

RESEARCH

Staff's and Managers' Conceptions of Participation for Adults with Profound Intellectual Disabilities or Profound Intellectual and Multiple Disabilities

Lena Talman¹, Jenny Wilder², Jonas Stier³ and Christine Gustafsson¹

¹ Mälardalen University, SE

² Stockholm University, SE

³ Dalarna University, SE

Corresponding author: Lena Talman (lena.talman@mdh.se)

One goal of disability policies in Sweden and other countries is to ensure that people with disabilities are afforded an equal level of daily life participation as other citizens. However, few studies have examined this in adults with profound intellectual disabilities (PID) or profound intellectual and multiple disabilities (PIMD). This study used a phenomenographic approach to interview managers and staff at a social care organisation in a medium-sized Swedish municipality. It aimed to elucidate and describe conceptions of participation to highlight conceptual variations. Divergent conceptualisations were found, reflecting a lack of organisational consensus about the meaning of participation. Trying to fulfil policy goals of daily life participation for adults with PID or PIMD without a common understanding of the meaning of participation is difficult, so people at all levels of an organisation need to have a shared understanding and definition of it.

Keywords: participation; phenomenography; profound intellectual disability; profound intellectual and multiple disabilities; social care

Introduction

This article focuses on managers' and staff's conceptions of participation for adults with profound intellectual disabilities (PID) or profound intellectual and multiple disabilities (PIMD) because they are the ones that facilitate or limit the adults' possibilities to participate in daily life decisions. Adults with PID or PIMD include persons with profound cognitive impairment (IQ < 25) and accompanying motor impairments, sensory impairments, communication impairments, and medical problems, such as epilepsy (Nakken & Vlaskamp 2007).

In Sweden, participation is a main goal in disability policy and in practice (Government Bill 1999/2000: 79). Despite this, research on how adults with PID or PIMD participate in daily life is scarce (Blomberg 2006). Instead, most research focuses on adults with mild or moderate intellectual disabilities (Dusseljee et al. 2011; Kåhlin, Kjellberg & Hagberg 2014). Hammel et al. (2008) have stressed that people with disabilities should be free to define the meaning of participation. In research on the participation of people with intellectual disabilities, it is common to interview them about their personal perspectives (Kåhlin, Kjellberg & Hagberg 2014; Patterson & Pegg 2009). These results show that participation for people with intellectual disabilities is hard to realise and is mostly about 'doing' and 'feeling'. Do these results also cover the perspectives of people with PID or PIMD? Because these people need support (mainly from staff) with special skills in alternative communication and good knowledge about how the individuals communicate, this is a participation challenge. Due to a combination of disabilities, people with PID or PIMD depend on others for their daily life participation (Granlund et al. 2013), in particular on group home staff or in-home personal assistants. This is the rationale for exploring staff's and managers' conceptions of participation for adults with PID or PIMD.

Participation for people with disabilities

Participation is a human right (Government Bill 2008/09: 28); in many countries, disability policy aims to ensure that people with disabilities can participate in daily life just like other citizens (Hammel et al. 2008). Participation is a cornerstone of Swedish disability policy, and the Swedish national action plan (Government Bill 1999/2000: 79) stipulates that society should facilitate the participation of all people with disabilities and provide conditions for independence and self-determination.

In Sweden, adults with PID or PIMD either live in group homes or in their own homes with personal assistance. Required support and services are provided in accordance with the Swedish act concerning support and services for persons with certain functional impairments (SFS 1993: 387). It states that people with disabilities have the same rights to participate in daily life, engage in social life and enjoy the same living conditions and opportunities for autonomy, self-determination and empowerment as other citizens. In 2009, Sweden incorporated the Convention on the Rights of Persons with Disabilities (SÖ 2008: 26) in its disability policy to further strengthen the rights for people with disabilities.

Starting early in life, people with PID or PIMD encounter long-lasting or lifelong professional interventions, (Blomberg 2006; Felce & Perry 1995). This means that others often circumscribe or expand their possibilities to participate in daily life decisions. In exploring what daily life participation means for people with disabilities, Molin (2004) noted that it is important to consider whether the individual wants, and is able, to participate and is offered opportunities to do so. Another dimension of participation is meaningful participation, that is, the individual must have the right to participate in all decisions that directly affect him or her (Hammel et al. 2008). To be able to achieve meaningful participation, the individuals' subjective experience of participation is very important (Maxwell, Augustine & Granlund 2012).

Participation for people with intellectual disabilities

Kåhlin, Kjellberg and Hagberg (2014) interviewed staff at group homes to explore their conceptions of what participation for elderly people with intellectual disabilities entails. Staff understood participation for elderly people with intellectual disabilities as 1) doing things *with* others (e.g. watching movies together), 2) doing things *for* others (e.g. helping staff with different domestic tasks) and 3) being present when someone else was having something done (e.g. being in the apartment while staff was cleaning). The participation of elderly people with intellectual disabilities was assessed on the basis of *doing* and *feeling*.

To date, few studies (Furehned 1997; Johnson et al. 2012; Mansell et al. 2008) have investigated the participation of adults with PID or PIMD. These studies show that participation for these adults largely depends on clear management guidance and professional qualifications and attitudes. These studies demonstrate that, to some extent, adults with PID or PIMD can choose with whom to interact if given the opportunities to do so. Therefore, their participation largely depends on support from other people. Dunn, Clare and Holland (2010) stress that staff often rely on their own personal values and life experiences when making decisions on how the adult with PID or PIMD can participate. Needless to say, the staff's perceptions of participation are not necessarily the same for the adult with PID or PIMD. To rely on others can also decrease participation and self-determination because staff may choose activities that they prefer rather than those the adult with PID or PIMD prefers. Another risk of relying on others is that it is not certain that the adult with PID or PIMD receives the needed support (Qian et al. 2015). According to group home staff, adults with PID or PIMD often lack the capacity to choose for themselves or to understand the consequences of their choices (Bigby et al. 2009; Clement & Bigby 2009). Consequently, it can be problematic if support staff thinks that the principles of choice, integration and participation are important yet not applicable to adults with PID or PIMD.

According to Dusseljee et al. (2011), adults with moderate intellectual disabilities participate in the community to a lesser extent than adults with mild intellectual disabilities do because these adults do not take part in the domains of work, social contact or leisure activities to the same degree. Not engaging in these activities can elevate the risk of social exclusion because leisure activities outside the home are often designed for people without disabilities. Others also often select the leisure activities believed to be appropriate for a person with a disability (Dolva, Kleiven & Kollstad 2014).

The measure of quality of life for adults with PID or PIMD is 'The extent to which people with intellectual disabilities take part in the activities of daily living, including the relationships that form part of their lives' (Mansell & Beadle-Brown 2012). Despite this, adults with PID or PIMD often spend their days disengaged and receive low levels of support mainly with simple activities such as eating or watching TV (Beadle-Brown et al. 2016). Self-determination is another important factor for quality of life (Schalock et al. 2002), and Wehmeyer (2015) writes that 'small or large, self-determined actions contribute to one's quality of life' (p. 117). However, research has shown that adults with PID or PIMD have the lowest levels of self-determination (Wehmeyer, Kelchner & Richards 1996; Nota et al. 2007).

Participation is considered a prerequisite for a good quality of life for people with intellectual disabilities (Clement & Bigby 2010; Kozma, Mansell & Beadle-Brown 2009; Schalock et al. 2002). Participation can be understood along three dimensions: the experience of participation, active participation and accessibility to and interaction with one's environment (Gustavsson 2004).

Participation can also be understood as a synonym for equal living conditions for people with and without disabilities and should not be confused with equal treatment because individual needs for support to achieve participation vary (Tideman 2004). Another aspect of participation is meaningful participation. This relates to the individual's right to participate in all decisions that directly affects him- or herself (Hammel et al. 2008). Hammel et al. argue that participation is personal and therefore must be meaningful for the individual. The individual has to decide what kind of participation he or she wants and how the participation should be carried out. Furthermore, Maxwell, Augustine and Granlund (2012) argue that the subjective experience of participation is crucial for the individual to achieve meaningful participation. Meaningful participation therefore is relevant when designing and providing care and support for adults with PID or PIMD since these adults often live in the 'here and now', with limited resources/capabilities for autonomy

and independence, and because participation for people with PID or PIMD mainly is achieved through the assistance of others. Therefore, this study aims to elucidate and describe conceptions of participation held by managers and staff that provide support and services to adults with PID or PIMD in order to highlight organisational and operational variations of those conceptions.

Methodology

The qualitative research methodology phenomenography was used to examine organisational and operational variations in the managers' and staff's conceptions of participation. The various understandings and conceptions, which are dynamic and context-specific, are considered fundamental to the way individuals experience their world (Marton 1981; Marton & Booth 2000) and were considered as important in the present study. Typically, phenomenography is used to identify multiple conceptions, or meanings, that a particular group of people has about a specific phenomenon (Marton & Booth 2000). In phenomenography, a common form of collecting data is through interviews. In this study, the first author conducted interviews from June 2015 to August 2015 in a social care organisation. The managers and staff that worked with adults with PID or PIMD at group homes or in private homes in the social care organisation were interviewed. The social care organisation was a division within a larger municipal organisation in a middle-sized Swedish municipality. The social care organisation consists of a divisional manager, three regional managers and several unit managers responsible for different units – in this case, group homes and in-home personal assistants, referring to this study's inclusion an approximate total of 100 persons. The interviews included all managers and a representative selection of staff that worked where adults with PID or PIMD lived.

Ethical considerations

Ethical approval for the study was obtained from the Regional Ethics Committee in Uppsala, Sweden (D.nr. 2013/375). The managers and staff were informed about the aim of the study, that participation was voluntary and that they could withdraw from the study at any time. They were also asked not to reveal the identity of the adults with PID or PIMD when they provided examples. To ensure the confidentiality of the informants, the interview extracts are identified by using the words of the manager or staff member and a number instead of the informant's name.

Informants and data collection

In the study informants were representatives of all staff and managers at the present social care organisation. The inclusion criterion was social care managers or staff working with adults with PID or PIMD in the municipality under study. To ascertain conceptions of participation within the organisation, managers at all organisational levels (see **Figure 1**) were interviewed. The division manager, all three regional managers and unit managers were interviewed. Staff members were selected if they worked as personal assistants or in any of the group homes where the adults lived. A total of 27 informants (10 managers and 17 staff) were interviewed. They ranged in age between 22 and 65 and had two to 35 years of professional experience in the field.

The interviews were preceded by two pilot interviews to validate the entry question. The same entry question was asked in all interviews: *What does participation mean for adults with PID or PIMD?* These were followed by probing questions to encourage the participants to develop and clarify their answers, such as *Can you give an example and*

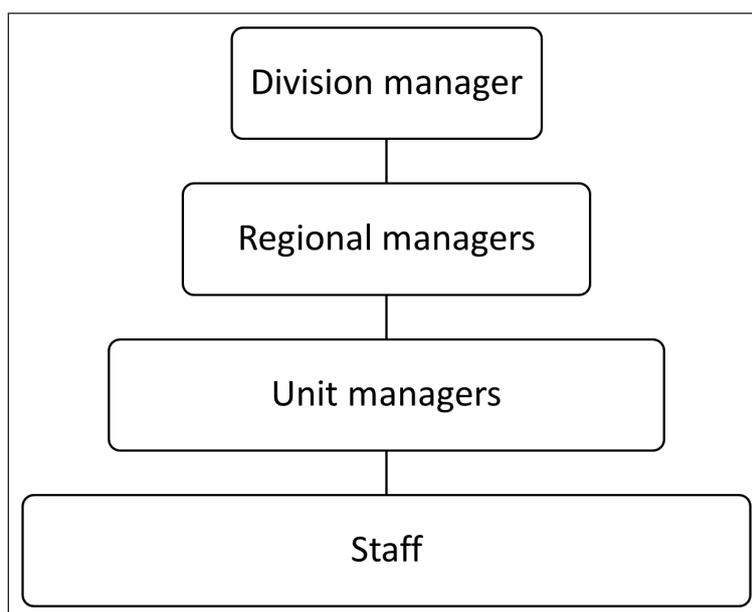


Figure 1: Hierarchy in the social care organisation.

what you mean? In cases where the informant obviously referred to their own experience, the dimension on what this could mean for adults with PID or PIMD was requested. The interviews lasted up to 30 minutes and were conducted at a location decided by the informant.

Data analysis

The interviews were transcribed verbatim and analysed based on phenomenographic techniques (Marton 1981; Marton & Booth 2000). The first and last author collaborated in the analysis and identification of categories – the so-called outcome space. Later, these were discussed with all co-authors until consensus was reached. To discern variations in conceptions of participation, the seven steps of phenomenographic analysis suggested by Dahlgren and Fallsberg (1991) and Sjöström and Dahlgren (2002) were followed.

In the first step (familiarisation), the interviews were repeatedly read to familiarise the researchers with the material and establish an overall impression of the interviews. In the second step (compilation), 322 relevant meaning units were identified. At the third step (comparison), sources of variation or agreement within meaning units were identified to determine similarities and differences between them and to assess the meaning of the meaning units. The fourth step (grouping) entailed a preliminary grouping of similar meaning units, and preliminary categories were created. In the fifth step (articulation), preliminary categories were compared to determine whether they were different from each other. At this stage, a revision of the preliminary categories was conducted to secure the differences between final categories. In the sixth step (labelling), the categories were named in order to highlight their essence. Finally, in the seventh step (contrasting), categories were contrasted to study the underlying structure (the outcome space) describing variations in conceptions of participation for adults with PID or PIMD. The outcome space represents the main results of a phenomenographic study. Based on the entire outcome space, a systematic analysis of how the different conceptions, or meanings, relate to each other was conducted (Marton & Booth 2000).

Variations of conceptions of participation

In general, participation was found to be abstract and difficult to conceptualise and verbalise for both managers and staff. For instance, Manager 4 was of the opinion that ‘You think it is so obvious what participation is, but when you start to break it down, it is difficult because it means different things for each individual.’ It was also hard to describe participation since, according to Staff 8, it was seen as personal: ‘Participation, it is so individual, so it is difficult to tell what it means.’ The municipal organisation lacked a documented definition of participation and how participation should be achieved, something that Manager 2 pointed out: ‘We do not have any definition of participation, so maybe we are not talking about the same thing when we discuss it.’ Moreover, staff had no instructions about what participation in daily life entails for adults with PID or PIMD, or how it should be achieved, as Staff 7 describes below.

We have no special instructions, just that we shall facilitate participation for the individual. This is difficult since a group of staff members often have extremely different thoughts of what participation is for the adult with PID or PIMD, and then there will be problems in the workgroup because every staff member works differently.

The informants had different conceptions of participation, ranging from *to decide* (e.g. make decisions about one’s own life) to *to do things* (e.g. eat by yourself). The results are illustrated in **Figure 2**.

The managers’ and staff’s conceptions of participation were divided into seven categories within the outcome space – see **Figure 2**. Participation was conceptualised as *to be seen*, *to want*, *to choose*, *to be present* and *to do* (the white squares

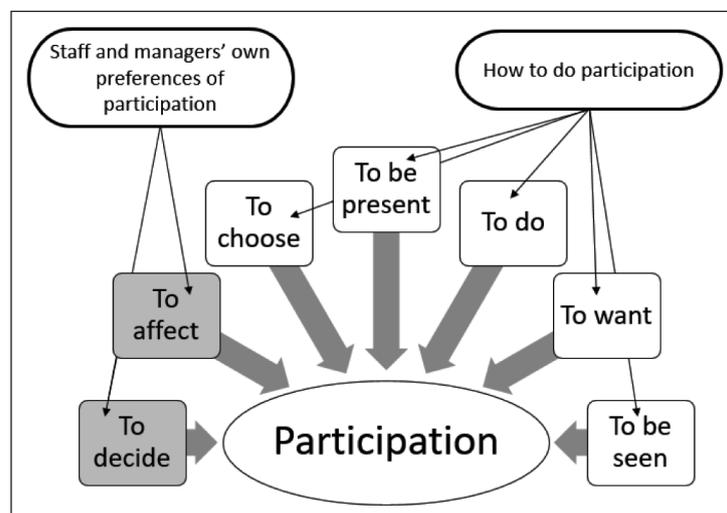


Figure 2: The outcome space.

in **Figure 2**). These statements focused on *doing* participation for adults with PID or PIMD (e.g. what participation is for adults with PID or PIMD). When managers and staff were unable to flesh out the *doing* component of participation, statements were considered to be more about what participation was for the managers and staff themselves within the categories *to decide* and *to affect* (grey squares in **Figure 2**). In the next section, these conceptions will be exemplified with quotations.

Staff's and managers' own preferences of participation

The categories *to decide* and *to affect* were about the managers' and staff's *own preferences* of what participation entails for human beings. It was as if they were trying to define participation without specifically referring to adults with PID or PIMD.

To decide

This category was about broader principles as described by Manager 9: 'Participation, if you think generally, is to gain insights into and self-determination over your life.' For Manager 5 it was a human right: 'I myself think that it is important that I get to decide about me and my life. It is every human's right to do so; no matter who you are in the world, you are entitled to it.' When the informants' statements were about the participation of adults with PID and PIMD, the concept was reduced to being allowed to decide about small everyday decisions, not the human right to make decisions about one's life:

What they (adults with PID or PIMD) want to eat or so, that they can decide for themselves, because otherwise it could easily be that you (staff) say, 'yes now we eat this or that'. Therefore, I think it is important that they get to decide for themselves. (Staff 16)

The informants made general statements seemingly applicable to everyone. However, the ability to decide was dependent on whether or not an individual was capable of communicating his/her decisions, wants or wishes. As Manager 10 defines it: 'To control my life in everything I can, that is participation, that nobody stands over me and makes the decisions if I myself can make the decision.' While the informants clearly held conceptions about being able to make decisions about one's own life, they also stated this as impossible for adults with PID or PIMD due to their disabilities. For instance, Manager 7 said: 'Well you could just say that adults with PID or PIMD get to decide over their own life as everybody else, but they cannot, not fully, because they have a disability.'

To affect

This category entailed being able to affect the decisions that were made. This conception was connected to the informants rather than to the adults with PID or PIMD. As Staff 5 expressed it: 'Participation, for me, is to be able to affect one's everyday life.' Exceptions arise when looking at participation from one's own perspective. Manager 1 stated that:

Participation is going on all the time for me from my perspective, and it is much about being able to be present and able to be prepared and affect my situation as far as possible. Even if I have PID or PIMD, participation means to affect a situation and to be present.

However, participation was connected to the fact that adults with PID or PIMD were physically present in the activity because the adult needed to be there to feel something with his or her senses in order to participate. Moreover, when staff and managers addressed their own participation and the participation of adults with PID or PIMD, the degree of participation always related to a person's ability:

Participation for me is to affect, to be involved in decisions. You might not always get what you want; it depends on what it is. But, I am sure one can be involved in all cases. Participation is not always about deciding; participation is about affecting a situation, as much as possible, based on their one's ability. (Manager 6)

How to do participation

The categories *to be seen*, *to want*, *to choose*, *to be present* and *to do* were about *doing* participation, how the managers and staff conceptualised participation directly for adults with PID or PIMD. These categories focused on basic daily life activities, such as eating on your own or making simple choices. It was also about being present in daily life activities and being seen as a human being with wants, wishes and demands.

To be seen

This category was conceptualised as receiving confirmation and being respected as an individual and as a person apart from the impairment. To be seen was conceptualised on a basic level with no thoughts about, or any connections to, human rights or special rights for people with disabilities. The staff's work approach to take the adult with PID or PIMD into account was, according to Staff 11:

To be seen so that the adult with PID or PIMD will be happy, yes, to take him or her seriously and that you as staff try to understand what the adult wants, or so; but, it can be difficult.

Participation was conceptualised as challenging for adults with PID or PIMD; therefore, the adults had to settle for being seen or having a meaningful day, as Staff 20 described it: 'Participation for adults with PID or PIMD is difficult, to have a meaningful day, perhaps, or that they will be seen as people, yes something like that.' Participation connected to this category could, according to Staff 21, be described as follows: 'They should feel good and satisfied ... they should feel seen.'

To want

This category meant that adults with PID or PIMD had wants, desires and likes and that these should be considered. As Manager 3 said: 'Participation ... it is a bit about doing what I (the adult with PID or PIMD) want to do, what I feel I want to do.' In order to do what you want as an adult with PID or PIMD, it is important to feel that the staff has knowledge about your wants, desires and likes, something Staff 23 talked about:

That I (the adult with PID or PIMD) feel safe with this staff, so I know that this staff knows roughly what I want and that the staff will help me and guide me so that I get what I want.

There were also conceptions that managers' and staff's responsibility was to search for the wants of the adult with PID or PIMD. These wants did not have to be about major decisions in life; rather, they could be about small things that were considered important for facilitating participation in the daily life of an adult with PID or PIMD, as Staff 16 explained 'That he or she can show, in any way, how he or she wants it in his or her life ... it can be something simple, but it can perhaps be important for this person.' The wants, wishes and likes of adults with PID or PIMD were not connected to making decisions in daily life because staff and managers often think that adults with PID or PIMD lack that ability, something that Manager 2 pointed out:

Participation, it is that each and every individual according to their ability, of course, shall be present and ... maybe not decide ... I don't think they (adults with PID or PIMD) always have the capacity, but they should be present and talk about what they like ... how they want it.

To choose

This category was about the staff doing in their daily work and facilitating PID or PIMD adults in making choices, often about what clothes to wear or what to eat, as Staff 8 explained it: 'That they have an opportunity to be able to choose ... what they want to eat, what clothes they will wear. I think that is participation for them.' In some way, to choose was also what adults with PID or PIMD were expected to be able to manage within the limits of their disability, according to Manager 7, 'Yes, if it is that level (PID or PIMD) ... I think it is to choose.' While it was considered important to have the opportunity to choose, it was also difficult to let adults with PID or PIMD choose due to their lack of communication skills. The lack of communication skills often meant that staff had to work hard to guess what the adult with PID or PIMD wanted, as Staff 14 describes below:

I think that we (staff) work all the time to try to find what she wants and can/has the ability to do, and she should get to do that. However, it is difficult; she does not talk so much, so you always have to try to perceive what she wants.

However, it could be easy to determine what an adult with PID or PIMD wants if you know the person and understand his/her nonverbal communication. To enable a person with PID and PIMD participation, it is, according to Staff 24, important for staff to understand how the individual communicates his or hers wants, wishes and what he or she likes:

On the weekends, all the residents are together; sometimes it works great, or they really want to be together, but sometimes, he wants to be alone in his apartment, and he shows it clearly. So, we go to his apartment and put on music, then maybe he starts to laugh and is happy, then I know he has chosen this. If I put on the music, and he gets angry, then it is not what he wants to do, and if I instead give him his toys and he starts laughing, good then he has made a choice.

To be present

This category means that the adult with PID or PIMD is aware of his or her surroundings in any way possible, as Staff 7 expressed it: 'Participation for adults with PID or PIMD is the same as being involved physically, mentally; so, to be present is participation.' Physical presence was important when staff and managers considered participation for adults with PID or PIMD because they did not think that adults with PID or PIMD were capable of interacting due to their profound disabilities as Manager 9 pointed out:

Some of the adults with PID or PIMD may participate by physically being in a room, to face the other people in the room, not only be placed somewhere without being included, even if there is not much interaction between that person and the surrounding people. That the person still has an opportunity to gaze over and physically be there, that I think, is a form of participation if they are profoundly disabled.

To be present also involved that the adult with PID or PIMD was participating with others, mostly in staff activities. This was considered important because, according to the staff and managers, adults with PID or PIMD are not often able to do things on their own; instead, there is a need to experience the activities with their five senses, and Staff 2 was of the opinion that

It is just important that they (adults with PID or PIMD) get to be there. I think it is the presence, to be there, and that you are not doing things behind their back – stand in the kitchen and cook and then just go in with the food – then they have not used any of their five senses. That they are present – I think it is important to be present even if they cannot do so much, but to be present.

Some managers and staff stated that just being present in activities was not enough to enable adults with PID or PIMD to participate; being accountable for something in a specific context was more important. Therefore, it is important that adults with PID or PIMD are listened to (e.g. does he or she like this activity and want to participate?). For instance, Staff 27 thought that

Participation is about getting a sense of being a part of a context. Not only being there, but also, in one way or another, to express that I think this or that in this context, or I react like this.

Being the main character in one's own life was something that Manager 8 considered important for the participation of adults with PID or PIMD. 'Participation is just being present, to be in the context and to be the main character.'

To do

To facilitate participation for adults with PID or PIMD simply means to enable independence, for them to be able to do things by themselves, such as eating or getting dressed. This category primarily addressed domestic factors, and it reinforced the idea that adults with PID or PIMD should do as much as possible by themselves. Staff 3 thought 'that the adult with PID or PIMD should be there and try to do as much as he or she can; that is the way I think about it.' In some way, this also means that an adult with PID or PIMD should try to live as normal an adult life as possible, given the limitations of their disability, as Staff 5 pointed out:

I think that they (adults with PID or PIMD) should be part of their everyday lives here. To cook, to shop and to take care of their laundry, to the extent that they are able to. Clean up, to the extent that they are capable, living their lives as close as possible to ours, this is participation for me.

The severity of the profound disability was something that hindered adults with PID or PIMD from doing things because staff saw the adults as not being capable. Thus, the adults were reduced to helping out when others were managing the doing. For instance, Staff 12 was of the opinion

That they (the adult with PID or PIMD) are present and do what they are capable of, and it is not so certain that they can do so much, but that they still are there whatever you (staff) are doing, and helping as much as they can.

It could also be that staff were doing too much because it was faster than letting an adult with PID or PIMD do it alone. How much an adult with PID or PIMD was able to do things was also dependent of his/her age, as Manager 8 described it:

I think that adults with PID or PIMD do things they are able to do, but I think that they could do more. I think so; but you (staff) can do it faster yourself. So, I think participation should be developed even more, especially with the younger ones. The older ones do not want to; one of our residents, he sits and smells and feels when staff is cooking; but, if he had been younger, perhaps he could have been more involved doing things while cooking.

Contextualisation of the variations of conceptions

The results show that the outcome space included seven categories at two levels of abstraction. The two categories *to affect* and *to decide* about one's own life were about staff's and managers' *own preferences* regarding participation since the adults with PID or PIMD were not considered capable of doing that due to their impairment. The five categories *to be seen*, *to want*, *to choose*, *to be present* and *to do* were about the informant's conceptions of how *to do*, that is, how to enable participation for adults with PID or PIMD. Kåhlin, Kjellberg and Hagberg's (2014) conclusion of what participation entails is similar: participation is about *doing*, *feeling* and *being present*.

Moreover the results show that participation was an abstract concept for managers and staff, which they found difficult to conceptualise and verbalise. The municipal organisation lacked both a definition of what participation for adults with PID/PIMD entails and guidelines for achieving such participation. Staff and managers also talked about participation being individual for each adult, which made it harder for them to describe what participation was for adults with PID or PIMD.

The aim was not to compare staff's and managers' conceptions, or whether their age or professional experience in the field made them respond in different ways. However, when analysing the interviews, the results showed no differences between how staff and managers conceptualised participation. Staff's and managers' age and professional experience in the field did not impact on how they conceptualise, understand and experience participation. The only difference revealed was that managers often expressed themselves in a more politically 'proper' way. This result contradicts the results of Furenhed (1997), Johnson et al. (2012) and Mansell et al. (2008) showing that staff/management professional qualifications facilitate participation for adults with PID or PIMD.

Conceptions of participation often connected to recurrent daily activities (e.g. eating, getting dressed and cleaning) and seldom to leisure activities. Dusseljee et al. (2011) reported on the higher risk of social exclusion when people have limited access to social contacts and leisure activities. Even though Dusseljee et al. are referring to adults with mild or moderate intellectual disabilities, it may be similar for adults with PID or PIMD because all people with disabilities have a higher risk of social exclusion. The lack of connection between participation and activities outside the home makes it difficult to reach the Swedish disability goal (Government Bill 1999/2000: 79) of facilitating social participation of people with disabilities.

According to Molin (2004), one condition for participation has to do with an individual's wants and desires. What the adult with PID or PIMD wanted was often brought up in the interviews. While it was considered important to take a person's wants into account, staff thought that they needed time to do so and that the degree of impairment was an important factor when enabling the participation of adults with PID or PIMD. Earlier research has identified the degree of the adult's disability as a predictor for the degree of self-determination (Wehmeyer, Kelchner & Richards 1996; Nota et al. 2007). On one hand, the Swedish disability policy and the Convention on the Rights of Persons with Disabilities (Government Bill 1999/2000: 79; SÖ 2008: 26) state that participation and self-determination are legal rights for all citizens, despite degree of disability. Hence, it is troublesome that the informants expressed that PID is an important factor limiting participation and thereby self-determination for the adults. On the other hand, being respected as an individual and a person beyond the impairment was seen as participation, but it was conceptualised on a basic level (e.g. feeling good or satisfied or being happy) with no thoughts about, or connections to, any rights for people with disabilities.

Both managers and staff stated that an individual's capability is crucial for how much the wants of the adult with PID or PIMD could be accounted for, as they thought that these adults did not have the ability to make choices or understand the consequences of their choices. This suggests that staff do not think that participation and/or self-determination on a higher level, such as to decide about or affect one's own life, are possible for adults with PID or PIMD due to their impairment. Bugby et al. (2009) and Clement and Bigby (2009) noted that staff discuss this matter; thus, the responsibility for the participation of adults with PID or PIMD, in some way, rests on the shoulders of the individual instead of upon those of the managers and staff.

Conceptions of participation varied among managers and staff, and it was obvious that the informants were not discussing the same thing and that managers and staff defined and achieved participation in their daily work subjectively. That staff's and managers' definition of participation relies on personal values and life experiences is similar to the findings of Dunn, Clare and Holland (2010). It is troublesome that staff define what participation is for adults with PID or PIMD since research has shown that people with disabilities should be free to define participation for themselves (Hammel et al. 2008). To achieve meaningful participation the subjective experience of participation is, according to Maxwell, Augustine and Granlund (2012), important, and this experience can be lost if staff defines participation. Research has also shown that adults with PID or PIMD can choose with whom to interact if given the opportunities to do so (Furenhed 1997; Johnson et al. 2012; Mansell et al. 2008), but it is not certain whether the adults receive the support needed (Qian et al. 2015).

Lack of consensus on, and definition of, participation makes it difficult for staff to support adults with PID or PIMD; this leads to staff being unable to fulfil a goal that is both undefined and without specified content. The lack of a common definition of participation also suggests that the adults' participation differs from day to day depending on the staff working. This means that one day participation for the adult is to do things by him- or herself and that another day participation is being there while the staff do things. To gain meaningful participation for adults with PID or PIMD, focus on the individual's subjective experience of participation is needed, and the adults need to participate in decisions that directly affect them (Hammel et al. 2008; Maxwell, Augustine & Granlund 2012). The challenge for staff to investigate the individual's meaningful participation might be a trigger for increased personalised care and support founded in the conceptualisation of participation, as defined by the individual adult with PID or PIMD.

It was difficult for staff and managers to verbalise what participation means or to explain how participation for adults with PID or PIMD was actually achieved. Therefore, some of the interviews were superficial because it was difficult to answer the question *What does participation mean for adults with PID or PIMD?* Moreover, the follow-up questions did not facilitate a response if an informant was stuck.

In research about people with PID or PIMD, it is common to use interviews by proxy since people with PID or PIMD often have limited communication skills (Granlund, Wilder & Almqvist 2013), which makes it difficult to determine what participation is from the perspective of the adults with PID or PIMD. Thus, interviewing staff and managers is a viable data collection choice since participation for these adults is mainly achieved through the assistance of others. However, this can be problematic since it is not possible to determine whether staff's and managers' conceptions of participation are consistent with those of adults with PID or PIMD.

This study provides knowledge about managers' and staff's conceptions of participation. Since participation is a legal right for all individuals, with or without disabilities, it is important to address how it is conceptualised in the care, support and services provided to people with PID and PIMD.

In qualitative studies, trustworthiness is crucial, which is why credibility, transferability and confirmability must be discussed (Lincoln & Guba 1985). To enhance the credibility of the study, the data were carefully collected and analysed, taking into account both content and context. To achieve trustworthiness and confirmability, all the authors were involved in the analysis process, and data were analysed and discussed until consensus was reached. An audit trail of the research process is presented in this paper, and the reader can consider the relevance of the categories because they are supported by quotations.

Conclusion

Divergent conceptions of participation were found in the studied organisation. This was due to a lack of consensus on the meaning of participation. When consensus on the meaning of participation is lacking, it can be difficult for staff to facilitate daily life participation for adults with PID or PIMD, which can in turn affect their level of participation. Therefore, the participation of adults with PID or PIMD can vary from day to day depending on the particular staff working. Thus, it is important that the organisation have a common definition of participation so that staff can achieve the participation goals when working with adults with PID or PIMD. The conceptions of participation were seldom connected to social contacts and leisure activities, given the higher risk of social exclusion. The wide range of conceptions makes it difficult to fulfil the goal of supporting adults with PID or PIMD to achieve participation. In order to meet the participation goals, people at all levels of an organisation need to have a shared understanding and definition of what the participation of adults with PID or PIMD entails.

The wide range of conceptions of the meaning of participation among managers and staff is problematic, and future research that problematise the differences in Swedish society and social care is needed. The adaption of the concept of meaningful participation can be a way to individualise participation, focusing on participation as defined by the individual adult with PID or PIMD. Other questions needing to be answered include whether there are structural root causes, historical reasons or developmental differences that causes low or non-participation of adults with PID or PIMD. Another important area for further research is to compare similarities and differences in both disability policy and social care between Sweden and other countries.

Acknowledgements

We are grateful to the managers and staff for their participation.

Competing Interests

The authors have no competing interests to declare.

References

- Beadle-Brown, Julie, J. Paul Leigh, Beckie Whelton, Lisa Richardson, Jeni Beecham, Teresia Baumker, and Jill Bradshaw. 2016. "Quality of Life and Quality of Support for People with Severe Intellectual Disability and Complex Needs." *Journal of Applied Research in Intellectual Disabilities* 29(5): 409–421. DOI: <https://doi.org/10.1111/jar.12200>
- Bigby, Christine, Tim Clement, Jim Mansell, and Julie Beadle-Brown. 2009. "'It's Pretty Hard with Our Ones, They Can't Talk, the More Able-bodied Can Participate': Staff Attitudes about the Applicability of Disability Policies to People with Severe and Profound Intellectual Disabilities." *Journal of Intellectual Disability Research* 53(4): 363–376. DOI: <https://doi.org/10.1111/j.1365-2788.2009.01154.x>
- Blomberg, Barbro. 2006. "Inklusion en illusion? om delaktighet i samhället för vuxna personer med utvecklingsstörning [Inclusion an illusion? Participation in society for people with intellectual disability]." PhD diss. Umeå University.
- Clement, Tim, and Christine Bigby. 2009. "Breaking Out of a Distinct Social Space: Reflections on Supporting Community Participation for People with Severe and Profound Intellectual Disability." *Journal of Applied Research in Intellectual Disabilities* 22(3): 264–275. DOI: <https://doi.org/10.1111/j.1468-3148.2008.00458.x>
- Dahlgren, Lars-Ove, and Margareta Fallsberg. 1991. "Phenomenography as a Qualitative Approach in Social Pharmacy Research." *Journal of Social and Administrative Pharmacy* 8(4): 150–156.
- Dolva, Anne-Stine, Jo Kleiven, and Marit Kollstad. 2014. "Actual Leisure Participation of Norwegian Adolescents with Down Syndrome." *Journal of Intellectual Disabilities* 18(2): 159–175. DOI: <https://doi.org/10.1177/1744629514523158>

- Dunn, Michael C., Isabel C. H. Clare, and Anthony J. Holland. 2010. "Living 'A Life Like Ours': Support Workers' Accounts of Substitute Decision-making in Residential Care Homes for Adults with Intellectual Disabilities." *Journal of Intellectual Disability Research* 54(2): 144–160. DOI: <https://doi.org/10.1111/j.1365-2788.2009.01228.x>
- Dusseljee, Joost C. E., P. Mieke Rijken, Mieke Cardol, Leopold M. G. Curfs, and Peter P. Groenewegen. 2011. "Participation in Daytime Activities among People with Mild or Moderate Intellectual Disability." *Journal of Intellectual Disability Research* 55(1): 4–18. DOI: <https://doi.org/10.1111/j.1365-2788.2010.01342.x>
- Felce, David, and Jonathan Perry. 1995. "Quality of Life: Its Definition and Measurement." *Research in Developmental Disabilities* 16(1): 51–74. DOI: [https://doi.org/10.1016/0891-4222\(94\)00028-8](https://doi.org/10.1016/0891-4222(94)00028-8)
- Furenhed, Ragnar. 1997. *En gåtfull verklighet – att förstå hur gravt utvecklingsstörda upplever sin värld* [A puzzling reality – understanding how profound intellectual disabled people experience their world]. Stockholm: Carlssons.
- Government Bill 1999/2000: 79. *From Patient to Citizen – A National Action Plan for Disability Policy*. Stockholm: Ministry of Health and Social Affairs.
- Government Bill 2008/09: 28. *Human Rights for People with Disabilities*. Stockholm: Ministry of Health and Social Affairs.
- Granlund, Mats, Jenny Wilder, and Lena Almqvist. 2013. "Severe Multiple Disabilities." In *The Oxford Handbook of Positive Psychology and Disability*, edited by Michael L. Wehmeyer, 452–474. New York: Oxford University Press. DOI: <https://doi.org/10.1093/oxfordhb/9780195398786.013.013.0028>
- Gustavsson, Anders. (Red.). 2004. *Delaktighetens språk*. [Language of participation]. Lund: Studentlitteratur.
- Hammel, Joy, Susan Magasi, Allen Heinemann, Gale Whiteneck, Jennifer Bogner, and Evelyn Rodriguez. 2008. "What Does Participation Mean?: An Insider Perspective from People with Disabilities." *Disability and Rehabilitation* 30(19): 1445–1460. DOI: <https://doi.org/10.1080/09638280701625534>
- Johnson, Hilary, Jacinta Douglas, Christine Bigby, and Teresa Iacono. 2012. "Social Interaction with Adults with Severe Intellectual Disability: Having Fun and Hanging Out." *Journal of Applied Research in Intellectual Disabilities* 25(4): 329–341. DOI: <https://doi.org/10.1111/j.1468-3148.2011.00669.x>
- Kozma, Agnes, Jim Mansell, and Julie Beadle-Brown. 2009. "Outcomes in Different Residential Settings for People with Intellectual Disability: A Systematic Review." *American Journal on Intellectual and Developmental Disabilities* 114(3): 193–222. DOI: <https://doi.org/10.1352/1944-7558-114.3.193>
- Lincoln, Yvonna S., and Egon G. Guba. 1985. *Naturalistic Inquiry*. Newbury Park, CA: Sage. DOI: [https://doi.org/10.1016/0147-1767\(85\)90062-8](https://doi.org/10.1016/0147-1767(85)90062-8)
- Mansell, Jim, and Julie Beadle-Brown. 2012. *Active Support: Enabling and Empowering People with Intellectual Disabilities*. London: Jessica Kingsley Publishers.
- Mansell, Jim, Julie Beadle-Brown, Beckie Whelton, Celia Beckett, and Aislinn Hutchinson. 2008. "Effect of Service Structure and Organization on Staff Care Practices in Small Community Homes for People with Intellectual Disabilities." *Journal of Applied Research in Intellectual Disabilities* 21(5): 398–413. DOI: <https://doi.org/10.1111/j.1468-3148.2007.00410.x>
- Marton, Ference. 1981. "Phenomenography – Describing Conceptions of the World Around Us." *Instructional Science* 10(2): 177–200. DOI: <https://doi.org/10.1007/BF00132516>
- Marton, Ference, and Shirley Booth. 2000. *Om lärande* [Learning and awareness]. Lund: Studentlitteratur.
- Maxwell, Gregor, Lilly Augustine, and Mats Granlund. 2012. "Does Thinking and Doing the Same Thing Amount to Involved Participation? Empirical Explorations for Finding a Measure of Intensity for a Third ICF-CY Qualifier." *Developmental Neurorehabilitation* 15(4): 274–283. DOI: <https://doi.org/10.3109/17518423.2012.689780>
- Molin, Martin. 2004. "Att vara i särklass – om delaktighet och utanförskap i gymnasiesärskolan [To be in special school – about inclusion and exclusion in upper-secondary special school]." PhD diss. Linköping University.
- Nakken, Han, and Carla Vlaskamp. 2007. "A Need for a Taxonomy for Profound Intellectual and Multiple Disabilities." *Journal of Policy and Practice in Intellectual Disabilities* 4(2): 83–87. DOI: <https://doi.org/10.1111/j.1741-1130.2007.00104.x>
- Nota, Laura, Lea Ferrari, Salvatore Soresi, and Michael Wehmeyer. 2007. "Self-determination, Social Abilities and the Quality of Life of People with Intellectual Disability." *Journal of Intellectual Disability Research* 51(11): 850–865. DOI: <https://doi.org/10.1111/j.1365-2788.2006.00939.x>
- Patterson, Ian, and Shane Pegg. 2009. "Serious Leisure and People with Intellectual Disabilities: Benefits and Opportunities." *Leisure Studies* 28(4): 387–402. DOI: <https://doi.org/10.1080/02614360903071688>
- Qian, Xueqin, Renáta Tichá, Sheryl A. Larson, Roger J. Stancliffe, and Allise Wuorio. 2015. "The Impact of Individual and Organisational Factors on Engagement of Individuals with Intellectual Disability Living in Community Group Homes: A Multilevel Model." *Journal of Intellectual Disability Research* 59(6): 493–505. DOI: <https://doi.org/10.1111/jir.12152>
- Schalock, Robert L., Ivan Brown, Roy Brown, Robert A. Cummins, David Felce, Leena Matikka, et al. 2002. "Conceptualization, Measurement and Application of Quality of Life for Persons with Intellectual Disabilities: Report of an International Panel of Experts." *Mental Retardation* 40: 457–470. DOI: [https://doi.org/10.1352/0047-6765\(2002\)040%3C0457:CMAAQ%3E2.0.CO;2](https://doi.org/10.1352/0047-6765(2002)040%3C0457:CMAAQ%3E2.0.CO;2)
- SFS 1993: 387. Act concerning support and services for persons with certain functional impairments. Stockholm: Ministry of Health and Social Affairs.

- Sjöström, Björn, and Lars Owe Dahlgren. 2002. "Applying Phenomenography in Nursing Research." *Journal of Advanced Nursing* 40(3): 339–345. DOI: <https://doi.org/10.1046/j.1365-2648.2002.02375.x>
- SÖ 2008: 26. *Konvention om rättigheter för personer med funktionsnedsättning* [Convention on the Rights of Persons with Disabilities]. Stockholm: Ministry for Foreign Affairs.
- Tideman, Magnus. 2004. Lika som andra – om delaktighet som likvärdiga levnadsvillkor. [Similar as others – about participation as equal living conditions]. In A. Gustavsson (Red.). *Delaktighetens språk* [Language of participation] (s.119–136). Lund: Studentlitteratur.
- Wehmeyer, Michael L., Kathy Kelchner, and Sandy Richards. 1996. "Essential Characteristics of Self Determined Behavior of Individuals With Mental Retardation." *American Journal on Mental Retardation* 100(6): 632–642.

How to cite this article: Talman, Lena, Jenny Wilder, Jonas Stier, and Christine Gustafsson. (2019). Staff's and Managers' Conceptions of Participation for Adults with Profound Intellectual Disabilities or Profound Intellectual and Multiple Disabilities. *Scandinavian Journal of Disability Research*, 21(1), pp. 78–88. DOI: <https://doi.org/10.16993/sjdr.53>

Submitted: 01 September 2017

Accepted: 05 April 2019

Published: 07 May 2019

Copyright: © 2019 The Author(s). This is an open-access article distributed under the terms of the Creative Commons Attribution 4.0 International License (CC-BY 4.0), which permits unrestricted use, distribution, and reproduction in any medium, provided the original author and source are credited. See <http://creativecommons.org/licenses/by/4.0/>.



Scandinavian Journal of Disability Research is a peer-reviewed open access journal published by Stockholm University Press.

OPEN ACCESS