-determination. This visual method has been recognized as appropriate for use with people with intellectual disabilities, including those who are unable or reluctant to verbalize their experience (Aldridge 2014). At the start of the first discussion, all participants (including social care professionals) were shown 21 color and black-and-white pictures. They were asked to choose the one that best illustrated their understanding of self-determination, and then to explain their choice. Twelve different pictures were chosen by at least one participant. Nine of the pictures were never chosen.

Dyad discussions

Between each round of focus group discussions, we asked dyad members to jointly reflect on their experiences through writing, videos, pictures, or any other medium. They were free to choose the time, duration, and location of these weekly meetings. They also received simplified oral and written instructions asking them to discuss:

- Situations where the participant with intellectual disabilities expressed self-determination (as seen from both the resident's and the special educator's points of view).
- Different representations of self-determination.
- The effectiveness of strategies used in each situation.

Data analysis

Our comprehensive approach to data analysis involved three phases:

1. A longitudinal analysis of how perceptions of self-determination evolved within each dyad, taking into account adjustments made by dyad members. Participants illustrated their perceptions and understandings of self-determination using conceptual maps, which helped us understand how perceptions developed over time within the same facility and how they varied across all three facilities.

2. A cross-sectional comparative analysis of the conditions that promoted self-determination in the context of professional support relationships across all dyads. We identified elements that fostered or hindered expressions of self-determination and organized them in a table, along with relevant quotations from participants.

3. A practical analysis of all focus group discussions designed to help identify concrete support strategies. This cross-analysis highlighted differences between the different facilities.

Each phase involved inductive qualitative content analysis (Miles and Huberman 2003). After familiarizing ourselves with the data, we independently coded the transcripts for key themes based on our knowledge of self-determination theory and our coding rulebook (Table 3). We entered the data into spreadsheets and discussed our findings at regular meetings. All transcripts were coded using meaning units, which were grouped according to whether they related to barriers or facilitators to self-determination.

Ethics approval and consent to participate

An ethics approval request to the Swiss Ethics Committees on research involving humans was not required for this study.

All participants consented to participate in the research study and all data was processed in strict confidentiality.

Table 3 Summary of themes and subthemes

Categories	Themes		Subthemes
1. Prior understanding of self-determination	1.1 Decision-making 1.2 Social skills 1.3 Identity and self-consciousness 1.4 Autonomy and freedom 1.5 Action 1.6 Barriers and facilitators		
2. Evolving understandings of self-determination	2.1 A shifting concept	a. b. c.	evolving perceptions of self-determination gradual adoption of the concept situational and relational perceptions of self-determination
	2.2 The importance of support	a. b.	distinction between the ability to makes choices and the ability to take action situational importance of support
	2.3 A situational concept	a. b. c. d.	self-determination in everyday situations pragmatic and situational model of self-determination evaluative perspective on self-determination the importance of privacy

Findings

Prior understanding of self-determination

When the research project began, participating residents had a prior understanding of self-determination that were either intuitive or the result of previously being taught about the concept. For example, one professional, Julie, quickly found common ground with Layla, the resident in her dyad: "We agreed, and it was interesting to see how conscious she was of what self-determination means." Other participants with intellectual disabilities had no prior understanding of the concept, but were able to formulate a representation using a photo-language or through discussions with staff. For example, one resident, Pablo, explained: "I didn't know what it meant, and then he explained it to me and I gave a few examples and that is when I understood what it meant." Among professionals, prior knowledge was based on general professional training (in the fields of social work, special education, etc.) and, in some cases, specialized training directly related to self-determination.

Using a photo-language, residents and professionals alike expressed prior understandings of self-determination with symbols of elevation (birds, flight, sky, ascension, etc.) and movement (paths, departures, travel, growth, etc.). These symbols partially echoed the perceptions of self-determination which emerged later in the project, perceptions that covered six main themes:

Decision-making

Participants with intellectual disabilities primarily perceived and understood self-determination in terms of decision-making. They therefore understood self-determination as a matter of making choices for and by themselves, and according to their own tastes and preferences. Professionals also referred to self-determination in terms of autonomous decision-making, including the opportunity and ability to make important or everyday choices. However, staff focused on the importance of making choices that are good for the community (either those living and working at the facility or society in general), as well as themselves. In the words of Louis, special educator: "I also thought about the ability to choose what you think is right not only for yourself, but also for others."

Social skills

When characterizing self-determination, residents stressed the importance of being able to apologize after making a mistake, to respect others, to adapt their reactions to specific situations, and to question themselves. They also referred to communication skills, such as the ability to explain things, to discuss potential decisions, and to express themselves. As Rebecca, one of the participants with intellectual disabilities explained: "For me, self-determination is also about questioning yourself, about being able to tell yourself, "Well, OK, I made a big mistake." I question myself by saying, "Yes, it's true, I made that mistake."

Staff also identified communication skills necessary for self-determination, including the ability to express needs and desires, to say no, to explain decisions, and to explain things clearly to others.

Identity and self-consciousness

Residents associated self-determination with staying true to themselves and understanding their rights and abilities. For example, John defined self-determination as follows: "It's what you can or cannot do." Residents also referred to the role played by self-confidence, including the ability to turn down an offer. In the same vein, staff mentioned various factors related to identity, such as knowing what you want, developing self-understanding, and acknowledging your thoughts and actions.

Autonomy and freedom

Citing the ability to carry out projects on their own, residents stressed the importance of autonomy and freedom for self-determination. Likewise, staff referred to freedom and a lack of constraints. This aspect of self-determination was mainly raised when participants were using a photo-language. For example, in reference to a picture of a bird flying away from its cage, Julie, special educator, explained: "This picture makes me think about freedom, about the choices and decisions you can make, about how you can express your desires without any conditions or constraints."

Action

Participants with intellectual disabilities noted the importance of being able to set goals and move forward with a project. For them, self-determination meant actually carrying out a task after making a decision. For example, one special educator, Alex, explained a resident's understanding of self-determination as follows: "For Celia, self-determination means continuing to move forward, not backward." At the beginning of the research project, staff showed greater interest in action as a component of self-determination. They also interpreted it somewhat differently than participants with intellectual disabilities, describing it terms of lifelong learning. As another special educator, Geraldine, explained: "It's a lifelong process. And when we're children, we learn how to make choices, how to make decisions. And we continue learning these things as we get older."

Barriers and facilitators

On occasion, residents mentioned that self-determination can be difficult to achieve, and that they required support to overcome obstacles. By contrast, staff regularly stressed this aspect of self-determination, including the need to set aside certain options when making a choice. They therefore understood self-determination in terms of acknowledging practical limitations and taking responsibility for your actions and decisions. They also recognized the role played by barriers and facilitators. As one special educator, Julie, explained: "Ultimately, self-determination isn't easy. When faced with a situation, what prevents you from expressing self-determination? And what helps you express self-determination?" At the start of the research project, the question of support was not raised by residents and staff mentioned it only in passing. For example, one educator, Max, made the following comment on a picture of a storm-battered tree: "When you face challenges, like the wind in this case, you need support to grow. That's what this fellow is trying to do."

Evolving understandings of self-determination
A shifting concept

Over the course of the research project, and on the basis of concrete, lived and shared experiences between the members of each dyad, the comments and actions of participants reflected evolving perceptions and understandings of self-determination. We also observed the gradual adoption of the term "self-determination" by residents. For example, Pablo remarked: "I like what she said because at least, since she wanted to go to [the event], she showed self-determination and I think what she did was good." Both staff and residents adapted their understandings of self-determination in light of their experiences and interactions. In this respect, their perceptions of self-determination were situational and relational rather than static and transversal. Indeed, in addition to each participant's personal understanding of self-determination, each dyad appeared to develop a specific understanding of concept. At their weekly meetings, dyad members relied on this interactional understanding when discussing everyday situations related to self-determination. Furthermore, focus group discussions provided an opportunity to synthesize institutional and theoretical understandings of the concept with those expressed by individual participants, specific dyads, and the larger group. As a result, we ultimately had trouble associating specific understandings of self-determination with individual participants. However, some ideas were expressed only by certain residents or professionals.

Within the context of each participating facility, we also had difficulty determining the extent to which the institutional framework may have influenced understandings of self-determination. However, residents likely integrated aspects of the definitions provided by professionals at the weekly dyad meetings. Early in the research project, these meetings tended to produce relatively complex definitions. But in most cases, participants came to focus on the decision-making component of self-determination. For example, some staff began their dyad meetings by asking residents to list all the choices they had made during the previous week. However, even with a focus on the decision-making component, understandings of self-determination continued to evolve. At one facility, professionals noticed that their dyad meetings gradually moved from discussing everyday choices to tackling problematic or even impossible decisions, as Mark explained: "And then, we immediately started talking in more detail about these choices, how they might create conflict, what compromises had to be made. There's also the societal dimension. Toward the very end, I brought up the question of choices that you would like to be able to make, but that you can't."

The importance of support

Staff at each of the three facilities developed a new understanding of self-determination based on decision-

making. In particular, they distinguished between the ability to make choices and express desires, on the one hand, and the ability to take action and achieve goals, on the other hand. This distinction reflects the fact that people with intellectual disabilities require support to achieve some of the goals they set for themselves. As one professional, Max, explained: "At first, we discussed the choices he had made since the last time. Then, we started talking about support. Because we realized that a lot of the time, he could accomplish things on his own. But in other cases, he needed support—help from other people or practical assistance like a bank card, money, or whatever—to achieve his goals."

Residents also emphasized the importance of support. Granted, they often referred to situations where they made decisions or took actions on their own. But they also recognized a need to seek out support in other situations. This could involve asking for help, asking for an opinion, asking for permission from staff, or simply knowing where to turn.

A situational concept

Staff noted the importance of associating self-determination with everyday situations. They feared that residents would otherwise have trouble grasping the concept, as Bill explained: "We're dealing with concepts here. And people like John often have trouble grasping concepts. So, if we start talking about self-determination, he won't know what it means. But if we start by talking about his everyday life experience, then we can help him understand self-determination."

Professionals at all three facilities therefore moved toward a pragmatic and situational model of self-determination, based on everyday institutional practices and interactions.

Staff also tended to look at self-determination from an evaluative perspective, understanding it in terms of whether a person felt satisfied after making a decision or achieving a goal. They reflected on how the meaning and application of the concept varied from one situation to the next and from one person to the next. Professionals gave encouragement to residents who demonstrated behaviors associated with self-determination, such as taking initiative, taking action, seizing opportunities, and taking control of their own lives. However, staff also recognized that self-determination does not require total freedom, and that it can therefore be expressed in an institutional context—even a relatively strict one.

Meanwhile, residents gradually introduced a privacy component into their understandings of self-determination, emphasizing a right to personal space and a desire to be left alone at times. Furthermore, gradual changes in how participants with intellectual disabilities understood self-determination were accompanied by an increase in self-determined behavior. Indeed, participation in the research project seemed to empower residents, who began to report situations where they showed more autonomy, initiative, spontaneity, and perseverance in pursing goals that were important to them. They also began to perceive self-determination in terms of seeing a project through to completion.

Discussion

Our research results point to an understanding of self-determination that is embodied and experiential, rather than purely conceptual. As Samantha, one of the special educators explained: "I think we live self-determination more than we talk about it." The participants in our study perceived and understood self-determination as a pragmatic, situational and interactional concept, which is anchored in both daily life and their everyday relationships. Indeed, they underscored how practical support (financial, administrative, organizational, etc.), emotional support (comfort, presence, listening, esteem, etc.), and informational support (decision-making, opinion-sharing, information-giving, etc.) all promote self-determination. These findings bolster the theory of social support (Rascle *et al*. 2005), which differentiates emotional support from instrumental or informational support, and which emphasizes how social support protects individuals.

Furthermore, our findings underscore the need for professional training that also recognizes the importance of various forms of support that people with intellectual disabilities can receive. Existing studies that address the importance of promoting and supporting self-determination among people with intellectual disabilities show that family members, social care professionals, and residents themselves all recognize the importance of self-determination (Carter *et al*. 2009, 2013; Shogren and Broussard 2011).

Our study highlights how a concept that is widely used in the field of special education can be understood in a variety of different ways. Thus, study participants described self-determination in terms of decision-making processes, social competencies, personal identity, autonomy, freedom, obstacles, and support. Likewise, existing studies explore the relationship between self-determination and decision-making (Shogren and Broussard 2011, Carter *et al*. 2013, Wehmeyer and Abery 2013), while highlighting the importance given to choice-making opportunities by people with intellectual disabilities (Antaki *et al*. 2008).

Participants in our study—both residents and staff—identified the ability to act independently and live autonomously as a key component of self-determination. Likewise, the relevant literature often defines the concept in terms of autonomy and self-control, whether in the context of evaluating a resident's development (Turnbull and Turnbull 2001, Branding *et al*. 2009) or

promoting self-management skills in relation to physical activity (Springer 2013). Existing studies also emphasize the importance of setting and achieving goals for people with intellectual disabilities and their family members (Branding *et al*. 2009, Madson Ankeny and Lehmann 2011, Shogren and Broussard 2011).

Both the results of our study and existing research associate self-determination with an ability to speak independently and to express opinions and desires (Branding *et al*. 2009). Focus group participants often cited the importance of communication and social support, leading to discussions about barriers and facilitators to self-determination. For instance, depending on the context, family members and professionals were seen as either promoting or hindering self-determination among participants with intellectual disabilities. Indeed, existing studies show that family members can actively develop and support decision-making skills among people intellectual disabilities (Saaltink *et al*. 2012). The literature also discusses a range of other barriers and facilitators to self-determination, including personal characteristics, family structure, educational and living environments, professional and community attitudes, and public policies (Stancliffe 1995, Wehmeyer and Bolding 2001, Nota *et al*. 2007, Branding *et al*. 2009, Shogren 2013). Other researchers have highlighted the benefits of improving residents' communication skills (Jourdan-Ionescu and Julien-Gauthier 2013), the role played by family members in encouraging better communication, the importance of relationships with family and friends, the benefits of participation in activities (Barr *et al*. 2003), and the value placed on family support by adults with intellectual disabilities (Widmer *et al*. 2008, Haigh *et al*. 2013).

Participants in our study did not perceive self-determination as a static or universal concept. Rather, they saw it as situational and evolving, something that could be taught and learned over the course of a lifetime. Likewise, existing studies describe how self-determination emerges in childhood but continues to develop into adulthood, and how older individuals can learn and develop skills and attitudes that allow them to become more self-determined (Madson Ankeny and Lehmann 2011, Soresi *et al*. 2011, Gomez-Vela *et al*. 2012). This highlights the relevance of promoting self-determination among people with intellectual disabilities, while recognizing the impact of their family, school, work, living, and social environments on related behaviors and representations (Stancliffe 1995, Stancliffe 2001, Wehmeyer and Bolding 2001, Shogren 2013). It is also important to raise awareness and to promote a better understanding of self-determination among people with intellectual disabilities, who may have limited knowledge of the concept and related behaviors (Carter *et al*. 2009). For example, one study shows that young girls with intellectual disabilities often consider themselves self-determined, but display limited awareness of their shortcomings in terms of relevant attitudes, skills, and knowledge (Trainor 2007). In addition to providing tools for better promoting self-determination among people with intellectual disabilities, we therefore also hope that our study will help these individuals achieve a more accurate and realistic understanding of their potential for becoming self-determined. Our findings suggest that basing the research process on concrete, lived and shared experiences between the participants allowed for the evolution of their perceptions and understandings, which is important when it comes to a population which may encounter difficulties when dealing with abstracts concepts.

Although public policy and institutional guidelines tend to present the value of self-determination as self-evident, professionals rarely apply the concept spontaneously in the field. Nor do those targeted by efforts to promote self-determination—people with intellectual disabilities—clearly understand what it is supposed to mean. Even at the end of our research study, this remained true for several participating residents. Indeed, like us, Madson Ankeny and Lehmann (2011) have found that the term rarely resonates among people with intellectual disabilities. Rather, these individuals speak in terms of the everyday decisions they have to make, their plans, and their preferences. It would therefore be interesting to investigate the political, institutional, and even economic aims underlying how the concept is used. In other words, researchers should question what the concept seeks to promote or make legitimate, and why it is considered so important in the field of intellectual disabilities.

Finally, one particularly interesting aspect our study is how, over the course of the research project, participants' understandings and perceptions of self-determination evolved. Indeed, residents and staff progressively contextualized the concept and noted increasingly successful efforts to express self-determination. Some participants with intellectual disabilities integrated the word into their vocabulary. In part, these developments reflect our methodology. Indeed, professionals recognized the value of having an external perspective on their everyday work, while also approaching their practices and representations more reflexively. Several residents also reported having a better understanding of self-determination at the end of the project. Like Madson Ankeny and Lehmann (2011), whose research methodology helped people with intellectual disabilities better appreciate their capacity for self-determination, we believe that dialog, based on concrete situations and involving both residents and staff, helped promote a better understanding of self-determination and related skills among participants with intellectual disabilities. Clearly, both the focus group discussions and the weekly dyad meetings encouraged participants to

collectively reflect on the meaning of the concept. Consequently, like the participants in our study, we believe that professionals need to be given opportunities to reflect on how best to promote and support self-determination among people with intellectual disabilities.

Conclusion

It is vital to question how the concept of self-determination is used in the context of professional training and institutional policies. Indeed, while researchers, teaching institutions, and facilities for people with intellectual disabilities rarely reflect on the meaning of self-determination, our study shows how the concept can have multiple perceptions and understandings based on different perspectives and experiences. Furthermore, it can remain very abstract, especially for the very population targeted by efforts to promote self-determination. Therefore, it is important to continue investigating how people with intellectual disabilities understand the concept and the importance of self-determination and how they perceive self-determination as manifesting in their lives.

Our research results highlight the need to better understand the relational and situational dimensions of self-determination, which are key to how people with intellectual disabilities and social care professionals understand and experience the concept. In particular, strategies for promoting self-determination among people with intellectual disabilities must address the different types of support—practical, emotional and informational—that residents receive from staff and family members. Finally, our findings support the importance of discussion and reflection on the concept of self-determination and its benefits both for people with intellectual disabilities and social care professionals.

Disclosure statement

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