

Participation in everyday life for adults with profound intellectual (and multiple) disabilities

Lena Talman



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**PARTICIPATION IN EVERYDAY LIFE FOR ADULTS WITH
PROFOUND INTELLECTUAL (AND MULTIPLE) DISABILITIES**

Lena Talman

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School of Health, Care and Social Welfare

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PARTICIPATION IN EVERYDAY LIFE FOR ADULTS WITH
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Lena Talman

Akademisk avhandling

som för avläggande av filosofie doktorsexamen i socialt arbete vid Akademin
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Akademin för hälsa, vård och välfärd

Abstract

Background: Adults with profound intellectual (and multiple) disabilities need society's support to live under "as normal circumstances" as possible. Support should be carried out in accordance with the Swedish disability policy vision of full participation in community and equality in living conditions.

Aim: To highlight and problematise the conceptualisation of participation, and how participation is achieved in implementation plans and in everyday life for adults with profound intellectual (and multiple) disabilities living in a group home or in their own home with support from personal assistants.

Method: Quantitative and qualitative methods were used to gain a deeper understanding of participation. In study I, 17 implementation plans were analysed. In study II, 27 social care managers and staff members were interviewed. In study III, 4 adults with profound intellectual (and multiple) disabilities living in a group home and their 13 staff members were observed.

Results: Documentation of participation focused on self-care and community, social, and civic life. In interviews with staff members and managers, the results showed that participation is abstract and hard to handle. Participation for the adults was about doing or being present in general daily activities. The conditions needed for facilitating participation were the adults' capabilities, staff members' knowledge, and resources in the social division. Moreover, the adults were listened to, supported in expressing their views, and their views were taken into account. However, they were not involved in decision-making processes nor did they share the power and responsibility for decision-making.

Conclusions: Participation for the adults is conditional, seldom involves decision-making processes, and is hardly ever connected to social contacts and leisure activities. In addition, attitudes about the adults' capability present a barrier to participation. The social care division need to better enable and facilitate participation by changing the conditions as well as educating the staff around changing their attitudes about the adults' capabilities. Managers and staff members need to have a shared understanding of what participation entails so that they all work in the same direction. Furthermore, the International Classification of Functioning, Disability and Health (ICF) can be used as a tool when drawing up individual plans so that the adults' wishes and preferences are considered. Shier's ladder of participation can be an instrument to increase participation in daily life for adults with PI(M)D.

Keywords: everyday life, participation, profound intellectual and multiple disability, social care

Persons with disabilities should be expected to fulfil their role in society and meet their obligations as adults. The image of disabled persons depends on social attitudes based on different factors that may be the greatest barrier to participation and equality. We see the disability, shown by the white canes, crutches, hearing aids and wheelchairs, but not the person. What is required is to focus on the ability, not on the disability of disabled persons.

(World Programme of Action Concerning Disabled Persons, 1982)

To Rainer and Kim

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List of Papers

This thesis is based on the following papers.

- I. Talman, L., Gustafsson, C., Stier, J., & Wilder, J. (2017). Staffs' documentation of participation for adults with profound intellectual disability or profound intellectual and multiple disability. *Disability and Rehabilitation*, doi:10.1080/09638288.2017.1340979

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<https://www.tandfonline.com/10.1080/09638288.2017.1340979>
- II. Talman, L., Wilder, J., Stier, J., & Gustafsson, C. (2017). Staff and managers' conceptions of participation for adults with profound intellectual disabilities or profound intellectual and multiple disabilities. *Submitted*.
- III. Talman, L., Wilder, J., Stier, J., & Gustafsson, C. (2017). Staff and managers' views on conditions for participation of adults with profound intellectual and multiple disabilities. *Journal of Applied Research in Intellectual Disabilities*, doi: 10.1111/jar.12516
- IV. Talman, L., Stier, J., Wilder, J., & Gustafsson, C. (2017). Participation in daily life for adults with profound intellectual (and multiple) disabilities: How high do they climb on Shier's ladder of participation? *Submitted*.

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Abbreviations

ICF	International Classification of Functioning, Disability and Health
IP	Implementation Plan
LSS	Act Concerning Support and Service for People with Certain Functional Impairments
PI(M)D	Profound Intellectual (and Multiple) Disabilities

Health and Welfare

The field of health and welfare focuses on the knowledge area on the border between health care and welfare. Thus, welfare is looked upon from a health perspective, and health is looked upon from a welfare perspective (Mälardalen University, 2015). The goal of good health is the same for all people regardless if they have disabilities or not (WHO, 2012). The overall goal of Swedish public health policies is to create the social conditions that promote good health on equal terms for all, including people with disabilities (S2012.028). To achieve this, it is important to see the whole person who can live a healthy life in spite of illness or disability. Health should therefore be regarded as a resource for everyday life, not as a prerequisite for living (Åkerlind, 2007). Nordenfelt (1995) points out that health is characterised by an individual's ability or inability to act on his or her behalf and highlights three important dimensions: the action of the person, the person's goals, and the circumstances in which the individual acts. Nordenfelt argues that goals and action capacity must be based on what the individual wants to achieve, and that what is right for one person may not be right for another. A prerequisite for achieving goals is, according to Nordenfelt, that people participate in decisions about their everyday lives. If participation in everyday life can be achieved, the conditions for health and well-being thereby increase.

The welfare state is connected with citizenship, and citizenship is about the rights and obligations of the people belonging to that state (Blomqvist, 2012). Blomqvist points out three types of citizenship rights: civil, political, and social. The values that the Swedish welfare state rests upon are, according to Blomqvist, social equality and universal rights. The welfare state's social policy and its implementation is a key element for attaining health and well-being for a country's citizens (Burström et al, 2010). The Swedish welfare state was created with health and well-being in mind and with the ambition to create a new and better society. According to WHO (2012), people with disabilities have special needs for achieving health and well-being. Therefore, in Sweden, the government has set up goals for how people with disabilities can achieve health and well-being. These goals have human rights as a starting point, which means that people with disabilities have the same rights and obligations to contribute to society's development as other citizens. The welfare state is of great importance to people with disabilities, as without it they would have difficulty getting what they need to achieve health and well-being and hence little opportunity to live a good life.

Attending to the special needs of people with disabilities is carried out in Sweden by the social work organisation in the municipalities. Therefore, many people with disabilities come into contact early in their lives with various professional programmes in the social work organisation. These programmes are often long-lasting and sometimes lifelong, so many people with disabilities live for extended periods in an environment created by and controlled by others (Blomberg, 2006; Felce & Perry, 1995; Ringsby, 2002; Tideman, 2000).

Social work

According to Malcolm Payne (2002), social work is about promoting social change, solving problems on an individual basis, and increasing human well-being. The International Federation of Social Workers (IFSW) defines it as follows.

Social work is a practice-based profession and an academic discipline that promotes social change and development, social cohesion, and the empowerment and liberation of people. Principles of social justice, human rights, collective responsibility and respect for diversities are central to social work. Underpinned by theories of social work, social sciences, humanities and indigenous knowledges, social work engages people and structures to address life challenges and enhance wellbeing (IFSW, 2014).

The aim of social work is to promote people's welfare and thereby their health. An important part of social work in Sweden are the social care division for people with disabilities. One of the main tasks for the social care division is to give support and service to adults with profound intellectual (and multiple) disabilities so that they have the same level of participation in daily life as other citizens. This thesis aims to increase the knowledge about participation for these adults. It reveals what is documented about the adults' participation, how managers and staff members talk about their participation, and how participation is achieved in everyday life for the adults. The knowledge that the thesis generates can be used in social care divisions to increase participation for adults with profound intellectual (and multiple) disabilities to enhance their well-being, by focusing on the principles of social justice, human rights, collective responsibility, and respect for diversities, which are all central to social work.

Introduction

Before the 1960s, most people with profound intellectual (and multiple) disabilities (PI(M)D) in Sweden lived their lives in large-scale institutions. Political reform starting in the 1960s and ending in the 1990s led to a major change as these institutions were closed and the people who were living in them moved out into the community. The purpose was for these individuals to live under “as normal circumstances” as possible, and that the norms, patterns, and conditions that applied to the rest of the population should be made available to all (Nirje, 1969).

Adults with PI(M)D need society’s support to live under as normal circumstances as possible and, in Sweden, they can live either in a private home with support from personal assistants or in a group home. The support and services provided by the so-called ‘social care’ is an integral part of Sweden’s social work. This support and services provided in the homes should be carried out in accordance with the Act concerning Support and Service for Persons with Certain Functional Impairments (LSS), (SFS 1993: 387) and include more than just caring. The support and services should also include recreational activities and enable the disability policy vision of “a good life for the individual”, which means full participation in the community and equality in living conditions, as well as conditions for autonomy and self-determination (Government Bill 1999/2000: 79; S2012.028). To enable this, individuals should participate in both large and small decisions that relate to their everyday lives.

The support and services carried out according to the LSS (SFS 1993:387) should be documented, and people in need of this help, and therefore of the activities specified by the LSS, shall have an implementation plan (IP). The IP is a policy document that is intended to document how the support and service should be carried out. The IP should be drawn up in consultation with the individual so that they participate in the decisions of how the activities are performed. If the individual cannot take part in the planning, then relatives or guardians should take part on their behalf. The IP serves as a control document for the government agency (The Health and Social Care Inspectorate), which is responsible for supervising activities under the LSS (National Board of Health and Welfare, 2014). Participation in everyday decisions by people with PI(M)D thus becomes a prerequisite for enabling this population to achieve the same quality of life as the rest of the population.

Participation is constructed in the interaction between the individual and their physical and social environment. The interaction, however, takes place in a legal, ideological, and organisational context, and people with PI(M)D are therefore often dependent on other people, often staff members, when it comes to their opportunity to participate. What participation in everyday life looks like for adults with PI(M)D, how it relates to the conditions that exist in society, and what conditions are needed for these individuals to be involved, is a largely unexplored field (Blomberg, 2006). Today it is still unexplored, therefore, knowledge of how involved adults with PI(M)D actually are in their everyday lives and how this involvement is accounted for in the IPs is important. With increased knowledge about participation, the staff members who work with adults with PI(M)D can better support them to lead meaningful lives.

In focusing on the different definitions and aspects of participation, Molin (2004) argues that both internal (individual factors) and external conditions are required. Tideman (2004) focuses on equal living conditions, and Gustavsson (2004) argues that participation entails three interrelated aspects: the individual's experience of participation, active participation, and accessibility and interaction with the environment. In terms of the research on participation for people with PI(M)D, there is some existing research concerning children (see, for example, Axelsson, Granlund, & Wilder, 2013; Axelsson, Imms, & Wilder, 2014). However, a survey of the field shows that research on adults with PI(M)D is limited. Most of the research concerns adults with mild or moderate intellectual disability (see, for example, Dusseljee, Rijken, Cardol, Curfs, & Groenewegen, 2011; Kåhlin, Kjellberg, & Hagberg, 2014). Looking at the research, an interesting question arises: What does participation for adults with PI(M)D look like according to those who support them, and does it differ from the definitions given in the research?

For most adults, participation means having the right to decide for oneself what parts of life they value and wish to pursue, but is this so for adults with PI(M)D who are in need of support and service to live their everyday lives? Important questions are: Is it the adult with PI(M)D who decides or at least participates in the decisions as to how their everyday life should be planned? Or is it the social care managers and staff members who decide, and is this based on what they think the individual wants or on what they themselves want or the organisation wants? Can the participation of adults with PI(M)D be facilitated in another way, not just by the people who care for them making decisions about what they think they value?

Aims

The overall aim of this thesis is to highlight and problematise social care managers' and staff members' perceptions of participation, and how this participation is achieved in implementation plans and in everyday life for adults with profound intellectual (and multiple) disabilities, who live in a group home or in their own home with support from personal assistants.

The specific aims are:

Study I To investigate what areas of ICF are documented in implementation plans for adults with PI(M)D. The aim is also to specifically investigate the component activities and participation outlined in the ICF classification, with the focus on participation. The study aims to answer the following research questions:

1. What ICF areas are documented in the implementation plans?
2. How is participation documented in the implementation plans?

Study II To clarify and define the perceptions of participation held by managers and staff who provide support and services to adults with PI(M)D in order to highlight the organisational and operational variations of those perceptions.

Study III To elucidate and describe participation in daily life for adults with PI(M)D living in a group home.

Background

This background section presents the areas that are of importance in the thesis. It starts with a definition of intellectual disabilities and PI(M)D, followed by a short description of the historical development concerning people with intellectual disabilities. Next, the phenomenon of participation is described from different perspectives. The theoretical model that is used to explore the different systems that influence everyday life for adults with PI(M)D are described, along with the systems. The section ends with a literature review about intellectual disability and participation.

Intellectual disability

An intellectual disability occurs before the age of 18, and means that the individual has an intelligence quotient (IQ) below 70 and difficulty with conceptual, social, and practical skills (AAIDD, 2017), which often leads to hampered communication and abstract thinking (Kylén, 1987).

In Sweden, intellectual disabilities are divided into four different levels: mild, moderate, severe, and profound (Grunewald, 1996; Ineland, Molin, & Sauer, 2013). According to Kylén (1987), human capability can be organised by the categories of space, time, quality, quantity, and reason. These five categories affect the ability to perform a given operation and are developed on different levels of abstraction. Kylén refers to these levels of abstraction as A, B, and C levels. People without intellectual disability encompass all the levels, while a person with an intellectual disability reaches a particular level, and that level determines the severity of their disability, i.e. level A (severe/profound), B (moderate), or C (mild).

An individual with PI(M)D has profound cognitive impairment (IQ < 25) and accompanying motor impairments, sensory impairments, communication impairments, and medical problems, such as epilepsy (Granlund, Wilder, & Almqvist, 2013; Nakken & Vlaskamp, 2007). Due to the consequences of the combination of disabilities, they are dependent on others for all aspects of their everyday life (Granlund et al., 2013).

From normality to participation

Since the 1960s, the support and service for people with intellectual disabilities in Sweden has moved from the normalisation principle to the concept of participation, and this movement is described below.

Normality

During the 1960s and early 1970s, normality began to be used to describe statistically the most common patterns of life in society. There are three dimensions to normality: normality as the statistical normal distribution, normality as the absence of deficiency/opposed to deviation, and normality as the ideal (Hacking, 1999). These three dimensions can vary over time and between different cultural contexts. Hacking argues that the “normal” cannot be defined other than in relation to what is not seen as normal, which makes it difficult to distinguish when facts go into values, and vice versa. According to Hacking, the concept of normality does two things at once; first, it describes the typical normality conceptions that exist, and second, it is built on pure assumptions about how something should be in a particular situation. Barnes and Mercer (1999) state that normality can either be seen as an objectively determined condition or as socially and culturally defined.

Kjellman (2003) points out that humans and society create stereotypes about people in order to separate the normal from the abnormal. This stereotyping is done in order to create a border between the normal and those who are perceived as abnormal, frightening, and impure. Shakespeare (2007) argues that normality is multifaceted and can be described from different perspectives. Normality is, according to Shakespeare, a historical and cultural concept, and, in Western countries, normality means being a healthy, independent, and rational human being.

The normalisation principle

At the end of the 1960s, Nirje (1969) introduced the ‘normalisation principle’ for people with intellectual disabilities. The goal of this principle was for people with intellectual disabilities to obtain an existence as close to the normal as possible. The principle was meant to provide guidance for creating services, and Nirje identified eight key components that were needed:

- A normal rhythm of day
- A normal routine of life
- A normal rhythm of the year
- Normal developmental experiences of the life cycle
- Having one’s choices, wishes, and desires taken into consideration and respected
- Living in a bisexual world
- A normal economic standard
- Standards of facilities similar to those others are accustomed to

The normalisation principle became a goal in working with marginalised groups in society, groups that were previously considered as abnormal or non-normal (Piuva, 2005). The idea of normalisation is that people with disabilities have a right to normal living conditions, such as they are, and the fact that they are people/citizens should motivate the support and service they receive, and not their disability (Söder, 2003). Söder points out that the Swedish disability policy has denounced the concept of normalisation because the risk of misinterpretation of the principle is high. A common misconception is that the person with a disability should be normalised. Normalisation has, therefore, according to Söder, not been included in disability policy documents since 1980.

Participation

Because of the high risk of misinterpretation of the normalisation principle, the focus in Swedish disability policy changed from normalisation to participation (Söder, 2003). The Swedish Ministry of Health and Social Affairs stated in 1991 that participation is about active participation in social life. They pointed out that preferences and interests may vary between people during different stages of life, and that participation is seen as a concept for people with disabilities to have the same rights and obligations as other citizens (SOU 1991:46).

In 1993, the UN implemented the Standard Rules for people with disabilities (United Nations, 1993), and these rules have had a great influence on Swedish policy (Ineland et al., 2013). At the same time, the focus concerning people with disabilities has transferred from normalisation to participation and equality (Kjellberg, 2002). Today, the norm of full participation in society for people with disabilities is a central goal of the Swedish disability policy (Government Bill 1999/2000:79; S2012.028). According to the LSS Act (SFS 1993:387), participation should be seen as a goal for support and service to people with PI(M)D that is carried out by the social division in the municipalities. Participation is a complex phenomenon, and since participation is a prerequisite for a good quality of life for people with intellectual disability (Clement & Bigby 2010; Kozma, Mansell, & Beadle-Brown 2009; Schalock et al., 2002), the conceptualisation of the phenomenon of participation for adults with PI(M)D in social care is important.

One definition of participation is *meaningful* participation. Meaningful participation relates to the individual's right to participate in all decisions that directly affect them (Hammel et al., 2008). This definition is also used in this thesis. Hammel et al. explain that participation is personal, and that participation therefore needs to be meaningful for the individual. They argue that the individual has to decide what participation they want, 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 seems to be relevant when designing and providing care and support to adults with PI(M)D since they often live in the "here and now" and have limited resources/capabilities for autonomy and independence.

Tideman (2004) considers participation as a synonym for equal living conditions for people with and without disabilities. Tideman argues that participation should not be mixed with equal treatment because individual needs for support to achieve participation vary. Participation can, according to Gustavsson (2004), be divided into three dimensions: the experience of participation, active participation, and accessibility to and interaction with one's environment. Gustavsson states that a person can experience participation even if they are alone.

The WHO focuses on the importance of participation and, along with the ICF, has switched its focus from “lack of handicap” to participation and highlights that the organisation is trying to offer a coherent vision of health based on biological, individual, and social perspectives (WHO, 2001). In doing this, WHO connects to the concept of universalism by stating that the norm of full participation for people with disabilities also applies to people without disabilities (Bickenbach, Somnath, Badley, & Üstün, 1999). According to WHO (2001), the component activities and participation in ICF cover the full range of areas in life, and participation is defined as an individual’s engagement in their particular life situation.

Shier (2001) has developed a model of participation, with a focus on children, known as the ‘ladder of participation’. Even though the model was developed for children, it has also been used with adults with intellectual disabilities (Gullacksen & Hejdedal, 2014). The model is based on five different levels of participation: 1) being listened to, 2) being supported in expressing one’s views, 3) having these views taken into account, 4) being involved in decision-making processes, and 5) sharing power and responsibility in decision-making. At each level, openings, opportunities, and obligations are important. *Openings* are about the willingness of the people in one’s environment to listen to and support the individual. *Opportunities* relate to the resources, skills, and knowledge that make the openings possible. *Obligations* refer to the policies and guidelines of the organisation that are aimed at increasing participation.

Molin (2004) discusses that in order for a person to be able to participate in his or her everyday life, both internal and external conditions are required. Internal conditions refer to individual factors such as the willingness of the individual to participate and the bodily functioning that is sufficient for the current task. The external conditions relate to how the environment is designed and the extent to which the opportunity for participation is offered. According to Molin, to get a picture of what participation looks like for an individual, we need to take into account if he or she wants to, can, and is offered the opportunity to participate.

According to the Swedish National Board of Health and Welfare (2007a), self-determination is closely linked to participation. Self-determination means that individuals should be able to decide for themselves in everyday situations. Self-determination is a fundamental human right for every citizen in a democratic society and is about gaining control over one’s own life (Wehmeyer, 1999). Self-determination is not identical to complete control over one’s own life (Wehmeyer, 1998). However, when individuals need support from society in the tasks of everyday life, they should be allowed the greatest possible influence and co-determination in what this support looks like. This is particularly important for people with PI(M)D, as their daily life depends highly on others (The National Board of Health and Welfare, 2007a).

Understanding participation

According to Granlund and Björk-Åkesson (2005), participation is a multidimensional phenomenon that needs to be conceptualised. Because of the complexity of both the phenomenon of participation and the environment in which adults with PI(M)D are living, a theory was used to understand the different systems that influence their everyday life (see Figure 1). To understand how the different systems influence participation for adults with PI(M)D, Bronfenbrenner's (1979) ecological system theory is used.

Bronfenbrenner's (1979) theory deals with five different systems: micro, meso, exo, macro, and the chronosystem. The chronosystem was added to the theory at a later stage (Bronfenbrenner & Morris, 2006). The microsystem is about personal relationships, in which the individual meets the other. The mesosystem is about relationships and linkages between the various microsystems of which the individual is a part. The exosystem is about relationships and links between several different environments, where the individual is included in some but not in others. The exosystem therefore points to relationships and connections between the environments that affect the individual indirectly. The macrosystem refers to the overall pattern of micro, meso, and exo systems within a certain culture, subculture, or other larger social context. The chronosystem is the highest level and is about individual and social change over time that affects the individual. The systems that influence everyday life for adults with PI(M)D are described below.

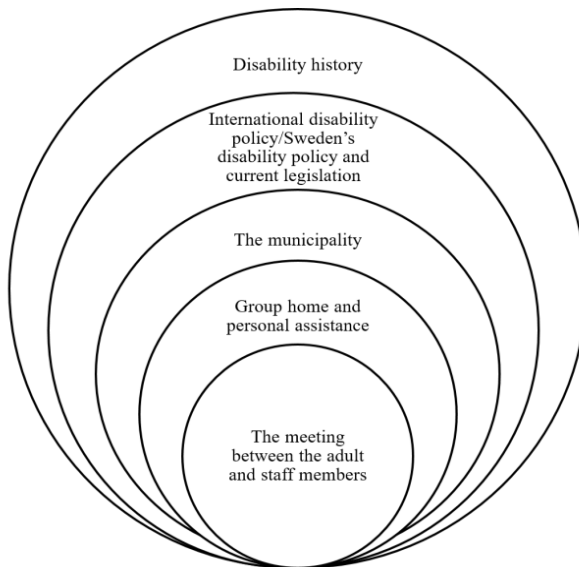


Figure 1. Application of Bronfenbrenner's system in illustrating the different systems that influence everyday life for adults with PI(M)D

Disability history

As described earlier, people with PI(M)D in Sweden lived in large-scale institutions before the 1960s, when the political reform started. This reform led to different living conditions—from the institutions to community-based group homes. As Nirje (1969) explained, the purpose was for this population to live under as normal circumstances as possible so that people with PI(M)D would supposedly live their lives equal to other citizens.

International disability policy

On an international level, human rights, the UN's Standard Rules, the UN Convention on the Rights of Persons with Disabilities, and medical and social disability models had an impact on the everyday lives of people with disabilities. On the one hand, it gave them the right to participate in society, and, on the other hand, society started to analyse how to work to increase the participation in society of people with disabilities.

Universal Declaration of Human Rights (UDHR)

The UN General Assembly adopted the UDHR in Paris on 10 December, 1948. The declaration contains 30 articles, many of which are divided into several points. The purpose of the declaration is to state that all human beings are born free and equal in dignity and rights, without distinctions of any kind (Government Bill 2008/09:28).

UN Standard Rules

The Standard Rules on the Equalization of Opportunities for Persons with Disabilities were adopted by the UN General Assembly in 1993 and are based on the experience gained during the United Nations Decade of Disabled Persons (1983–1992). The political and moral foundation for the Standard Rules are the international rules on human rights. Their purpose is to ensure that people with disabilities are citizens with the same rights and obligations as other citizens (United Nations, 1993).

UN Convention on the Rights of Persons with Disabilities

The newest and most important document when it comes to living conditions for people with disabilities is the UN Convention on the Rights of Persons with Disabilities. The Convention's aim is to promote, protect, and ensure the full and equal enjoyment of all human rights and fundamental freedoms for people with disabilities and to promote respect for their inherent value (Government Bill 2008/09:28). This Convention strengthened the human rights that people with disabilities already had been recognised to have under previous conventions.

The medical and social disability models

According to Barnes and Mercer (1999), the medical (individual) model of disability has been dominant since the mid-19th century and especially in the industrial capitalist societies. The medical model is based on a medical definition and treatment of the impairment. In this model, impairment is seen as an unhealthy condition with an associated disability or, as Barnes et al. (2002) formulate it, in the medical model of disability, the impairment is considered equivalent to the disability. In this model, impairment is measured by how the physical, sensory, and intellectual capacities deviate from what is termed as normal. Barnes and Mercer (1999) describe that impairment and disability in this model are regarded as a personal tragedy, with a focus on the bio-physiological defects. Therefore, the solution to the “problem” is medical, and medical treatment and/or rehabilitation is the only way for the individual to overcome the disability and the social obstacles involved. Barnes and Mercer point out that the medical perspective gained a dominant position because it had government support. Furthermore, physicians and other professional groups’ claims of expertise were accepted.

The social model of disability emerged in the United Kingdom in the 1960s and 1970s. This model challenges the commonly held perception of disabled people as passive, infirm, and incapable. It claims that the limitations people with disabilities experience do not depend entirely on themselves. The oppression that people with disabilities are victims of depends on different social, economic, and cultural structures and/or processes or, in other words, on the social interaction between the disabled and non-disabled populations (Barnes et al., 2002). The goals of the social model are, according to Barnes and Mercer (1999), to eliminate the barrier between the personal and social level. On the personal level, individuals must be allowed to determine their own goals, and on the social level, participation in society must be made available to all. Barnes et al. point out that the social model of disability does not deny the importance of impairment, but that the focus is rather on the economic, political, and social barriers that construct the disability.

The main difference between the medical and the social models lies in who is causing the disability, and how the concept of normality is defined. In the medical model, the individual impairment makes people disabled, and normality is an objectively determined condition. In the social model, on the other hand, it is society that makes people disabled, and normality is socially and culturally defined (Barnes & Mercer, 1999).

Sweden's disability policy and current legislation

Around the same time the social model of disability emerged in the United Kingdom, the environmental relative disability model developed in Sweden. This model sees disability as a relationship between the individual and the environment. The individual has an impairment, but it is in the interaction between the individual and the environment that the disability occurs. According to Holme (1999), the environmental relative disability model was established in 1989 in the so called 'disability investigation'. The rationale for this disability model was that the environment can change, thereby reducing the number of disabling situations, avoiding the stigmatisation of individuals with disabilities, and enabling their integration in society.

This change in the disability model reformed the treatment of the individual. The earlier focus had been on the individual's disability, and this focus shifted to the possibilities the individual had, in interaction with one's surroundings, to be able to perform different activities. The goal of the national action plan on disability policy, "From Patient to Citizen" (Government Bill 1999/2000:79), has the social community as its basis. This means that society must be designed so that people with disabilities, of all ages, become fully involved in society, and so that there is equality in living conditions for all people with disabilities. To achieve this goal, the focus is on identifying and removing barriers to full participation in society. Furthermore, discrimination should be prevented and combated, and it is essential that conditions for autonomy and self-determination are created. The government's strategy for its disability policy in 2011–2016 (S2012.028) and the Government Bill 2016/17:188 follows the goals of the national action plan and points out that the national goals do not have any deadline.

The norm of full participation in society for people with disabilities is a central goal of disability policy in many countries. Participation has thus become an important concept among local organisations and political decision-makers when it comes to the care of people with disabilities (Hammel et al., 2008). An important starting point, when it comes to the living conditions of people with disabilities, is the UN Convention on the Rights of People with Disabilities. With the ratification of the Convention, the Swedish state has strengthened the rights of people with disabilities to participate in society (Government Bill 2008/09:28), and the Convention has become an important document in Swedish social work. In addition to the Convention in Sweden, there is the LSS law (SFS 1993: 387).

Act concerning Support and Service for Persons with Certain Functional Impairments (LSS)

LSS (SFS 1993: 387) is a law that sets out the rights for people with considerable and permanent functional impairments. The goal is that these individuals should be able to live the same life as other citizens. The law shall guarantee good living conditions, which means that the individuals shall receive the support and service they need in everyday life. LSS applies to:

1. people with an intellectual disability, autism or a condition resembling autism
2. people with a significant and permanent intellectual impairment after brain damage in adulthood due to an external force or a physical illness
3. people who have other major and permanent physical or mental impairments which are clearly not due to normal ageing and which cause considerable difficulties in daily life and consequently an extensive need of support and service

LSS (SFS 1993: 387) entitles the individual to 10 different activities for specific support and service, if the person needs such assistance in daily life, and the needs are not satisfied in any other way.

These are:

1. Counselling and other personal support
2. Personal assistance
3. Companion service
4. Personal contact
5. Relief service in the home
6. Short stay away from home
7. Short period of supervision for schoolchildren over the age of 12
8. Living in family homes or in homes with special services for children and young people
9. Residential arrangements with special services for adults or other specially-adapted residential arrangements
10. Daily activities

LSS specifies that the individual shall have the rights to self-determination and empowerment (Section 6). The application of these rights is that the individual has the right to participation in planning and decision-making in all dimensions of everyday life. LSS, Section 21a and b, provides rules concerning documentation. The rules state that the activities carried out shall be documented on an ongoing basis. It is important that the documentation is done with respect for the individual's integrity and that the individual is informed of what is documented.

The National Board of Health and Welfare has issued regulations and general advice on documentation under LSS (SOSFS 2006: 5). The Board's regulations must be followed, while the Board's general advice only contains recommendations on how the constitution can or should be applied. According to LSS (SFS 1993:387), the performance of the approved activities should be documented, and the documentation should describe how the goal of the activities is to be reached. People who have PI(M)D and are in need of support or service to live their everyday lives should, therefore, according to the National Board of Health and Welfare, have an IP unless the activities are documented elsewhere, or if it is clearly unnecessary (SOSFS 2006:5).

The municipality

Swedish municipalities are responsible for providing health and welfare to their citizens. The municipalities have a substantial degree of independence and are free to make local decisions about the support and service that is provided to the citizens who need it, as long as they follow the laws. This independence is known as local self-government, has a long tradition, and is protected in the Swedish constitution. This does not mean that the citizens have different access to welfare since the national government has decided that a citizen's access to welfare should be on equal terms irrespective of where they live in the country (SKL, 2017).

Group home and personal assistance

According to the LSS law (SFS 1993:387), the living arrangement in a group home shall guarantee good living conditions. A group home is a residence with several apartments clustered around a common kitchen and living room. Every adult with PI(M)D has his or her own apartment. There are staff members present around the clock to help the adults with everything concerning everyday life. The adult with PI(M)D is in control of their apartment and decides who can enter or not, and other people (e.g. staff members) are not allowed to enter the apartment on their own when the adult is not at home. It is usual that the adult with PI(M)D living in the group home has one or two of the staff members as contact person. This contact person (or persons) is supposed to have deeper knowledge about the adult (The National Board of Health and Welfare, 2007a). A personal assistant is a staff member who provides support and service in the adult's own home (The National Board of Health and Welfare, 2007b). Support and service is carried out with the same intention as in the group home and shall guarantee that the adult with PI(M)D has good living conditions.

The meeting between the adult and staff members

In Sweden, it is assumed that staff members work towards the intentions formulated in the LSS law (SFS 1993:387). Staff members' attitudes towards the adults with PI(M)D that they support can affect their participation both positively and negatively. A number of researchers have argued that the managers' and staff members' negative attitudes about the capability of adults with PI(M)D affects these adults' everyday life participation (Bigby, Knox, Beadle-Brown, & Clement, 2015; Bigby, Knox, Beadle-Brown, Clement, & Mansell, 2012). Positive attitudes of staff members are therefore needed to ensure participation for these adults (Jones, Ouellette-Kuntz, Vilela, & Brown, (2008).

Participation for people with intellectual disability

Research has shown that people with intellectual disabilities have poorer physical and mental health, a smaller social network, and seldom work in the regular labour market (Axmon, Björne, Nylander & Ahlström, 2017; Umb-Carlsson, 2007). Molin (2004) points out the need to take into account the individual's wishes to participate, their ability to do so, and the existing opportunities for participation. If the adult's wishes, ability, and the opportunities are not considered, it will be difficult to achieve participation for people with disabilities. To attain the main goal of participation, all people with disabilities should receive daily support and services that they individually need. At the same time, these people are dependent on the support of society—that is, many of them find themselves in highly asymmetrical power relations with fewer opportunities to pursue their wishes and decide on the course of their lives compared with other people (Söder & Grönvik, 2008). Hammel et al. (2008) have stressed that people with disabilities should be free to define the meaning of participation for themselves. For example, in the research on the participation of people with intellectual disabilities, it has become common to interview them about their personal perspectives (see Kåhlin et al., 2014; Patterson & Pegg, 2009; Wennberg & Kjellberg, 2010).

Kåhlin et al. (2014) interviewed both residents and staff members when researching participation for older people with intellectual disability living in group homes. They found that staff members described residents' participation along three dimensions: doing things with others (watching TV), doing things for others (helping staff members with domestic chores), and witnessing someone else's doing (e.g. being in the kitchen while someone else is cooking). The meaning of participation for the participants was 'doing' and 'feeling', and the preconditions for participation were resident-related factors, social and physical environmental factors, and organisational and policy factors.

Dusseljee et al. (2011) looked at the participation of people with intellectual disabilities in the community. They concluded that participation in the community is harder to achieve for adults with moderate intellectual disabilities than for those with mild intellectual disabilities. This is because people with more severe intellectual disabilities have very limited interaction in the community, in work domains, in social contacts, or in leisure activities, which elevates their risk of social exclusion.

Another risk of social exclusion from the community is that leisure activities outside the home are often organised specifically for people without disabilities. Moreover, others, such as staff members or family members, often select the kind of leisure activities that are appropriate for a person with a disability (Dolva, Kleiven, & Kollstad, 2014). Bigby and Wiesel (2015) showed that community participation is framed by normative rules around which all people are expected to conform, e.g. how one should behave in public places.

Chenoweth and Clements (2011) studied the service user's (among them adults with intellectual disability) opportunities to participate within organisations that provide disability services. The organisations had tried to identify ways to work together with the service user and define potential roles (e.g. how the service user could be involved in planning) in order to increase participation. However, the potential roles were seldom available for service users with intellectual disabilities because of the nature of their disability, e.g. lack of communication skills.

Moreover, there is research on the participation of children with PI(M)D. This research has focused on children's physical presence (being there) in activities and children's engagement (willingness to participate) in activities (Axelsson et al., 2013; Axelsson & Wilder, 2014). In Axelsson and Wilder's study, children with PI(M)D were shown not to participate in family activities as often as children without disabilities, although children with PI(M)D showed as much engagement in child-driven family activities (e.g. playing, joking) as did children without disabilities (Axelsson et al., 2013). Furthermore, the facilitators of participation were found to be the availability and acceptability of the activity, good knowledge about the child, positive attitudes among people close to the child, the child's sense of belonging, opportunities for the child to influence decisions and to be able to understand, and finally, the child's feeling of being needed (Axelsson et al., 2014).

Participation for adults with PI(M)D

The most common measure of the quality of life for adults with PI(M)D 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, p. 39). This measure refers to the Association for the Scientific Study of Intellectual Disability (IASSID). Despite the knowledge that activities and social relationships are crucial for quality of life, adults with PI(M)D often spend their days disengaged and receive low levels of support, mainly engaged in simple activities such as eating or watching TV (Beadle-Brown et al., 2016).

Furehned (1997) highlighted the living conditions of people with PI(M)D in Sweden. His interpretations focused on the understanding and meaning of a ‘good life’. He showed that people with PI(M)D chose whom they wanted to interact with, but their participation was dependent on the other person’s ability to care and show emotional empathy, and their willingness to live up to the principle of every human’s equal value. Similar results have been found by other researchers, e.g. Johnson et al. (2012) and Mansell, Beadle-Brown, Whelton, Beckett and Hutchinson (2008). Burton Smith, Morgan, and Davidson (2005) examined daily choice-making for adults with intellectual disabilities. Their results showed that choice-making is connected to the degree of impairment rather than the individual’s age. Adults with PI(M)D ‘had the choice availability equivalent of non-disabled children aged 3 years and 10 months (p. 234), and daily choice-making for adults with PI(M)D was significantly lower than for adults with milder or no intellectual disability.

For adults with PI(M)D, participation is achieved through the assistance of others, mostly from group home staff members, personal assistants or family members (see, for example, Johnson, Douglas, Bigby, and Iacono, 2012; Dolva et al., 2014; Dusseljee et al., 2011). Bigby, Clement, Mansell, and Beadle-Brown (2009) as well as Clement and Bigby (2009) have found in their research that staff members working with people with disabilities agree that the policy vision about the principles of choice, integration, and participation is important. Despite this, they often doubt that the principles can be applied to people with PI(M)D because they are not considered to have the ability to choose for themselves or understand the consequences of their choices.

Different studies show that participation for adults with PI(M)D largely depends on clear management guidance and the staff’s professional qualifications and attitudes (Furehned, 1997; Mansell et al., 2008). An important way to increase opportunities for social inclusion for adults with PI(M)D is therefore to ensure the job satisfaction of paid staff members (Johnson et al., 2012).

Dunn, Clare, and Holland (2010) point out that staff members often rely on their own values and life experiences when making decisions on how adults with PI(M)D can participate. Dunn et al. argue that it is troublesome to rely on others (often staff members) for participation since it is not certain that others' perceptions of participation are the same as for the adult with PI(M)D. There is therefore the risk that relying on others for participation will decrease the adults' participation level since the staff members may choose activities that they prefer instead of the activities the adult with PI(M)D prefers. It is also important to know the adults and the way they communicate to be able to interact with them (Goldbart, Chadwick, & Buell, 2014). According to Forster and Iacono (2008), staff members point out that adaptive communication is essential when interacting with people with PI(M)D, and staff members need to rely on prior knowledge to interpret communication with adults with PI(M)D, since their communication is primarily non-verbal (Hostyn, Daelman, Janssen, & Maes, 2010).

According to Qian, Tichá, Larson, Stancliffe, and Wuorio (2015), there is a risk that adults with PI(M)D will not get the support they need to achieve participation. Their research has shown that adults with PI(M)D have a low level of engagement in daily life, 21% engagement in non-social activities and only 3% in social activities. Qian et al. pointed out that they found significantly higher levels of social engagement among individuals with greater adaptive skills. Hanzen, van Nispen, van der Putten, and Waninge (2017) found out that the engagement for adults with PI(M)D depends on the people surrounding them understanding their needs.

The degree of participation of people with PI(M)D is associated with positive attitudes of the people in the surrounding social environment, mainly staff members, but also of other people in the community (Bigby et al., 2012; Bigby et al., 2015; Jones et al., 2008). Staff members often consider people with PI(M)D as being different from people without disabilities, e.g. they may assume that they lack the skills for everyday activities (Bigby et al., 2012). Researchers argue that staff members' negative attitudes towards the capability of adults with PI(M)D affect these individuals' participation in the activities of everyday life (Bigby et al., 2012; Beadle-Brown et al., 2015). Negative attitudes of staff members and other people in the community towards people with PI(M)D and their abilities can, according to Bigby et al., result in their lower interaction with the community. If people with PI(M)D do not take part in their community to the same degree as other people do, there is a risk of decreased social participation (Jones et al., 2008), leading to social exclusion (Dusseljee et al., 2011; Perry et al., 2013). Beadle-Brown et al. pointed out that the quality of life for adults with PI(M)D is relatively poor and that they spend substantial time isolated and disengaged.

Theoretical approach

For this study, I sought a theory that could clarify how participation for adults with PI(M)D is constructed within the social and cultural context in the society. While recognition of the role these adults play in achieving participation in society is crucial, it is also important to look at the role of society. Theories of power and recognition focus either on the individual and the individual's experience (Honneth, 2003) or on the society and its role (Taylor, 1994). Fraser's (2003) theory of redistribution and recognition, rather, is about the society and the individual, and the individual's place in the society. Therefore, this theory was considered suitable for this thesis since it can encompass the different systems (individual and organisational) that influence everyday life for adults with PI(M)D. Fraser's theory has a gender perspective as its starting point, but the theory has also been used in research on disability (e.g. Danermark, 2005).

Fraser's theory of redistribution and recognition

Fraser (2003) argues that both recognition and redistribution are required to create justice in today's society, and that the two different approaches must be integrated. The approaches have their background in two different ideas about the causes of inequality in society, which she terms cultural and socio-economic injustice.

Cultural injustice is about various social representations, interpretations, and communication patterns, which may mean that individuals are forced into the dominant culture of the society despite the fact that this culture can be hostile and alien to their cultural identity. Cultural injustice can also include a lack of respect for and a rendering invisible of the individual and/or the group.

Socio-economic injustice relates to the political-economic structure prevailing in society, and this may include the economic marginalisation of individuals and groups due to low-paid or no work, exploitation, and a low standard of living. There are significant differences between cultural injustice and socio-economic injustice, but since they co-exist in society today, the result is that certain groups are consistently disadvantaged. These injustices should therefore be removed.

The two social inequalities have different so-called cures. The cure for cultural injustice is recognition. Recognition refers to cultural change in the sense of devalued cultures being upgraded or re-evaluated and cultural diversity being valued. The cure for socio-economic injustice takes the form of a redistribution of power and advantage. It involves a political-economic restructuring that could, for example, change the division of labour and the distribution of income. The requirements for recognition and redistribution differ, and, in the case of recognition, it is about consolidating group identity, which often promotes the separation of different groups.

On the other hand, the demands for redistribution are about repealing the economic inequalities that separate groups from each other. These different requirements are, according to Fraser, a dilemma because recognition means that a specific group is strengthened, while redistribution means the group is weakened. This dilemma means that recognition and redistribution are in conflict with and counteract each other. Fraser believes that people exposed to both cultural and economic injustices need both recognition and redistribution, and they need to both claim and dispute their specific nature.

To tackle this dilemma, Fraser argues that there are two different methods or cures. The first method is affirmation, and the second is transformation. Affirmation is the method of eliminating injustice without really changing the structures that create inequality, while transformation is about changing the structures that create inequality. Fraser's solution to the dilemma that people exposed to both cultural and economic injustices need to both claim and dispute their specific nature is to find approaches that minimise the conflicts between recognition and redistribution, as she believes that concrete solutions to the dilemma are missing.

This approach implies, according to Fraser, that recognition must be a matter of social status, and, therefore, what requires recognition is not the group-specific identity but rather the individuals' status as full participants in social interaction. In other words, what needs to be remedied is not so much the diminishing of the group identity per se, but rather the group's social subordination, in the sense that the individuals in the group are not allowed to participate equally in society. To remedy this injustice, a recognition policy is required, one that does not merely reduce the problem to a question of identity, but rather is aimed at overcoming subordination by establishing the group as a full member of society, able to participate on equal terms with others.

When recognition is considered a matter of social status, Fraser argues that the socially-regulated cultural value patterns must be examined to determine if the patterns create recognition or non-recognition. If the cultural value patterns in a society help to create equal conditions for participation, this promotes equal status and recognition. If the value patterns, however, serve to consolidate inequalities and shut out certain groups of people, they lead to unequal status and non-recognition, which means that certain groups are relegated to a subordinate status in society. This subordinate status should not merely be viewed as assimilation in the sense that these groups of people, through other people's attitudes and values, are devalued or disregarded. The subordinate status means they are not regarded as equal citizens in society.

If, because of this subordination, people are not regarded as equal citizens, Fraser believes that different equity arrangements in society are required. However, it is of utmost importance to realize that these equity arrangements are not about raising the value of different groups. They are instead about abolishing the subordination of certain groups in society so that their members can interact with others based on the same conditions and thus be considered as full and equal citizens in society. It is therefore crucial to create cultural value patterns that promote participation on equal terms.

However, Fraser also points out that it is important not to lose sight of the significance of redistribution. She believes that recognition is considerably impeded if the subordinated people or groups lack the resources to make them equal to other citizens in society. She draws attention to the fact that both inequality in terms of resources and inequality in recognition contribute to overall social injustice.

Methods

In addressing the questions of how participation is described in IPs, how social care managers and staff members perceive participation, and how participation is achieved in everyday life for adults with PI(M)D, this study used a combination of quantitative and qualitative methods to gain a deeper understanding of the studied phenomenon (Creswell, 2013; Patton, 2002). An overview of studies I–III is presented in Table 1.

Table 1 Overview of the studies

Study	Design	Data collection	Data analysis
I	Quantitative	IPs for adults with PI(M)D (n = 17)	Descriptive and correlation analyses
II	Qualitative	Individual interviews 10 managers and 17 staff members (n = 27)	Phenomenographic analysis
III	Qualitative	Observations of 13 staff members and 4 adults with PI(M)D (n = 17)	Deductive analysis Shier's ladder of participation

Participants and data collection

The main target group in this thesis are adults with PI(M)D. In study I, their IPs were studied. In study II, social care managers and staff members that work with support and service for adults with PI(M)D were interviewed. In study III, four adults with PI(M)D and staff members that work in the group home where these adults live were observed.

The unit managers in the municipalities' social care division decided if the adults in their different units where to be included or excluded in the study group. However, it was not easy for the unit managers to decide if a person belonged to the target group PI(M)D or not because many of the adults living in the group home did not have a diagnosis. Nonetheless, the unit managers finally decided that 17 adults in total met the criteria of inclusion. According to the unit managers in the studied social care division in this municipality of about 50,000 inhabitants, these 17 adults represent the total population of adults with PI(M)D in the studied municipality.

The municipality

The municipality where the studies took place is a middle-sized municipality in Sweden. The municipality has (as do other municipalities in Sweden) a special social work organisation that cares for the citizens living in the municipality who are in need of support and service of a different kind. Within the organisation there is a division for social care that have the responsibility for taking care of people with disabilities. In the actual municipality, the social care division is built up as described in Figure 2.

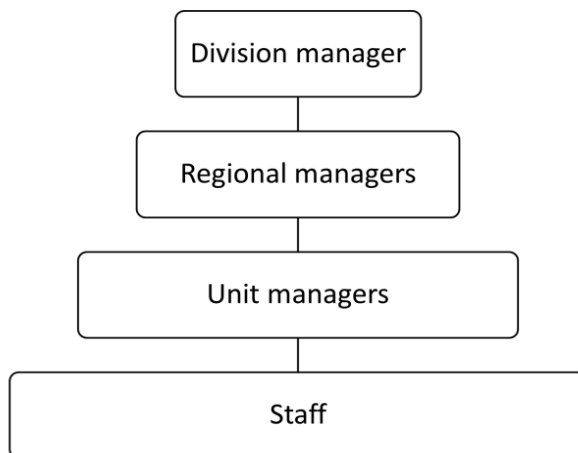


Figure 2. The social care division in the studied municipality

Document analysis of implementation plans

Study I was a document analysis of existing IPs, based on the ICF, for adults with PI(M)D who lived in a group home or in their own home with personal assistance. Seventeen IPs were anonymised by a contact person in the division of social care in the municipality and collected by the researchers. Study I was a total study (all adults, according to the unit managers, with PI(M)D in the studied municipality). The inclusion criteria of participants in the study were: 1) adults (over 18 years of age) with PI(M)D, 2) adults receiving LSS-activities and therefore living in a group home or in a private home with support from personal assistants. The IPs belonged to nine women and eight men aged 23–67. Four of the adults lived in private homes with support from personal assistants, and 13 lived in different group homes. The documents varied both in format and in content. Some were handwritten and some were written on a computer. The IPs also differed in length and were 2–17 pages long. The everyday life activities and how they should be carried out were documented very thinly in some IPs and very detailed in others.

Interviews with managers and staff members

In study II, individual interviews were used to collect data. The main inclusion criteria were that the participants were either managers in social care or staff members that worked with individuals in the municipality who have PI(M)D and lived either in a group home or in a private home with support from personal assistants. To be able to capture perceptions in the whole social care division, it was considered crucial to interview managers at all levels in the division. Moreover, it was important to interview the unit managers responsible for the staff members in the group homes or the personal assistants working in the adults' homes. The number of participants were 27 (10 managers and 17 staff members). Three of the staff members worked as personal assistants, and 14 worked at different group homes. The managers and staff members were 22–65 years old and had 2–35 years' experience. The interviews were based on a phenomenographic approach seeking the managers' and staff members' perceptions of participation for adults with PI(M)D. An open interview guided by one question: "What is participation for adults with PI(M)D?" was used. The follow-up questions varied depending on the progress of the interview. Examples of follow-up questions to informants were: Can you give an example? How do you mean? The interviews were carried out in a place decided on by the interviewee and were 10–30 minutes long, which is a common length for phenomenographic interviews (Larsson, 1986).

Observations at a group home

In study III, observations, with a focus on participation in daily activities, were made of the interaction between adults with PI(M)D living at a group home and the staff members that were working there. Inclusion criteria for the group home observations were that the adults living at the group home were adults with PI(M)D. The observations in the group home focussed on staff members' day-to-day practices concerning the participation of the adults who lived there. This means that the researcher observed staff members and the adults they were caring for in different activities, with a focus on when and how the staff members invited the adult to participate in the activities carried out. Observations were conducted on 13 different occasions. The observations were conducted between 10 a.m. and 7 p.m. on different weekdays, and the observation lasted between 3.5 and 6 hours, for a total of 60 hours. Observations were not conducted in the mornings or in the evenings due to intimate activities, e.g. taking a shower, and being dressed or undressed, since, for ethical reasons, the staff members did not want the researcher to be present on these occasions.

To supplement the observations, discussions took place with staff members concerning questions that were raised during the observations. During the observations, field notes were taken. After the observations, notes of a more synthesising character were written. The field notes contained the activities observed, the researcher's methodological and analytical reflections, and the researcher's discussion with the staff members.

Data analysis

In the three studies, different analytical methods were used. In study I, descriptive and correlation analyses were conducted using the codes in the ICF. In study II, the interviews from a phenomenographic approach were analysed, with a different focus. In study III, analyses of field notes from observations at a group home were deductively analysed using Shier's (2001) ladder of participation.

Analysis of the implementation plans

Practitioners use the ICF to code health and health-related issues (Fayed, Cieza, & Bickenbach, 2011). The municipality where the study took place decided in 2010 to use the ICF when writing IPs and that the documentation in the IPs should focus on the nine different life areas in the ICF component, Activities and participation.

International Classification of Functioning, Disability and Health (ICF)

The ICF is a health-related classification that assumes a holistic view of human beings and is a combination of the medical and the social disability models. The goal of the ICF is to provide a structure and a standardised language for describing functional abilities and disabilities in relation to health. Using the ICF, human health properties within the context of personal life situations and surroundings can be classified. The ICF is not a classification of people; it rather reflects the interaction between health characteristics and the contextual factors that create disability.

The classification is used as a tool to highlight the components that affect the individual's participation in different everyday situations. The ICF is structured in two parts, with different components that interact with each other (Figure 3). The first part covers functioning and disability. The components belonging to this part are body functions, both physical and psychological; body structure, which involves the body's organs and parts; activity, which is an action or task that a person performs; and participation, which relates to the individual's involvement in a life situation. The second part includes the contextual factors such as, architectural characteristics, the attitudes of the society or the legal system, and personal factors such as ethnicity or age.

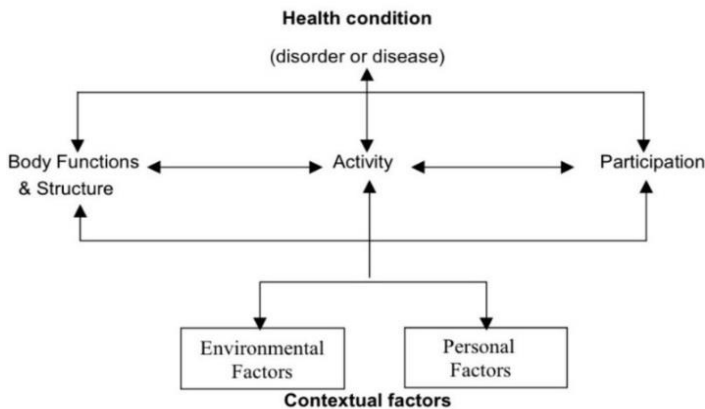


Figure 3 Description of how the components interact with each other in ICF (WHO, 2001).

In ICF, participation is defined as an individual's engagement in a life situation, and activity is defined as the execution of a task or action. Participation can be classified separately or together with activity (WHO, 2001). Activity and participation are not synonymous, however, so classifying them together can reduce the concept of participation to the physical presence in the activity carried out and render the individual's engagement less important (Hammel et al., 2008). In other words, people (e.g. staff members, relatives, community members) may be satisfied that the person is doing an activity and not put any emphasis on if the person wants or does not want to do it.

The subjective experience of participation is important, and participation cannot be analysed without measuring this (Granlund et al., 2012). Hurst (2003) thinks that the ICF can be a useful tool for analysing an individual's participation.

The ICF, properly used, shows that the major negative aspects of a disabled person's life are socially induced. The ICF can be used as an analysis of how rights for anyone can be achieved. It can be a matrix of measurable indicators of sustainable development and a society based on celebrating difference and ensuring rights for all (p. 576).

Coding rules

I decided to use the coding rules set up by Cieza, Geyh, Chatterji, Kostanjsek, Ustun, and Stucki (2005), and to formulate the rules for analysis for this study and data set. The prefix (d) in ICF is used to code the domains within the component *Activity* and *Participation*, but users of the ICF are free to change the prefix (d) to the prefix (a) or (p) to denote activity or participation (WHO, 2001). To capture participation, we decided to use the (d) and the (p) code. The rule choosing a (p) code was that text should indicate an engagement from the person with PI(M)D; otherwise, the (d) code was used. Indicators of engagement were, for example, 'want to', wishes, and likes. The code e340, *Personal caregivers or assistants*, was frequently used in the IPs, so this environmental factor was only coded if the personal caregiver or assistant was doing something together with the person with PI(M)D, not only doing something for them.

In order to reach consensus concerning meaningful concepts and the choice of codes, four IPs were randomly chosen to be analysed by two researchers. One of these four IPs was read through by the researchers separately, and the meaningful concepts were marked and coded. Thereafter, the researchers met to compare the choices of meaningful concepts and codes. The choices of meaningful concepts were similar, but there were differences in the choices of codes. The coding rules were therefore slightly modified to try to capture the diversity of participation in activities. Thereafter, the two researchers separately coded the same IP again and compared the coding, and this time the choices of codes were similar. Both researchers then coded the other three randomly chosen IPs and compared the choices of codes. The coding was similar, and therefore it was decided that consensus had been reached. One of the researchers continued to code the other 13 IPs following the set coding rules. When the 17 IPs had been coded, all daily activities and the codes were entered into SPSS statistics software. Descriptive as well as correlation analyses were performed to analyse the research questions. To test relationships between the daily activities and ICF codes, Spearman's rank correlation test was used, and the P value was set to $P < 0.05$ (Brace, Snelgar, & Kemp, 2012).

Analysis of the interviews

The interviews were transcribed verbatim, and thereafter were analysed based on a phenomenographic approach, where the aim was to describe different ways that people experience a phenomenon in their surrounding world (Larsson, 1986; Marton, 1981; Marton & Booth, 2000). In the analysis, the seven steps of phenomenographic analysis suggested by Dahlgren and Fallsberg (1991) and Sjöström and Dahlgren (2002) were followed in order to catch the variations of perceptions of the phenomenon. During the first step (Familiarisation), the interviews were transcribed verbatim, thereafter unstructured, and repeatedly read to become familiar with the material and establish an overall impression of the interviews. In the second step (Compilation), statements significant to the study's aim were collected. Within these statements, sources of variation or agreement were identified (third step, Comparison). The fourth step (Grouping) involved a preliminary grouping of similar descriptions. Thereafter, the categories were compared to determine the differences between them (fifth step, Articulation). In the sixth step (Labelling), the naming of the categories to highlight their essence took place, and finally in the seventh step (Contrasting), the categories were contrastively compared to study the underlying structure, the so called outcome space, that describes the variations of conceptions of what participation for adults with PI(M)D entails.

Analysis of the observations

After each observation, the field notes were read through, and the details that been briefly noted from the observations were described in detail. Further reflections from the observations of the interactions between the adults and different staff members, with a focus on participation were also written down. The field notes from the observations were read through several times, and text that indicated participation in the observed daily activity for the adults with PI(M)D were marked. Thereafter, the field notes were deductively analysed by using the methods of Elo and Kyngäs (2008). In the analyse a structured categorisation matrix based on Shier's (2001) ladder of participation was developed (Table 2) and the marked text in the field notes were sorted into Shier's five different levels of participation.

Table 2 Categorisation matrix based on Shier's (2001) ladder of participation

Adults with PI(M)D	Field notes indicating that
are listened to	The adult expressed a view that staff member(s) listened to.
are supported in expressing their views	Staff member(s) stimulated the adults to express their views or supported them when they did so.
views are taken into account	The adult's views were taken into account/influenced the decision-making.
are involved in decision-making processes	The adult was directly involved when decisions were made.
share power and responsibility for decision-making	Staff member(s) shared their power and gave some of it away.

Shier's (2001) ladder of participation was originally developed for children, but today it is also used for adults whose participation is dependent on support from the environment (Gullacksen & Hejdedal, 2014). The model is based on five different levels of participation. In Shier's original model, every level starts with the word *Children*, and this has been replaced with the phrase *Adults with PI(M)D* to fit the target group in this thesis:

1. Adults with PI(M)D are listened to.
2. Adults with PI(M)D are supported in expressing their views.
3. Adults with PI(M)D views are taken into account.
4. Adults with PI(M)D are involved in decision-making processes.
5. Adults with PI(M)D share power and responsibility for decision-making.

Connected to each of the five levels of participation are three stages of commitment: openings, opportunities, and obligations. The first stage, openings, is about the willingness of the people in the environment to listen to and support the adult with PI(M)D. This stage is, according to Shier, only an opening because it is not certain that the opportunity to make it happen is available. The second stage, opportunities, is about the people providing the care having the resources, skills, and knowledge to listen to and support the adult with PI(M)D. The third stage, obligations, refers to whether organisational policies and guidelines are in place to increase the participation for the adults with PI(M)D. To fully achieve the last level, Shier states that it 'requires an explicit commitment on the part of adults to share their power; that is, to give some of it away' (p. 115).

Ethical considerations

Ethics approval for the doctoral project was obtained from the Regional Ethics Committee in Uppsala, Sweden (D.nr. 2013/375). All the people included in the studies, and the legal guardians for the adults with PI(M)D, were informed both orally and in writing about the purpose of the research and the methods that were being used. They were informed that their participation was voluntary and that, at any time, without explanation, they could cancel their participation, and it would not affect the continuing relationship with the social care division. Furthermore, they were informed about what would happen with the data material if they decided to cancel their participation. They were also made aware of who the research principal and correspondent was. After receiving this information, all informants and the legal guardians for the adults with PI(M)D signed a consent form. Data collected were treated confidentially and, in the results, the individual's identity was anonymised. The participants were not expected to be exposed to harm, pain or discomfort, but because the study concerns dependants, a series of ethical considerations were necessary.

In study I, the IPs were de-identified by a contact person in the division of social care in the municipality and handed over to the researchers to ensure the anonymity of the adults with PI(M)D. The only information the researchers got were age, gender, and place of residence (group home or private home). In study II and III, the social care managers and staff members interviewed were asked not to reveal the identity of the adults with PI(M)D when they provided examples. In study III, the observations were approved by the adult's legal guardian. The approval from this guardian was necessary since it was not possible to obtain informed consent from the adult with PI(M)D. At each observation, the adult with PI(M)D was informed that they would be observed by the researcher while interacting with staff members in different activities of everyday life. If the adult in any way did not seem comfortable with being observed, no observations were made. If the adult, during the observation, in any way showed the slightest sign of discomfort or unwillingness to participate, the observations were interrupted. Due to the intimate activities in the morning and late evening (shower, toileting, and so forth), no observations were made at these times. If any of the informants, managers, staff members, or adults with PI(M)D were uncomfortable after the interviews or observations and needed support concerning the issues raised, the municipality provided professional support for this.

Results

In this section, a brief summary of the main results of each study are given. All three studies have, in one way or another, contributed to the overall aim of the thesis.

Documentation of participation (I)

The areas documented in the IPs, in the social care division in the studied municipality, mainly belonged to the ICF components *Activities and participation* (d) and *Environmental factors* (e). The most common codes were *Personal care providers and personal assistants* (e340) and *Eating* (d550). There was limited documentation on *Body functions* (b); half of the codes belonging to this component were about *Mental functions*, and the most frequently used code was *Regulation of emotion* (b1521). *Personal factors* (pf) and *Not definable* (nd) were not so commonly documented, while *Health conditions* (hc) was only documented on seven occasions in two IPs. *Body structures* (s) was not documented at all in any of the IPs. In the IPs, there were 635 different daily activities, or meaningful concepts (Cieza et al., 2005). Twenty-eight of the daily activities belonged to Body functions, 23 to Not definable, 17 to Personal factors, 13 to Environmental factors, three to Health conditions, and the remaining 551 belonged to Activity and participation.

When analysing the distribution of the daily activities in the nine life areas of the component Activity and participation, the results showed that Self-care, followed by Community, social and civic life, was most often documented. An interesting aspect of the daily activities documented in the life area Community, social and civic life, such as listening to music, watching television, and going to the public swimming pool or McDonalds, was that the activities were more or less the same in every IP, regardless of the individual's age or sex. There was very little documentation on Communication, Major life areas, and Interpersonal interactions and Relationships. The life area Learning and applying knowledge was not documented at all in any of the IPs, as shown in figure 4.

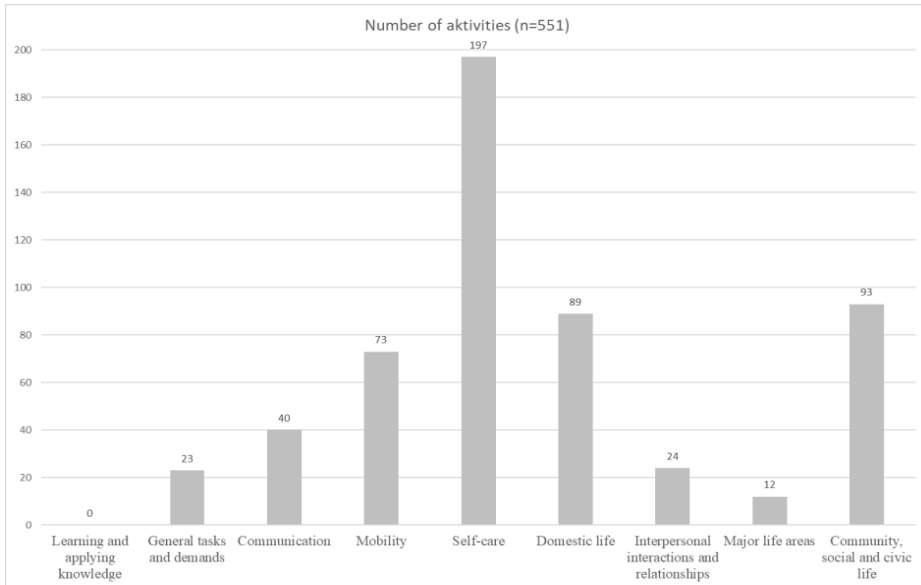


Figure 4 Amount and distribution of daily activities in the nine chapters in the component Activity and participation (n = 551)

When using the (p) code to especially focus on *Participation*, the chapters *Community, social and civic life* and *Self-care* referred to individuals' participation according to the IPs. There were no codes referring to *Learning and applying knowledge* or *General tasks and demands*, and only one code referred to *Communication*. The most frequently used code referring to participation was *Recreation and leisure* (p920), which belongs to chapter 9, *Community, social and civic life*, in the component *Activity and participation*.

To focus on participation, correlation analysis was carried out between the codes within the *Activities and participation* component. Only two significant correlations were found: one between *Carrying out daily routine* (d230) and *Communicating with - receiving - spoken messages* (d310), and one between *Communicating with - receiving - body gestures* (d3150) and *Washing body parts* (d5100). For adults with PI(M)D, activity and participation are achieved with the assistance of others, and *Personal care providers and personal assistants* (e340) was significantly correlated with *Recreation and leisure* (p920), *Washing body parts* (d5100), and *Eating* (d550). Correlations were also significant between *Personal care providers and personal assistants* (e340) and the chapters *Self-care* and *Community, social and civic life*, and the components *Activity and participation* and *Personal factors*.

Perceptions of participation (II)

The results in study II showed that the phenomenon of participation was abstract and hard to handle for both managers and staff members. In the social care division, there was no consensus about what participation means when they discussed it, and even if they used ICF when documenting in the IPs, they did not use ICF's definition of participation. This makes it even harder for both managers and staff members since the phenomenon is defined subjectively, and it is therefore uncertain that they are talking about the same thing when discussing participation. Moreover, the social care division did not have any guidelines for how participation should be achieved in daily life for adults with PI(M)D. The social care managers and staff members had different perceptions of participation in a wide range from "to do things", such as eat by yourself, to "to decide", such as decide over one's own life. When it came to what participation involves, there was a wide range of perceptions. The analysis of the interviews resulted in perceptions that were divided into seven different categories, the so-called 'outcome space' (Figure 5).

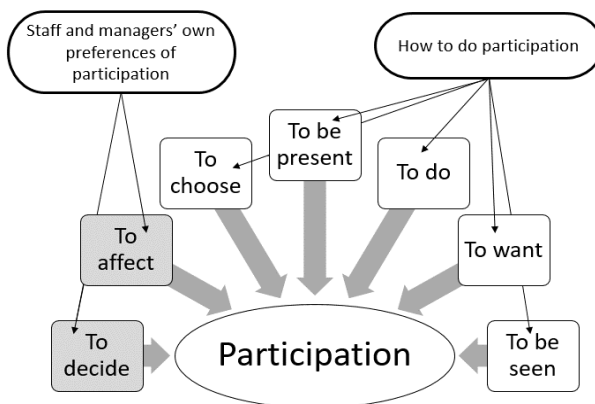


Figure 5 The outcome space

The first two categories were about managers' and staff members' *own preferences* regarding their *own* participation. *To decide* was about making decisions about one's own life. *To affect* was about being able to affect the decisions that are taken. The other five categories were about managers' and staff members' conceptions of how *to do*, that is, how to enable participation for adults with PI(M)D. *To be seen* was about being respected as an individual, as a person beyond the impairment. *To want* was about what the adult with PI(M)D wants, wishes, and likes. *To choose* meant that the person with PI(M)D was offered a choice between, for example, the red and the blue sweater. *To be present* was, for example, being in the kitchen when staff members were preparing dinner. *To do* was simply doing things by yourself, such as eating or getting dressed.

Conditions for participation (II)

According to both social care managers and staff members, there were conditions, both on the individual and the organisational level, that were necessary for facilitating participation. In the analysis, these conditions were divided into three different levels: the adults with PI(M)D, the managers and staff members, and the organisation. For the adults with PI(M)D, the conditions for participation were about their capability or degree of impairment, where lower capability or more severe impairment decreased the possibility for participation. The conditions for managers and staff members were the knowledge—both common about disabilities and specific about the individual—they had to learn from more experienced staff members, including the special communication skills about symbolic language they needed in order to understand the adults. On top of that, they needed to allow enough time for the adults to respond since it takes them time. They also needed to be attentive to the power difference so that they did not take over the decisions from the adults; to be professional, they needed to be sensitive and aware. According to staff members, the organisation had a crucial role, especially when it came to opportunities for the staff members to work towards participation. The conditions for participation, as social care managers and staff members perceive it, is shown in Figure 6.

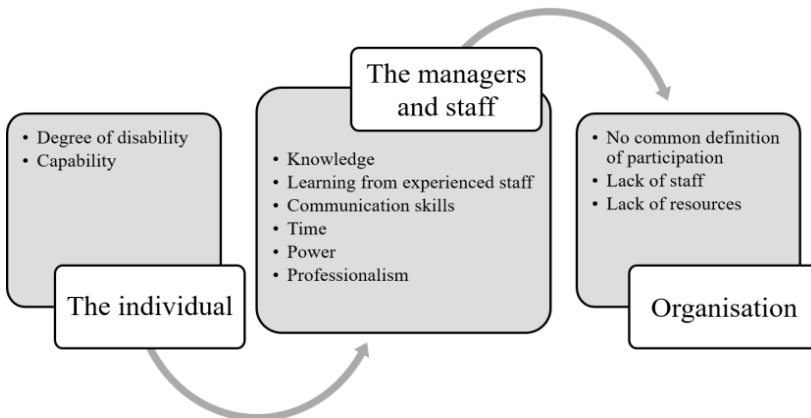


Figure 6 Social care managers' and staff members' perceptions of conditions for participation for adults with PI(M)D

The interview results showed that participation for adults with PI(M)D were dependent on the conditions at three levels. The conditions described in Figure 4 reveal what social care managers and staff members, according to the interviews, think is needed to realise participation for adults with PI(M)D. If the conditions are not to some extent fulfilled, the managers and staff thought that participation in daily life was difficult and, in some cases, impossible to achieve for the adults with PI(M)D.

Ladder of participation (III)

The results from the observations showed that the adults with PI(M)D often reached the first three levels in Shier's (2001) ladder of participation.

1. to be listened to
2. to be supported in expressing their views
3. to have their views taken into account

To be listened to is the first level in the ladder of participation, and the results show that this was something that were observed often, even if the adults with PI(M)D could not communicate by speaking or protesting or pointing at things. The staff members were often focused on small signs such as the adult's body language or what they were looking at. On the other hand, there were occasions when staff members did not listen to the adults with PI(M)D.

The second and third levels in the ladder of participation are about being able to express one's own view in the activity and having that view taken into consideration. The results show that this was commonly observed. It seemed that it was easy for all of the observed adults with PI(M)D to express their views and that the staff members often, but not always, supported their expressions and took their views into account. The fourth level, *to be involved in decision-making processes*, was reached on one occasion by one of the four adults observed during the study period. The fifth and last level in Shier's ladder of participation, which is that the staff members are supposed *to share the power and responsibility for the decision-making*, was not reached on any occasion during the observations. The staff members rarely or never offered possibility for the adults to decide. The staff members seemed to think that they knew the adults with PI(M)D, including what they would like, and therefore often decided for them.

There are three stages of commitment connected to the five levels of participation in Shier's (2001) ladder of participation; openings, opportunities, and obligations. Openings were common, and there were many openings where staff members could listen to the adults with PI(M)D. Despite the many openings, however, the opportunities for participation were sometimes limited due to environmental circumstances, such as lack of transportation or limited time. Obligations (organisational policies and guidelines on how to increase participation) did not exist.

Discussion

The overall aim of this thesis was to highlight and problematise the perceptions of participation and how participation was achieved in IPs and in everyday life for adults with PI(M)D, from the perspective of social care managers, staff members, and researchers. The results show that documentation (I) of participation focused on self-care, e.g. eating or taking a shower, and community, social and civic life, e.g. recreation such as listening to music or watching television. When talking (II) about participation, the results show that participation is abstract and hard to handle and that participation for the adults was about doing or being present with respect to general daily activities such as eating or cleaning the apartment. Participation for adults with PI(M)D was seldom connected to social contacts and leisure activities (II, III). Moreover, there were conditions (II) needed for participation, such as the adults' capability, the social care managers' and the staff members' knowledge, and the organisations' resources. During participation (III), the adults were listened to, they were supported in expressing their views, and their views were taken into account. However, the adults were not involved in decision-making processes nor did they share the power and responsibility for the decision-making. The purpose of this thesis is to discuss and problematise these findings.

Writing about participation

The study results show that the focus of the IPs was on the ICF components *Activities and participation* and *Environmental factors*. Notes about *Personal factors*, such as habits and personal preferences, were seldom documented, even though the IPs in the municipality have a section where personal factors should be written down. According to Furenhed (1997), personal factors are important preconditions for participation and a way to understand the wishes of the adults. The component *Body functions* was seldom documented other than problems the adults had with emotional regulation, e.g. getting angry or too excited. The *Body structures* component was not documented at all. This can be problematic since the help the adult's need to perform an activity, often relies on the individual's body functions and the staff members' ability to respond to their difficulties. Environmental factors such as wheelchairs and walking aids, which could compensate for the lack of body functions, were often documented but never in connection with the recorded activities.

The results also show that staff members mainly document basic daily activities and, to a lesser extent, leisure time activities. Only focusing on one aspect of everyday life in the documentation makes it difficult to determine whether the goal, ‘good living conditions’, and the opportunities to live as others do, as outlined in LSS (SFS 1993:387), are reached. There is also an elevated risk for social exclusion when social contacts and leisure activities are few (Dusseljee et al., 2011; Perry et al., 2013). Maybe this is a form of what Fraser (2003) calls “social subordination”. Adults with PI(M)D might not be seen as full members of society able to participate on equal terms as others. Therefore, the staff may consider leisure time activities as less important to encourage and develop.

In the IPs, one omitted area was communication, despite that it is a prerequisite for participation and that people with PI(M)D often have limited communication skills (Blomberg, 2006; Furenhed, 1997). There were no correlations between communication and activities other than the communication used by staff members to tell or show the adult how to act in activities related to daily routines and hygiene. This indicates that staff members used communication mostly to direct the adult with PI(M)D, e.g. about how to act in activities related to daily routines and hygiene. Overall, communication used in a broader sense than spoken language, such as sign language or the use of pictures and symbols, was rarely focused on in the IPs, and this may constitute a barrier for participation if the documentation in the IPs reflects reality. Interestingly, Fraser (2003) points out that one form of cultural injustice relates to communication patterns, and that since the adults with PI(M)D do not have the spoken language ability of the dominant culture, they therefore have a higher risk of being disrespected than others in society.

The daily activities documented in the IPs were always carried out with staff members, and, consequently, the most common ICF code in the IPs was Personal care providers and personal assistant, e.g. staff members’ support to individuals in their daily activities. According to previous research, participation for adults with PI(M)D depends on others’ abilities to care, to feel empathy and a sense of common humanity, and on their willingness to live up to the principle of every human’s equal value (Furenhed, 1997; Johnson et al., 2012; Mansell et al., 2008).

This results indicate that if the documentation reflects real life, staff members were supportive and focused on the individual’s participation both related to daily activities and leisure time. Despite this, the leisure time activities written down, such as listening to music, watching television, and going to the public swimming pool or McDonalds, were more or less the same in every IP, regardless of the individual’s age or sex. The leisure time activities were typically carried out with staff members or alone, but seldom with friends or relatives. The reason for the adults’ similar leisure time activities could be that the social expectation is for people to conform and behave in a way that is culturally acceptable (Bigby & Wiesel, 2015), and that these leisure activities

are the ones that the adults with PI(M)D can handle in a culturally acceptable way. Therefore, the recognition of adults with PI(M)D as different individuals with different interests can, according to Fraser (2003), be one antidote to the homogeneity of leisure time activities. Other reasons for the similar leisure time activities, and that the activities seldom were carried out with friends or relatives, could be the lack of close relations, the staff member's lack of creativity, or the limited organisational resources.

In the IPs, personal factors, such as the adults' desires, were seldom written down, and nothing was documented about if the adult with PI(M)D had the necessary body functions to be able to perform the documented activities. However, the individual's desire and the physical ability to perform an activity are two important prerequisites for participation (Molin, 2004). Therefore, it is troublesome that there is a lack of documentation in the IPs regarding these important prerequisites. The lack of documentation about the individual's desire and physical ability to perform an activity could, on the one hand, indicate a lack of respect for the individual (Fraser, 2003) while, on the other hand, it could just be that the staff members think other things are more important to document.

Approximately 80% of the documented activities in the ICF component *Activity and participation* related to *Self-care, Domestic life, and Mobility* and were mostly about eating, drinking, shopping, getting dressed, doing housework, moving around, using equipment, and toileting. Nothing was written in the IPs about *Learning and applying knowledge*, and very little was documented about interactions and relationships with others, education, work and employment, or economic life. Maybe these are areas that the social care managers and the staff members do not consider relevant for adults with PI(M)D. Not focusing on these areas can be connected to the result in study II where social care managers and staff members pointed out that these adults were not capable enough to do everything that other people do. Changing the social care managers' and staff members' negative attitudes could increase the adults' participation since positive attitudes are an important condition for the possibility of participation (Jones et al., 2008; Bigby et al., 2015). Social care managers' and staff members' negative attitudes about the adults' capability could also make it difficult to meet the political disability policy's intention that people with disabilities shall live as others do.

Talking about participation

When talking about participation, social care managers and staff members pointed out that participation was an abstract concept that they found difficult to conceptualise and verbalise. The social care managers mentioned that the municipal social care division lacked a documented definition of what participation for adults with PI(M)D entails. Moreover, the staff members indicated that the division did not have any guidelines for how participation should be achieved in daily life for adults with PI(M)D.

The results show that the conceptions of participation for social care managers and staff members were at two different levels of abstraction: their own preferences and how to enable participation for adults with PI(M)D. Their own preferences were about participation as decision-making or at least about affecting decisions in their own life. Both the social care managers and the staff members talked about their views that adults with PI(M)D were not capable of decision-making, especially since the adults did not understand the consequences of their decisions.

Moreover, the results show that the social care managers' and the staff members' focus was on what adults with PI(M)D were able to do, despite their impairment. When talking about participation, it was often connected to general daily activities (e.g. eating, getting dressed, and cleaning the apartment), and, to a lesser extent, leisure activities. Adults with PI(M)D are disconnected from social contacts, and they infrequently engage in leisure activities. Dolva et al. (2014) pointed out that few social connections and/or leisure activities are organised specifically for people with disabilities. As Dusseljee et al. (2011) and Perry et al. (2013) point out, there is a higher risk of social exclusion when people have limited access to social contacts and leisure activities.

Perceptions of participation varied among the social care managers and the staff members. This could be challenging for managers and staff members because it was not obvious that they were discussing the same phenomenon. The lack of consensus about the meaning of the phenomenon of participation, and how it should be achieved, is problematic as this suggests that it is both unreflected upon and undefined. The social care division lacked a definition of participation, which made it more difficult because the way that managers and staff members defined and achieved that phenomenon in their daily work was subjective. The lack of a consensus of the meaning of participation suggests that people's participation can differ from day-to-day depending on the staff member that is working with them. The lack of a consensus on what participation means makes it difficult for staff members to support adults with PI(M)D; it leads to the staff members being unable to fulfil a goal that is both undefined and unspecified.

Communication was one thing that the social care managers and staff members talked about, and they thought that communication was important in “both ways”. They considered it important to understand the language the adult with PI(M)D used, whether it was spoken words, signs, or body language, and to learn how to communicate with the person in a way that they could understand. When the social care managers and staff members talked about participation, they also talked about the conditions needed for participation. According to these interviewees, the important conditions for participation were the capability of the adult with PI(M)D and his or her personality, while environmental factors were less important. Another condition for participation that emerged in the interviewees was that the organisation needed to be supportive. There was a lack of staff members and resources to facilitate social participation and enable the adults’ interaction with the social surroundings outside the ‘home’. This can be seen as a form of socio-economic injustice and an economic marginalisation of this population. Fraser’s (2003) solution to this problem is transformation, which is about changing the structures that create inequality. One activity towards transformation that could be done to create equal participation for adults with PI(M)D is for the staff to have more opportunities to interact with the adults during work times and to bring them out into the community more. Kåhlin et al. (2014) also point out organisational factors, such as community policy, and lack of staff or other organisational resources, as important preconditions.

The adults’ wishes were, according to both social care managers and staff members, considered an important condition to achieve participation. However, these wishes were often talked about (study II) but seldom documented (study I). This indicates that there is a discrepancy between what social care managers and the staff members say about the importance of the individual’s wishes and how important it is to document this. On the one hand, managers and staff members talked about the importance of accounting for the individual’s wishes, but that it was not always easy to understand their wishes, and they also needed time to do that. On the other hand, the observations (study III) revealed that staff members had time at their disposal but often used the time to interact with each other instead of the adults in the group home. Earlier research (Qian et al., 2015) has shown that there is a risk that adults with PI(M)D will not get the support they need to achieve participation since they have to rely on others. Their research showed that adults were engaged 21% of their time in non-social activities and only 3% in social activities.

Both the social care managers and the staff members talked about their belief that adults with PI(M)D were not capable of decision-making, especially since the adults did not understand the consequences of their decisions. Bigby et al. (2009) and Clement and Bigby (2009) noted that staff members discussing this matter suggests that the responsibility, or the lack thereof, for the participation of adults with PI(M)D is, in some way, placed on the individual instead of being seen as the obligation of managers and staff members.

“Doing” participation

Staff members were often “doing” participation with the adults with PI(M)D by listening to them. The staff members usually took their wishes into account, but they also forgot to do so at many occasions. The adults with PI(M)D seldom engaged in activities in their daily life, and only one of the adults had any social relationship at all with people other than staff members. Mansell and Beadle-Brown (2012) state that the concept of quality of life for adults with PI(M)D means that they are engaged in the activities of their daily life and that they have social relationships connected to their daily life. It is clear that these requirements were not reached for the adults.

The staff members claim that they have good knowledge of what the adults with PI(M)D like and dislike since they have supported them for many years. Therefore, it should be quite easy to “do” participation with them, e.g. staff members know which decisions the adult is able to make. On the one hand, staff members did not invite the adults in any kind of decision-making since they thought they already know what the adult with PI(M)D wanted or didn’t want. On the other hand, even though there were many openings where the staff members could listen to the adults with PI(M)D, the opportunities were sometimes limited due to environmental circumstances such as lack of transportation or limited time. The fact that staff members do not let the adults decide for themselves means that the adults with PI(M)D have fewer opportunities to pursue their wishes and decide on the course of their lives, which Söder and Grönvik (2008) concluded. Since collective responsibility and respect for diversity are central to social work, recognition (Fraser, 2003) can be a way to solve the adult’s lack of decision-making. It seems that adults with PI(M)D need recognition in the sense that they feel counted and invited in decision-making as often as possible. A result of the lack of their decision-making is that the key goal about participation in LSS (SFS 1993:387) is harder to reach. Therefore, it is not certain that the social care division are able to ensure that adults with PI(M)D have ‘good living conditions’ and opportunities to live like others do.

When “doing” participation, staff members often drew on their own preferences and made decisions for the adults with PI(M)D. Staff members did not give the adults the opportunities to choose, e.g. the adults were asked what they wanted, but the staff members did not always wait for their decisions. According to Fraser (2003), this could be a form of subordination since adults with PI(M)D do not interact with staff members based on the same conditions since staff members are the ones in charge. To change the power relation Shier’s (2001) ladder of participation can be an instrument. By using the ladder in daily work, staff members can be aware of the adult’s level of participation and work towards improvement.

Participation at different system levels

When exploring participation according to Bronfenbrenner's (1979) theory, from the chronosystem to the microsystem, there is a reduction in participation for adults with PI(M)D. At the chronosystem, there has been an increase over time in participation, especially since the end of 1960s when the large-scale institutions started to close down. The closedown has led to different living conditions since adults with PI(M)D moved out into the community, and, as Nirje (1969) pointed out, the purpose was to live under as normal circumstances as possible. When it comes to the macrosystem, participation has increased a lot since 1948 when the Universal Declaration of Human Rights was adopted. In Sweden, participation for adults increased significantly in 1994 when LSS was established, and on an international level, the UN Convention on the Rights of Persons with Disabilities has put participation high on the agenda. However, regarding the exosystem, the municipality level, it seems like participation has been reduced compared to the policy vision on the macrosystem level. The social work division responsible for the support and service to adults with PI(M)D have not defined participation, and they have no guidelines for how participation for adults with PI(M)D should be implemented. On the mesosystem level, participation has reduced even more since there is a lack of both staff members and resources to facilitate participation. At the final level, the microsystem, the participation of adults with PI(M)D has reduced to an even greater extent. It is assumed that staff members are working towards the intentions that are formulated in the LSS (SFS 1993: 387). However, participation is abstract and hard to handle for the staff members, who also have very little organisational support when trying to facilitate participation for the adults with PI(M)D. Their participation is therefore reduced to 'doing' or 'being present' in general daily activities, e.g. eating, toileting, taking a shower or cleaning the apartment. The adult's capability or degree of impairment is considered crucial in terms of which level of participation is possible. While, in theory, the disability policy stipulates that adults with PI(M)D should have the fullest possibility to participate in their everyday lives, in reality, their participation is poor (Beadle-Brown et al., 2015). However, results from Study III shows that the adults with PI(M)D often reaches the three first levels in Shier's (2001) ladder of participation. If staff members use the ladder in their daily work, it is possible to improve the adult's level of participation

Methodological considerations

A central limitation in the whole project is the definition of adults with PI(M)D. The unit managers in the municipalities' social care division created the definition. At first, there should be four adults with PI(M)D that had personal assistance and 10 adults with PI(M)D living in a group home. But unit managers in the group homes were unsure about adding five more adults that may or may not belong to the target group. When collecting the IPs, there were four adults with PI(M)D that had personal assistance, but two of the unit managers for the group homes had changed the number of adults belonging to the target group. One group home had changed the unit manager. The old unit manager had decided that there were no adults with PI(M)D living in the group home, but the new manager decided that two of the adults living in the group home belonged to the target group. In a discussion with two of the unit managers, they explained that it was not so easy to decide if a person belonged to the target group PI(M)D because many of the adults living in a group home do not have any diagnosis. The criteria that the social care unit managers seemed to use to decide the grade of intellectual disability was if the adult could communicate in spoken language or not; the poorer the verbal communication, the more severe the intellectual disability. In total, 17 adults met the criteria, who also made up the total population of adults with PI(M)D in the municipality, according to the unit managers. Since the IPs of all 17 adults with PI(M)D were analysed in study I, and all social care managers and a random selection of staff members that worked with the 17 adults were interviewed in study II, the results of these studies can be regarded as reliable for the studied social care division. In study III, only four of the 17 adults with PI(M)D, living in the same group home, participated. Therefore, the result from study III can only be regarded as reliable for the studied group home, not the whole social care sample in this municipality.

Another limitation, or maybe an advantage, could be my preunderstanding of people with different disabilities. On the one hand, I have over 30 years of experience within the family, as well as being a board member of different disability organisations, and over 10 years' experience teaching and working with social care managers and staff members. On the other hand, I had no prior experience about the target group, adults with PI(M)D, or the concept of group homes or personal assistance. Therefore, I was familiar with the social care division but not with the daily life of adults with PI(M)D. Even without any experience of adults with PI(M)D, it was necessary for me to be aware of the risk of preunderstanding people with different disabilities and therefore carefully follow the research methods in the studies so as not to draw subjective conclusions from the results.

Study I

A limitation concerning study I is that participation as defined in the coding rules is not commonly expressed in the IPs. Therefore, the easiest way to use ICF as a tool might have been to use only the (d) code (activity/participation) to not separate activities and participation. However, the aim was to capture participation in a more subjective way, by using the (p) code, and some of the meaningful concepts in the IPs were focused on what the individual wanted, wished, and liked. It was also troublesome to code the meaningful concepts that did not focus on the set rules for participation. WHO (2001) recommends that the (a) code be used for the coding activity when the (p) code is used for the coding participation. However, it was not possible to decide that the meaningful concepts were an activity isolated from participation; therefore, the (d) code for activity and participation had to be used instead of the recommended (a) code. The document analysis can be said to have reached good validity and reliability, as the researchers followed the commonly used coding rules by Cieza et al. (2005). The choice of meaningful concepts and the coding of them was conducted with expert consultation and by two researchers, in a consensus, which also strengthened the study's validity and reliability (Creswell, 2009). One limitation in this study was the rather small sample size of 17 IPs. It should be noted that, although the sample was a total population sample, the results might not be generalised to a population in other municipalities. The results should be considered as an example, which the reader can compare to other contexts. It is also important to keep in mind that the result shows what was documented in the IPs, and it is not certain that the documentation was consistent with the social care managers' and staff members' practical work.

Study II

On the one hand, the limitations in study II concern the details in the interviews of what comprised participation for adults with PI(M)D. It was very hard to get under the surface about what participation for adults with PI(M)D really means, because the phenomenon is abstract, and the organisation does not have a consensus on its meaning. It was very difficult for both staff members and managers to verbalise what participation means or to explain how participation of adults with PI(M)D was actually achieved in their daily activities. Therefore, some of the interviews are superficial concerning what participation for adults with PI(M)D consisted of. It was very difficult for some of the respondents to give an answer to the question "What is participation for adults with PI(M)D?" Moreover, the follow-up questions did not facilitate a response if an informant was stuck. On the other hand, to get the managers and staff members to talk about the conditions for participation was quite easy, and the interviews revealed many different conditions that were seen as necessary for the adults with PI(M)D to achieve participation.

People with PI(M)D often have limited communication skills (Granlund et al., 2013), which make it difficult to determine what participation is from their own perspective. Therefore, interviewing social care managers and staff members about participation for the adults is a feasible choice of data collection. Since participation is a legal right for all individuals, with or without disabilities, it is important to address how it is conceptualised in the social care division that provides care, support, and services to people with PI(M)D. However, it can also be problematic since it is not certain that the social care managers' and the staff members' conceptions of participation are similar to those of the adults with PI(M)D. In qualitative studies, trustworthiness is crucial (Lincoln & Guba, 1985), and to enhance the credibility, the data were carefully collected and analysed taking into account both content and context. The context was taken into account both by the researcher's knowledge of the culture in the social care division and by inviting all levels (managers and staff members) to participate. The content was taken into account by using the phenomenographic method and reporting the result to the participants so that they could verify that the result was reasonable in their point of view. To achieve trustworthiness and confirmability, all the researchers were involved in the analysis process, and the data were analysed and discussed until consensus about the managers' and staff members' different perceptions of participation and the different conditions for participation was reached.

Study III

The aim to study participation by observations was both difficult and easy since it took some time to be accepted by staff members in the group home. The staff members were quite suspicious at the beginning (they thought that the researcher was evaluating their work and was going to report it to the manager), so some of the time got lost while explaining the purpose of the observations. On the other hand, they soon got used to the observing researcher, who, after a while, was more or less treated as one of the staff members.

A limitation concerning the observations is the time spent at the group home. The observations lasted for 60 hours and were done at 13 different occasions. The time spent can therefore be considered much too short for getting to know the adults with PI(M)D. However, the aim of the observations was to observe how staff members were facilitating participation for the adults who lived in the group home, and it was therefore not necessary to get to know the adults. During the observations, only the three first levels of Shier's (2001) ladder of participation were observed regularly. The fourth level was observed at one single occasion, and the fifth level was not observed at all. Maybe a longer period of observations could have revealed activities in which the last two levels in Shier's (2001) ladder were more common.

In qualitative studies, transferability and credibility are important in order to receive trustworthiness (Lincoln & Guba, 1985). Transferability was reached by a detailed description of the research process, and credibility was received by taking both content and context into account while collecting and analysing the data. The researcher took the context into account by visiting the group home three different times before the observations to become familiar with the group home's culture. The content was taken into account by the researcher discussing the results with the staff members after every observation.

Conclusions

As we have seen, participation is a complex and multidimensional phenomenon. In order to meet the disability policy goals of full participation in the community, people at all levels of an organisation need to have a shared understanding of what participation of adults with PI(M)D entails so that they can work in the same direction. Yet, among researchers, policy-makers, and social care workers, there is a relative lack of consensus on the meaning of participation and on the appropriateness of existing care approaches to participation for people with PI(M)D. By the same token, divisions of social care, social care managers, and staff members are often left to both define and facilitate participation themselves. This is a challenge both to social care managers and staff members, and it affects the adult's level of participation.

In the IPs that are drawn up in the social care division, it is important that the documentation clearly shows what the adult with PI(M)D wants, wishes, and likes and how they want support to be carried out. In this mission, the ICF can be used as a tool in everyday life planning for adults with PI(M)D. The classification can be used to support social care managers and staff members and ensure that information about the most important factors in an individual's functioning in the environment are not omitted in documentation.

The results show that participation was seldom connected to social contacts and leisure activities. Adults with PI(M)D therefore have a higher risk of social exclusion since having so few social contacts and leisure activities limits their interaction with the surrounding community. The result also showed that participation was characterised in quite the same way for the adults with PI(M)D, and they were offered almost the same leisure time activities, with only a few exceptions. This indicates that organisational, more than individual, factors determine what the adults with PI(M)D do in their everyday life, and it is therefore important that staff gets the organisational support to be able to individualise and facilitate the adults' leisure time activities. Participation for adults with PI(M)D is dependent on conditions in three different dimensions: the adult with PI(M)D, the managers and staff members, and the organisation, which indicates that the adults' participation is conditional. A big challenge for social work is therefore to work towards changing the conditions to better facilitate participation for adults with PI(M)D.

Furthermore, the results reveal that adults with PI(M)D are listened to, they are supported in expressing their views, and their views are taken into account. However, they are seldom involved in decision-making processes, and they do not share the power and responsibility for decision-making. Therefore, social care managers and the staff members decide more about the adult's everyday life than they do themselves. An important task for the social care division is therefore to promote participation for adults with PI(M)D since the principles of social justice, human rights, and respect for diversity is central to social work (ISWF, 2014).

Social care managers' and staff members' attitudes about the adults' capability (e.g. the poorer verbal communication, the more severe the intellectual disability) seems to be a barrier for participation. The fact that managers and staff members decide about the adults' capability makes the power relations uneven and reduces the adults' possibilities to exercise self-determination and everyday life autonomy. This lack of participation in decision-making is a serious barrier for achieving the participation goals in the Swedish disability policy. In this regard, the social care division have an important educational mission to change managers' and staff members' attitudes about the adults' capability and to work towards what Fraser (2003) refers to as recognition so that this specific group of adults is strengthened in society.

Future research

To increase the knowledge of how to improve participation for adults with PI(M)D, future studies are necessary. The lack of consensus among social care managers and staff of the meaning of participation for adults with PI(M)D is problematic. Possible ways to get more knowledge and reach a consensus about the meaning of participation for adults with PI(M)D is to conduct focus groups or maybe a Delphi-study. Social care managers' and the staff members attitudes' about the adults' capability is one of the barriers for participation. Therefore, good examples of when, where, and how participation can be facilitated both by managers and staff members in the physical set-up of homes is needed. Another interesting question for future research is how findings about participation in IPs correlate with the sex, age, and living circumstances. This question requires a bigger sample than in this thesis. Further observations to find out how participation is facilitated by social care managers and staff members in the adults' everyday life are also needed. These observations should be done over a longer time and include the adults' work (daily activities) to capture the participation of these adults in different contexts. It could also be of interest to focus on if there are structural root causes, historical reasons, or developmental differences that cause little or non-participation of adults with PI(M)D. Last but not least, studies on how technology can be utilised to facilitate participation for adults' with PI(M)D could be interesting.

Swedish summary

Bakgrund: Vuxna med flerfunktionshinder behöver samhällets stöd för att leva under ”så normala omständigheter” som möjligt. Stöd och service skall utföras i enlighet med den svenska funktionshinderspoltiska visionen om full delaktighet i samhället och jämlikhet i levnadsvillkor. För att möjliggöra detta, bör individen delta i beslut som rör hans eller hennes vardag.

Syfte: Att belysa och problematisera uppfattningar av delaktighet, hur delaktighet beskrivs i genomförandeplaner och genomförs i vardagen för vuxna med flerfunktionshinder som bor på gruppboende eller i sitt eget hem med stöd från personlig assistans.

Metod: Kvantitativa och kvalitativa metoder användes för att få en djupare förståelse av delaktighet. I studie I analyserades 17 genomförandeplaner. I studie II intervjuades 27 chefer och personal. I studie III observerades 4 vuxna med flerfunktionshinder och deras 13 personal i de boendes gruppboestad.

Resultat: Dokumentationen av delaktighet fokuserade på personlig vård samt samhällsgemenskap, socialt och medborgerligt liv. När personal och chefer intervjuades framkom det att de ansåg att delaktighet är abstrakt och svårt att hantera. Delaktighet för vuxna med flerfunktionshinder handlade främst om att de kan utföra eller att vara närvarande i dagliga aktiviteter. Förutsättningar för de vuxnas delaktighet var deras egen förmåga, personalens kunskaper och resurser i organisationer. Personalen lyssnade på de vuxnas önskemål, de fick stöd i att uttrycka sin vilja som även beaktades, men var inte inblandad i beslutsprocesser och delade inte heller på makt och ansvar för beslutsfattandet.

Slutsatser: Delaktighet för de vuxna är villkorad, innebär sällan delaktighet i beslutsprocesser, är nästan aldrig kopplade till sociala kontakter och fritidsaktiviteter och attityder om de vuxnas förmåga hindrar deras delaktighet. Sociala omsorgsorganisationer behöver möjliggöra delaktighet genom att förändra villkoren så att delaktigheten underlättas och erbjuda utbildning som förändrar attityderna om de vuxnas förmåga. Chefer och personal behöver också ha en gemensam förståelse av vad delaktighet innebär så att de arbetar mot samma mål. Dessutom kan ICF användas som ett verktyg vid upprättandet av genomförandeplaner så att de vuxnas vilja och önskemål inte glöms bort och Shier's delaktighetsstege kan användas för att öka de vuxnas delaktighet i vardagen.

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Staffs' documentation of participation for adults with profound intellectual disability or profound intellectual and multiple disabilities

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ABSTRACT

Purpose: This study investigated what areas of International Classification of Functioning, Disability and Health were documented in implementation plans for adults with profound intellectual disability or profound intellectual and multiple disabilities with focus on participation.

Methods: A document analysis of 17 implementation plans was performed and International Classification of Functioning, Disability and Health was used as an analytic tool.

Results: One hundred and sixty-three different codes were identified, especially in the components Activities and participation and Environmental factors. Participation was most frequently coded in the chapters Community, social and civic life and Self-care. Overall, the results showed that focus in the implementation plans concerned Self-care and Community, social and civic life. The other life areas in Activities and participation were seldom, or not at all, documented.

Conclusions: A deeper focus on participation in the implementation plans and all life areas in the component Activities and participation is needed. It is important that the documentation clearly shows what the adult wants, wishes, and likes in everyday life. It is also important to ensure that the job description for staff contains both life areas and individual preferences so that staff have the possibility to work to fulfill social and individual participation for the target group.

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► IMPLICATIONS FOR REHABILITATION

- There is a need for functioning working models to increase participation significantly for adults with profound intellectual disability or profound intellectual and multiple disabilities.
- For these adults, participation is achieved through the assistance of others and support and services carried out must be documented in an implementation plan.
- The International Classification of Functioning, Disability and Health can be used to support staff and ensure that information about the most important factors in an individual's functioning in their environment is not omitted in documentation.

Introduction

Early in their lives, and continually, people with profound intellectual disability or profound intellectual and multiple disabilities come in contact with professional efforts because of their need of support and service. An individual with profound intellectual disability has profound cognitive impairments (IQ < 25) and often motor impairments, sensory impairments, and medical problems, such as epilepsy. An individual with profound intellectual and multiple disabilities has profound cognitive impairments (IQ < 25) but also profound motor impairments, sensory impairments, and different medical problems. Diagnoses of profound intellectual disability or profound intellectual and multiple disabilities are difficult to separate and these adults often live in the same group homes and are cared for by the same staff [1]. Due to the consequences of combinations of disabilities, they are dependent on others for all aspects of their everyday life. [1]. As a consequence, they live in environments created by and controlled by others [2–5]. This also means that other people often control the possibilities for people with profound intellectual disability or profound

intellectual and multiple disabilities to participate in everyday life decisions.

Participation is according to Schalock et al. [6] considered to be a central aspect of quality of life. Research shows that quality of life for people with profound intellectual disability or profound intellectual and multiple disabilities is relatively poor and they spend substantial time isolated and disengaged because of low quality of support [7]. Studies [8–10] on the living conditions of adults with profound intellectual disability or profound intellectual and multiple disabilities have shown that although they to some extent can choose with whom they want to interact, their participation largely depends on other people's abilities to care, empathize, and show humanity and willingness to adhere to the principle of every human's equal value. However, although studies show that support staff for people with profound intellectual disability or profound intellectual and multiple disabilities agree that principles of choice, integration, and participation are important [11,12], they often do not think that the principles can be applied to them [12].

It is argued within different research fields that staff do not consider people with profound intellectual disability or profound intellectual and multiple disabilities to have the ability to choose for themselves or to understand the consequences of their choices [8,11–13]. Staffs' attitudes toward people with profound intellectual disability or profound intellectual and multiple disabilities can affect participation both positively and negatively [14,15]. To ensure participation for people with profound intellectual disability or profound intellectual and multiple disabilities, improvements of positive attitudes of staff are needed [13]. Staff often consider people with profound intellectual disability or profound intellectual and multiple disabilities as being different from people without disabilities [14], e.g., they may think that they lack skills for household activities. Participation for people with profound intellectual disability or profound intellectual and multiple disabilities depends on whether staff see the differences as positive/neutral, e.g., they are people just like us, only a bit different, but still developing individuals, or if they have negative attitudes, e.g., they are different and therefore not like us [14,15], e.g., they are more like children than grownups. The degree of participation for people with profound intellectual disability or profound intellectual and multiple disabilities is associated with positive attitudes of the social environment, mainly staff, but also other people in the community. Community participation is framed by normative rules to which it is expected that all people conform, e.g., how one should behave in public places [16]. Negative attitudes of staff and other people in the community toward the target group and their ability to be people just like us can result in lower interaction with the community. If people with profound intellectual disability or profound intellectual and multiple disabilities do not take part in their community to the same degree as other people do, there is a risk of decreased social participation [13]. Not taking part in the community to the same degree as other people also elevates the risk for social exclusion for the target group [17,18].

According to the World Health Organization (WHO) [19], the component Activities and participation in International Classification of Functioning, Disability and Health (ICF) covers the full range of life areas and participation is defined as an individual's engagement in a life situation. A definition that also is used in this study. Using the ICF definition of participation in group homes research has shown that staff described residents' participation along three dimensions: doing things with others (watching TV), doing things for others (helping staff with domestic chores), and being in someone else's doing (being in the kitchen while someone else was cooking) [20]. Kåhlin, Kjellberg, and Hagberg concluded that the meaning of participation for the participants in their study was "doing" and "feeling" as well as the contents of preconditions for participation, i.e., resident-related factors, social and physical environmental factors, and organizational and policy factors. Research about service users' opportunities to participate in organizations that provided disability services showed that organizations had tried to identify ways to work together with service users and define potential roles to increase participation, e.g., how the service user could be involved in planning and in some cases manage the services. Potential roles were seldom available for service users with intellectual disability or with communication difficulties because of the nature of their disability, e.g., lack of communication skills [21].

Social policy of participation for people with disabilities

In the support and service for people with disabilities, participation is an important concept for local organizations and political decision-makers [22]. A focal goal of disability policy is to ensure

people with disabilities the same level of participation in society as other citizens.

The Swedish national action plan "From patient to citizen – a national action plan for disability policy" [23] and the current disability strategy [24] stipulate that society must enable social participation for people with disabilities. Additionally, living conditions should be equal for all citizens, regardless of functional capacity.

In Sweden, participation is a key goal in the Act Concerning Support and Service for Persons with Certain Functional Impairments (hereafter referred to as the law of support and service) [25] and a vision of the Swedish disability policy [23,24]. To realize this goal, there is a need for functioning working models to significantly increase participation [26,27]. To grasp what participation is for people with disabilities in everyday life individual desires, capabilities, and opportunities to participate must be taken into account [28].

The law of support and service stipulates rights for persons with considerable and permanent functional impairments in Sweden and specifies that goals are to ensure individuals "good living conditions" and opportunities to live like others do [25]. To realize this, an individual should receive the necessary daily support and service he or she needs. The individual shall also participate in the planning and decision-making in all aspects of his or her everyday life [25,29]. Adults with profound intellectual disability or profound intellectual and multiple disabilities in Sweden either live in residential care homes/group homes or in their own homes with personal assistance. Support and services in the home or in group homes are carried out in accordance with the law of support and service. This law states that the goal is to "make it possible for the individual to live as others do," i.e., full participation in social life, equal living conditions and opportunities for autonomy, self-determination, and empowerment [23].

Support and services according to the law of support and service must be documented [25]. Therefore, people eligible for support and services should have an implementation plan [30]. The implementation plan differs from, e.g., action plans or individual plans. The implementation plan is a kind of policy document and should contain information on how the support and service should be carried out by staff. The support and service should be planned together with the individual so that he or she participates in the decisions made. If the individual cannot take part in the planning, relatives or guardians should take part on their behalf [29]. The staff who carries out the support and service are responsible for the documentation. The managers on the other hand are responsible for that implementation plans exist for each individual. For adults with profound intellectual disability or profound intellectual and multiple disabilities, participation is achieved through the assistance of others and one goal of the implementation plan is to document and communicate to staff how to support participation for the persons they assist in daily activities. The implementation plan also serves as a control document for the government agency (The Health and Social Care Inspectorate), which is responsible for supervising activities under the law of support and service.

Aim and research questions

The aim of this study was to investigate what areas of ICF were documented in implementation plans for adults with profound intellectual disability or profound intellectual and multiple disabilities. The aim was also to specifically investigate the component

Activities and participation with focus on participation. The study aims to answer the following research questions:

- What ICF areas are documented in the implementation plans?
- How is participation documented in the implementation plans?

Methods

An explorative, descriptive, document analysis of 17 implementation plans was conducted. Implementation plans were collected for all people with profound intellectual disability or profound intellectual and multiple disabilities, 18 years old or above in a mid-sized (55,000 inhabitants compared to a big municipality >200,000 inhabitants or a small community <50,000 inhabitants) municipality in Sweden. As such, the study is a total population study.

Participants and data collection

Criteria for the inclusion of participants in the study were (i) adults (over 18 years of age) with profound intellectual disability or profound intellectual and multiple disabilities, and (ii) to be receiving services according to the law of support and service and therefore to be living in group homes or in private homes with personal assistance, and to have an implementation plan. Managers for group homes and personal assistance in the studied municipality's social care organization investigated potential participants. They found 17 adults that met the criteria, nine women and eight men 23 to 67 years old. Four of them lived in their own homes with personal assistance and 13 lived in group homes.

Implementation plans of 17 informants were de-identified and anonymized by a contact person in the division of social care in the municipality and handed to the researchers in February 2014. The 17 IPs were written by staff working directly with the adults

in focus. The staff were either assistant nurses or had no education. They had been working with the target group between two to 35 years and were 22 to 65 years old. The implementation plans differed in format, content, and length (between two and 17 pages). Some were handwritten and some were written on a computer. How the activities should be carried out was in some implementation plans documented very briefly and in others in great depth.

International Classification of Functioning, Disability and Health (ICF)

The ICF [19] is a health and health-related classification. Drawing upon a holistic view – including biological, individual, and social perspectives – of human beings, it offers a coherent vision of health. The ICF is one of the United Nation's social classifications incorporated in the Standard Rules to ensure participation and equality of people with disabilities. The ICF can be used to document characteristics of health and functioning and offers a conceptual framework and a common language. By changing the focus from health as a "lack of handicap" to a focus on participation, it is stated that the norm of full participation for people with disabilities is the same as for people without disabilities [31].

The classification entails two parts, functioning and disability and contextual factors, both environmental and personal with different components that interact with each other (see Figure 1). One component in contextual factors is Activities and participation, where the full range of life areas (from basic learning or watching to composite areas such as interpersonal interactions or employment) is covered. The component denotes activities (a) or participation (p) or both together (d). Activity is defined as the execution of a task or action by an individual, and participation is defined as an individual's engagement in a life situation, so Activities and participation are not synonymous. When using ICF to identify a person's everyday functionality, participation can be

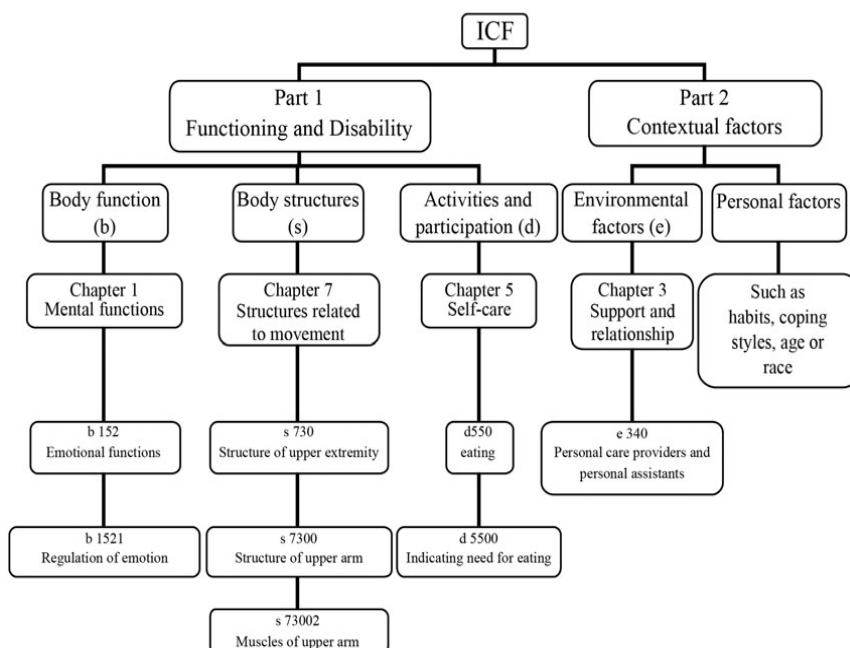


Figure 1. The structure of ICF with examples from chapters and connected codes.

classified separately or together with the activity component [19]. However, classifying the components together might reduce participation to the physical presence in the activity carried out and make the individual's engagement less important [22]. Furthermore, it is important that people with disabilities are free to define participation based on their own conditions [22] and in revisions of the ICF, people with disabilities and disability organizations have been involved.

The ICF is used by practitioners to code health and health-related issues [32]. The municipality where the study took place decided in 2010 to use ICF when writing implementation plans, and the implementation plans were to specially focus on the nine different life areas in the component Activities and participation. Research on the ICF focuses on constructing reliable core sets using the Delphi method [33], and core sets means the most commonly used codes for different everyday activity areas, such as eating. Additionally, the ICF has been used in research linking text documents to ICF codes, e.g., education policy documents [34] and habilitation plans for children with disabilities [35] to further understand aspects of, e.g., participation.

Data analysis

From the 17 implementation plans, 635 different daily activities were extracted as meaningful concepts. The meaningful concepts were as follows: Using a few signs and show us what to do or Walks with a Walker indoors with assistance, also moves by crawling. The meaningful concepts were thereafter analyzed and linked to ICF codes to capture the content, as these examples show: Using a few signs (d3351) and show us what to do (d3350) or Walks (d450) with a Walker (e1201) indoors with assistance (e340), also moves by crawling (d4550). It was often the same codes that appeared in the implementation plans, but the number of codes differed if the implementation plans were documented briefly or in great depth, e.g., the same codes appeared a number of times in a meaningful concept if the activity was documented in great depth.

The analysis was initiated with a consensus process in which consensus reliability was sought for both meaningful concepts and the coding of the implementation plans. Consensus was achieved by the researchers LT and JW. It was decided to use the commonly used coding rules [36] and to slightly modify them to try to capture participation as diverse from activity.

Consensus process

Four implementation plans were randomly chosen and analyzed initially in the consensus process. One of the four implementation plans was read through by each researcher separately and meaningful concepts [36] were marked and coded. After this, the researchers compared the choices of both meaningful concepts and codes. When comparing concepts and codes, we could see that the choices of meaningful concepts were similar, but there were differences in choices of codes. Therefore, the coding rules were modified slightly to differentiate participation from activity.

According to the WHO [19], the prefix (d) is used to code the domains within the component Activity and participation, but users are free to change the prefix (d) to the prefix (a) for activity or (p) for participation. To capture participation in our analysis, both the (d) and (p) codes were used. The rule for choosing the (d) code or the (p) code was that if the text indicated an engagement from the person with profound intellectual disability or profound intellectual and multiple disabilities, the (p) code was used. Indicators of engagement were, e.g., "wants to," "wishes"

and "likes." If the code unit did not have any indicator for engagement, the (d) code was used. It could be argued that it might have been more correct to instead use the (a) code for activity, but the researchers decided that they could not be sure that the content of the meaningful concept did not include participation and therefore the (d) code was used instead of the (a) code. During the consensus process, we could see that code e340 Personal care providers and personal assistants to help a person with profound intellectual disability or profound intellectual and multiple disabilities cope with daily activities was frequently used in the implementation plans. Therefore, code e340 was only used if the personal caregiver or assistant was doing an activity together, with the adult, not only doing an activity for him or her, e.g., cooking a meal together with the adult or cooking a meal for the adult. This choice made the analysis focus even more on the participation of the adults with profound intellectual disability or profound intellectual and multiple disabilities.

When the rules were modified as described above, LT and JW separately coded the same four implementation plans again and compared the coding and this time the choices of codes were similar. In this stage, inter-reliability was found satisfactory. LT continued to code the other 13 implementation plans following the set rules.

When the 17 implementation plans had been coded, all codes and actual daily activities of the participants were entered into SPSS. The codes were also indexed and analyses were conducted on both chapter and component levels. For statistical analyses, descriptive as well as correlation analyses were conducted. To test relationships between daily activities and ICF codes, Spearman's rank correlation test was used and the p values were set to $p < 0.05$ [37].

Ethical considerations

Ethical approval for the study was obtained from the Regional Ethics Committee in Uppsala, Sweden (D.nr. 2013/375). To ensure confidentiality, the implementation plans were de-identified and anonymized by a contact person in the division of social care in the municipality and handed over to the researchers. The only information the researchers had about the individual was age, gender, and place of residence (group home or private home with personal assistance).

Results

Altogether the linking generated 1782 codes (see Figure 2), mainly about Activities and participation, including both the linked (d) and (p) codes. The codes that could, from the used linking rules (the text should indicate an engagement for the activity described from the person with profound intellectual disability or profound intellectual and multiple disabilities), be related directly to Participation were 91. Environmental factors was the second most common component, while Body functions had 94 codes. Personal factors was slightly more common than both Participation and Body functions while Not definable was marginally less common. Health conditions was only present in two of the 17 implementation plans and Body structures was not present at all.

Activities and participation (d)

Nearly half of the documented codes related to Activities and participation. The most common code, at least twice as common as the others, was Self-care, such as taking a shower or brushing

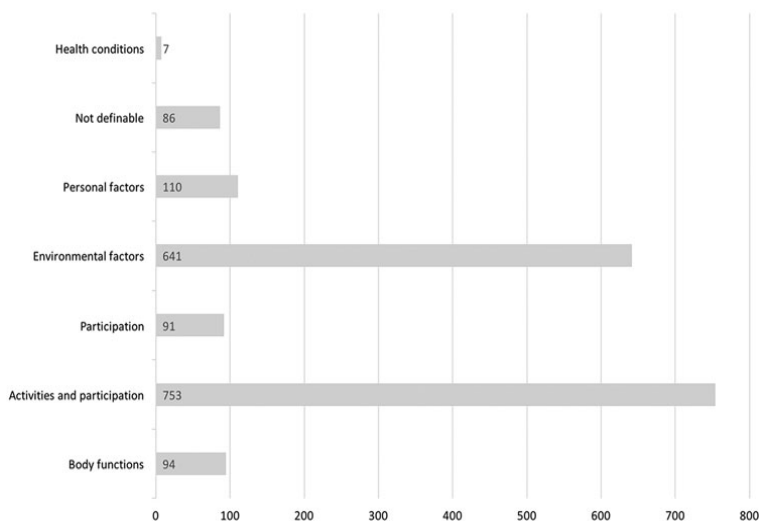


Figure 2. Numbers of codes linked to the different ICF components ($n = 1782$) and their distribution.

one's teeth, followed by Communication, Mobility and Domestic life, e.g., cleaning the apartment or doing the laundry. The most frequently used codes were Eating and Communicating with – receiving – spoken messages.

Participation (p)

When focusing on participation in Activities and participation, 27 different codes were used 91 times (see Table 1). Almost half of the codes were related to Community, social and civic life with focus on leisure activities. The second most used codes belonged to Self-care. There were no codes connected to either Learning and applying knowledge (e.g., basic learning or focusing attention) or General tasks and demands (such as undertaking multiple tasks, Carrying out daily routine, or handling stress). When focusing participation, one single code was connected to Communication. The most frequently used codes were Recreation and leisure followed by Arts and culture.

Environmental factors (e)

In the Environmental factors component, 16 different codes were used 641 times (see Table 2). Three of them were used most frequently: Personal care providers and personal assistants (e.g., staff supporting the adult), Assistive products and technology for personal indoor and outdoor mobility and transportation (walking devices and wheelchairs), and Assistive products and technology for personal use in daily living (prosthetic and orthotic devices, remote control systems, and timer switches). Environmental factors were common in the implementation plans, except from Personal care providers and personal assistants which often were written as a fact statement (e.g., she has a wheelchair) and seldom in relation to any activities.

Body functions (b) and Body structures (s)

Regarding Body functions, 28 different codes were used where some more frequently were used (see Table 2). Half of the codes were related to Mental functions, and the most frequently used code was Regulation of emotion (Mental functions that control

the experience and display of affect) and was mainly related to the adults lack of control. No codes were used in relation to Body structures in any of the 17 implementation plans.

Personal factors (pf), Not definable (nd) and Health conditions (hc)

The ICF does not offer any codes in the Personal factors component because of the large social and cultural variance associated with them [19]. Therefore, data pertaining to Personal factors were only marked with the label (pf). Personal factors is the particular background of an individual's life and living and can, e.g., include habits, coping styles, age, or race. Not definable (nd) was used when the meaningful concept could not be linked to any of the existing ICF codes and Health conditions (hc) was used to describe meaningful concepts that referred to a diagnosis or a health condition.

Most frequently used codes

When identifying the most frequently used codes in the linking process (see Table 3), the environmental code Personal care providers and personal assistants (staff supporting the adult) together with Personal factors (coping strategies and habits) and meaningful concepts that were classified Not definable were most commonly used. Activities and participation only had slightly more than half as many codes, mostly about Self-care and Domestic life than codes related to the Environmental, e.g., wheelchairs and walking aids. The most frequently used codes related to Activities and participation were Eating followed by Communicating with – receiving – spoken messages (staff giving the adult verbal instructions when taking a shower) and Drinking.

Distribution of daily activities within the activity/participation component

The analyses showed that there were 635 daily activities, or in other words meaningful concepts [37], documented in the implementation plans. Of these meaningful concepts, 28 belonged to Body functions, 23 to Not definable, 17 to Personal factors, 13 to

Table 1. Absolute and relative frequencies of ICF categories in the Activities and participation component and codes linked as Participation that occurred ≥ 8 times in the 17 implementation plans.

ICF code	ICF code description	Absolute frequency	Relative frequency (%)
d550	Eating	43	6.77%
d310	Communicating with – receiving – spoken messages	35	5.51%
d560	Drinking	33	5.20%
d920	Recreation and leisure	33	5.20%
d3350	Producing body language	29	4.57%
d6200	Shopping	25	3.94%
d5400	Putting on clothes	24	3.78%
d640	Doing housework	24	3.78%
d465	Moving around using equipment	22	3.46%
d530	Toileting	21	3.31%
d230	Carrying out daily routine	19	2.99%
d4701	Using private motorized transportation	19	2.99%
d5200	Caring for skin	19	2.99%
d5201	Caring for teeth	19	2.99%
d6400	Washing and drying clothes and garments	19	2.99%
d3150	Communicating with – receiving – body gestures	18	2.83%
d6402	Cleaning living area	18	2.83%
d5101	Washing whole body	17	2.68%
d5401	Taking off clothes	14	2.20%
d4602	Moving around outside the home and other buildings	13	2.05%
d540	Dressing	13	2.05%
d740	Formal relationships	13	2.05%
d330	Speaking	12	1.89%
d4702	Using public motorized transportation	12	1.89%
d57020	Managing medications and following health advice	12	1.89%
d4104	Standing	11	1.73%
d5202	Caring for hair	11	1.73%
d9202	Arts and culture	11	1.73%
d5100	Washing body parts	10	1.57%
d630	Preparing meals	10	1.57%
d850	Remunerative employment	10	1.57%
p920	Recreation and leisure	22	3.46%
p9202	Arts and culture	9	1.42%
p560	Drinking	8	1.26%

Table 2. Absolute and relative frequencies of ICF codes in Environmental factors and Body functions that occurred ≥ 4 times in the 17 implementation plans.

ICF code	ICF code description	Absolute frequency	Relative frequency (%)
e340	Personal care providers and personal assistants	472	74.33%
e1201	Assistive products and technology for personal indoor and outdoor mobility and transportation	65	10.24%
e1151	Assistive products and technology for personal use in daily living	42	6.61%
e115	Products and technology for personal use in daily living	22	3.46%
e11520	General products and technology for play	9	1.42%
e1251	Assistive products and technology for communication	7	1.10%
e1150	General products and technology for personal use in daily living	5	0.79%
e1250	General products and technology for communication	4	0.63%
b1521	Regulation of emotion	37	5.83%
b152	Emotional functions	4	0.63%
b770	Gait pattern functions	4	0.63%
b780	Sensations related to muscles and movement functions	4	0.63%

Environmental factors, three to Health conditions, and the remaining 551 belonged to Activities and participation. When analyzing the distribution of the daily activities/meaningful concepts in the nine chapters of the ICF component Activities and participation, the results showed that Self-care followed by Community, social and civic life was most often documented. On the other hand, Learning and applying knowledge was not documented in any implementation plan, as shown in [Figure 3](#).

Correlations

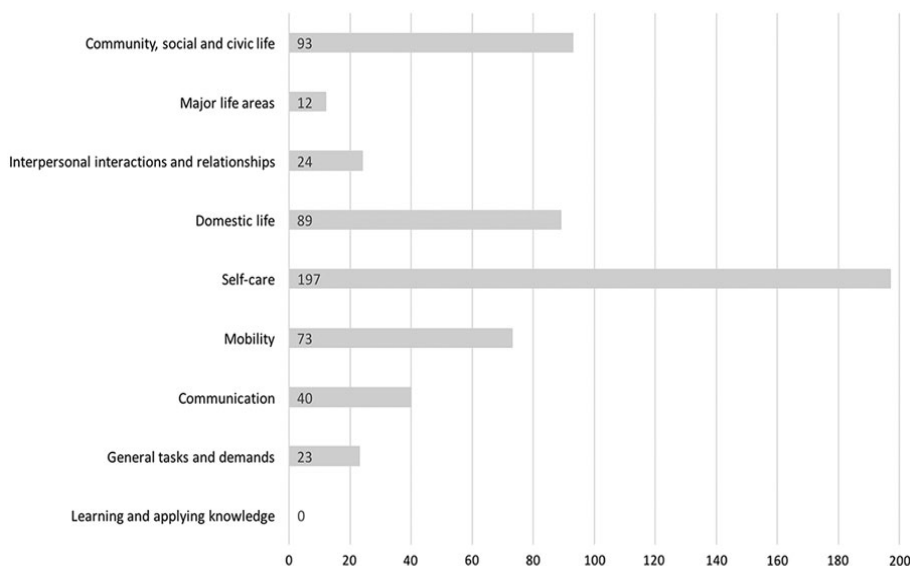
The environmental code Personal care providers and personal assistants (staff supporting the adult) was the most frequently used code and correlation analysis was therefore conducted to see which components, chapters, and codes in ICF correlated with this specific code (see [Table 4](#)). There were significant correlations

between Personal care providers and personal assistants and Recreation and leisure, Washing body parts, and Eating. Correlations were also significant between Personal care providers and personal assistants and the ICF chapters Self-care and Community, social and civic life and the ICF components Activities and participation and Personal factors.

When analyzing for correlations between different codes related to Activities and participation, two significant correlations were found (see [Table 5](#)). Correlations were significant between Carrying out daily routine and Communicating with – receiving – spoken messages, which means that staff verbal instructed the adult how to carry out different daily activities. Correlations were also significant between Communicating with – receiving – body gestures and Washing body parts, e.g., staff instructed the adult with body language about how to wash the hands or the face.

Table 3. Absolute and relative frequencies of the most frequently (≥ 20) ICF codes in the 17 implementation plans, including Personal factors and Not definable.

ICF code	ICF code description	Absolute frequency	Relative frequency (%)
e340	Personal care providers and personal assistants	472	74.33%
Pf	Personal factors	110	17.32%
Nd	Not definable	86	13.54%
e1201	Assistive products and technology for personal indoor and outdoor mobility and transportation	65	10.24%
d550	Eating	43	6.77%
e1151	Assistive products and technology for personal use in daily living	42	6.61%
b1521	Regulation of emotion	37	5.83%
d310	Communicating with – receiving – spoken messages	35	5.51%
d560	Drinking	33	5.20%
d920	Recreation and leisure	33	5.20%
d3350	Producing body language	29	4.57%
d6200	Shopping	25	3.94%
d5400	Putting on clothes	24	3.78%
d640	Doing housework	24	3.78%
d465	Moving around using equipment	22	3.46%
e115	Products and technology for personal use in daily living	22	3.46%
p920	Recreation and leisure	22	3.46%
d530	Toileting	21	3.31%

**Figure 3.** Amount and distribution of daily activities in the nine chapters in the component Activities and participation (including both the linked (d) and (p) codes) ($n = 551$).**Table 4.** Significant correlations between e340 Personal care providers and personal assistants and other codes, chapters, and components.

Spearman's rho e340	d5100	d550	p920	d5_totaly	p9_totalt	d_totaly	pf
Correlation Coefficient	1.000**	1.000**	.501**	.518**	.649**	.392**	.475**
Sig. (two-tailed)	.	.	.009	.000	.001	.000	.001
N	12	9	26	159	24	323	44

**Correlation is significant at the 0.01 level (two-tailed).

*Correlation is significant at the 0.05 level (two-tailed).

Discussion

The aim of this study was to investigate what areas of ICF were documented in implementation plans for adults with profound intellectual disability or profound intellectual and multiple disabilities. The aim was also to specifically investigate the component Activities and participation with focus on participation. The most often documented components in the implementation plans were Activities and participation and Environmental factors, and Personal factors was occasionally documented. The documentation of Body

functions was scarce and focused on the problems the adults with profound intellectual disability or profound intellectual and multiple disabilities had with emotional regulation (code b1521 Regulation of emotion), whereas Body structures was not documented at all. This can be considered a problem because the individual's capability and what help that is needed to perform different activities often relies on body functions. The lack of documentation of body functions can therefore make it difficult to understand the individuals' needs for support. Environmental

Table 5. Significant correlations between all linked codes related to the *Activities and participation* component.

Spearman's rho	d310	d5100
Correlations		
d230		
Correlation coefficient	1.000**	.
Sig. (two-tailed)	.	.
N	4	0
d3150		
Correlation Coefficient	.	-1.000**
Sig. (two-tailed)	.	.
N	0	3

**Correlation is significant at the 0.01 level (two-tailed).

factors were often documented, while resident-related factors (e.g., Body functions, Body structures, and Personal factors) were less commonly documented. Resident-related factors are important pre-conditions for participation [8]; therefore, following our results, there seems to be a need for more documentation about resident-related factors in implementation plans in order to fully understand the needs of individuals.

The ICF was used to explore what components, chapters, and codes were most frequently communicated in the implementation plans. The results showed that the codes Personal factors (pf) and Not definable (nd) were occasionally used; these refer to, e.g., habits, personal traits and personal preferences. These aspects of everyday life are missing in the ICF, a fact that has been highlighted in research discussions [38]. Despite this, it is possible to discern the chapters in focus and what areas that are omitted in the implementation plans. For example, in the studied implementation plans one omitted area is communication. This is despite the fact that communication is a prerequisite for participation and that people with profound intellectual disability or profound intellectual and multiple disabilities often have limited communication skills [2,8]. Correlations were found between the codes Carrying out daily routine (d230) and Communicating with – receiving – spoken messages (d310) and between the codes Communicating with – receiving – body gestures (d3150) and Washing body parts (d5100). This could indicate that staff used communication mostly to instruct the adult with profound intellectual disability or profound intellectual and multiple disabilities, e.g., about how to act in activities related to daily routines and hygiene. According to the documentation, communication as spoken language or body language in conjunction with activities was mostly used by staff, and there were no correlations between communication and activities other than communication used by staff to tell or show the adult how to act in activities related to daily routines and hygiene. Overall, communication used in a broader sense than spoken language, e.g., sign language or the use of pictures, was rarely focused on in the implementation plans. In turn, this may constitute a barrier for participation. Our results indicate that documentation about communication could be increased to broaden participation in all areas.

Prerequisites for participation are the individual's desire, the physical ability to perform the task and that opportunities to participate are offered [28]. Our results showed that it was not documented, if the adult with profound intellectual disability or profound intellectual and multiple disabilities had the necessary body functions to be able to perform in given tasks or in offered opportunities, since body structure and body function were seldom documented. Moreover, only 91 of a total of 1782 codes were documented in 14 of the 17 implementation plans about what the adult with profound intellectual disability or profound intellectual and multiple disabilities wanted, wished for, and liked

and how he or she wanted support to be carried out. This indicates that participation was neither sufficiently nor thoroughly documented. On the other hand, this does not suggest that participation in real life did not exist, but it is difficult to know when it was not documented in the implementation plans.

One of the functions of implementation plans is to give directions to support staff in their care work. The implementation plan is individual and developed as a tool for staff to enable support and services in everyday life based on the person's needs, wishes, and wants. If the individual or relatives/guardians are involved in the planning, it can increase participation in everyday life. It is important that people with disabilities are free to define participation based on their own personal preferences [22] and a facilitator for participation for adults [24] is to get opportunities to influence. It is, therefore, crucial that the individual or close kin is involved in planning how documented activities are to be carried out.

The daily activities documented in the implementation plans were typically carried out together with staff; consequently, the most common code in the implementation plans was Personal care providers and personal assistant (e340). This code was used when staff supported individuals in their daily activities. As mentioned in the methods section, in our analyses we chose to only use the code e340 if the personal caregiver or assistant was doing something together with the individual, not only doing something for the individual. In the light of participation, the results show that the code e340 correlated not only with the code Recreation and leisure (p920), but also with Chapter 9 Community, social and civic life in its entirety. For adults with profound intellectual disability or profound intellectual and multiple disabilities, participation depends on others' abilities to care, feel empathy, humanity, and willingness to live up to the principle of every human's equal value [8–10]. The results indicate that if the documentation reflects real life, staff were supportive and focused on the individual's participation when it came to leisure time.

Despite this, the daily activities were more or less the same in every implementation plan, regardless of the individual's age or sex, and were typically carried out together with staff or alone, seldom with friends or relatives. Examples of daily activities were listening to music, watching television, going to the public swimming hall, or McDonald's. Our findings indicate that staff might find it difficult to define potential roles (e.g., how the service user could be involved in choosing and planning the activities) for adults with profound intellectual disability or profound intellectual and multiple disabilities, which is in concordance with earlier findings [21]. Something that can also influence the findings is the expectation that all people shall conform and behave in a way that is culturally assumed [16] and that this fact limits the available activities. Staffs' attitudes are an important condition for the adult's possibility for participation [13–15].

According to the Swedish law of support and service, the goal is to "make it possible for the individual to live as others do." The results show that in the area Activities and participation very little was documented in the implementation plans on activities linked to the chapter's Major life areas, General task and demands, Interpersonal interactions and relationships, and Communication (99/635). Moreover, nothing was documented about activities in the chapter Learning and applying knowledge. Instead, the focus in the implementation plans was on activities belonging to the chapters Community, social and civic life, Self-care, Domestic life, and Mobility (452/635). Only 93 of these 452 activities belonged to Community, social and civic life and the remaining 359 activities to the three other chapters – including eating, drinking, shopping, getting dressed, doing housework, moving around using equipment and toileting. In the documentation, staff largely

focused on basic daily activities and merely to a lesser extent on leisure time activities. Only focusing on one aspect of everyday life in the documentation makes it difficult to determine whether the goal, “good living conditions” and opportunities to live like others do, in the law of support and service, Section 5, is reached. There is also an elevated risk for social exclusion when social contacts and leisure activities are few [17,18].

Methodological discussion

In this study, a document analysis of implementation plans was conducted. Criteria for participant inclusion were adults with profound intellectual disability or profound intellectual and multiple disabilities, for whom an implementation plan had been established and who lived in group homes or private homes with personal assistance according to the law of support and service [25]. In total, 17 persons met the criteria and these 17 made up the total population of adults with profound intellectual disability or profound intellectual and multiple disabilities in one Swedish municipality. The document analysis can be said to reach good validity and reliability, as it followed the common coding rules [37] and was conducted by expert consultation and by two researchers in a consensus process.

Participation as defined in the coding rules is not commonly expressed in the implementation plans; thus, the easiest way to use the ICF as a tool was to only use the (d) code and not separate activities and participation. On the other hand, there were meaningful concepts focusing on what the individual wanted, wished, and liked, and the aim was to capture participation in a more subjective regard. The recommendation is that the (a) code is used for coding activity [19], but the researchers chose not to use it because it was not possible to decide based on the text in the implementation plans that it was an activity isolated from participation. Thus, the analyses came to focus even more on participation. This could have been a consequence of the fact that staff provided considerable assistance in daily activities, something that became visible by the frequently occurring code e340.

Conclusion

The results showed that the documentation made it difficult to determine whether the disability policy goal “full participation in society” was achieved. The life areas documented on the basis of the nine chapters in the ICF component Activities and participation in the implementation plans focused on Self-care and Community, social and civic life. The other life areas Learning and applying knowledge, General tasks and demands, Communication, Mobility, Domestic life, Interpersonal interactions and relationships, and Major life areas were not as frequently used, or not at all documented. Furthermore, communication was seldom documented and this could indicate that it was not considered important enough to document. This is troublesome since adults with profound intellectual disability or profound intellectual and multiple disabilities has individual ways of communicate (e.g. sounds and body language). Another important finding was that participation was characterized in quite the same way for all individuals. According to the implementation plans, the participants had almost the same leisure time activities, with only a few exceptions. The documentation could thereby indicate that organizational more than individual factors determined what the adults with profound intellectual disability or profound intellectual and multiple disabilities did in their everyday life. The Activities and participation component in the ICF covers the full range of life areas, and to capture participation for an individual, it is important that the

documentation includes them all. Moreover, it is also important that the documentation clearly shows what the adult with profound intellectual disability or profound intellectual and multiple disabilities wants, wishes, and likes and how he or she wants support to be carried out. The ICF can be a tool in everyday life planning for adults with profound intellectual disability or profound intellectual and multiple disabilities, as the classification can be used to support staff and ensure that information about the most important factors in an individual’s functioning in his or her environment is not omitted in documentation.

Limitations and future directions

One limitation in this study was the rather small sample size of 17 implementation plans. It should be noted that although the sample was a total population sample, the results cannot be generalized to a whole population. The results should be considered as an example which the reader may be able to compare to other contexts.


Future research to explore participation for adults with profound intellectual disability or profound intellectual and multiple disabilities is needed. An interesting question is how the documentation correlates with the sex, age, and living circumstances of the participants. Due to the small sample in this study, it was not possible to correlate the findings with the sex, age, and living circumstances of the participants, and therefore a larger sample is needed in future research. In order to understand how participation for adults with profound intellectual disability or profound intellectual and multiple disabilities is carried out, it is important to interview staff and managers about their conceptions of participation for these adults. It is also important to investigate how participation is carried out in real life by observations of how staff are “doing” participation in the adults’ everyday life.

Disclosure statement

The authors report no declarations of interest.

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Staff and managers' conceptions of participation for adults with profound intellectual disabilities or profound intellectual and multiple disabilities

One goal of disability policies in Sweden, and other countries, is to ensure that people with disabilities are afforded the same level of participation in daily life as other citizens. However, few studies have examined this in adults with profound intellectual disabilities or profound intellectual and multiple disabilities. 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 the phenomenon. Trying to fulfil policy goal of daily participation in life for adults with profound intellectual disabilities or profound intellectual and multiple disabilities without a common understanding of the meaning of the phenomenon 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 staffs' conceptions of participation for adults with profound intellectual disabilities (PID) or profound intellectual and multiple disabilities (PIMD) since managers and staff are the ones that facilitate or limit the adults' possibilities to participate in daily life decisions. In Sweden, participation is a main goal both in disability policy and in practice (Government Bill 1999/2000:79; S2012.028). Despite that, research on how adults with PID or PIMD participate in daily life is a relatively scare (Blomberg 2006). Most research on participation of adults with intellectual disabilities focuses on adults with mild or moderate intellectual disabilities (see Dusseljee et al. 2011; Kåhlin, Kjellberg, and Hagberg 2014; Bigby and Wiesel 2015). Hammel et al. (2008) have stressed that people with disabilities should be free to define the meaning of participation. For example, in research on participation of people with intellectual disabilities, it has become increasingly common to interview them about their personal perspectives (see Kåhlin, Kjellberg, and Hagberg 2014; Patterson and Pegg 2009; Wennberg and Kjellberg 2010). Since people with PID or PIMD have limited communication skills, and the interviewer needs special skills in alternative communication and good knowledge about how they communicate it is difficult to interview them to obtain their perspectives. Therefore, it is common to use interview by proxy. Due to combination of disabilities, people with PID or PIMD are dependent on others for most of the aspects of their daily life (Granlund,

Wilder, and Almqvist 2013). For adults with PID or PIMD, participation is achieved through the assistance of others, mostly from group home staff or in-home personal assistants. Thus, to better understand how to support their participation, it is crucial to explore staff and managers' conceptions of what that entails for adults with PID or PIMD.

Participation for people with disabilities

Participation is a human right (Government Bill 2008/09:28; S2012.028); in many countries, a disability policy aims to ensure that people with disabilities can freely participate in daily life just like other citizens (Hammel et al., 2008). Participation is a cornerstone of Swedish disability policy (S2012.028). The Swedish national action plan (Government Bill 1999/2000:79) and the disability strategy (S2012.028) stipulate that society should facilitate participation of all people with disabilities and provide conditions for independence and self-determination.

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

Early in life, people with PID or PIMD encounter professional interventions that are long lasting or lifelong, (Blomberg 2006; Felce and Perry 1995; Ringsby Jansson 2002; Tideman 2000). This means that others often circumscribe or expand their possibilities to participate in daily life decisions. To explore what participation in daily life means for people with disabilities, Molin (2004) noted that it is important to consider if the individual wants, and is able to, participate and is offered opportunities to do so. Another dimension of participation is meaningful participation, which focus on that 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 and 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,

such as being in the apartment while staff was cleaning. 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 participation of adults with PID or PIMD. These studies show that participation for adults with PID or PIMD largely depends on clear management guidance and professional qualifications and attitudes. These studies also demonstrate that, to some extent, adults with PID or PIMD can choose with whom they would like to interact if they are given the opportunities to do so. Therefore, their participation largely depends on support from other people. Research has shown (Dunn, Clare, and Holland, 2010) that staff often rely on own values and life experiences when making decisions on how the adult with PID or PIMD can participate. To rely on others for participation can therefore be difficult since it is not sure that their perception of participation is the same as for the adult with PID or PIMD. To rely on others can also decrease participation and self-determination since staff may chose activities that they prefer instead of the activities the adult with PID or PIMD prefer. Another risk with relying on others is, that it is not certain that the adult with PID o PIMD gets the support they need (Qian et al. 2015). According to group home staff, adults with PID or PIMD often lack capacity to choose for themselves or to understand the consequences of their choices (Bigby et al. 2009; Clement and Bigby 2009). Consequently, it can be problematic if support staff thinks that the principles of choice, integration and participation are important for, but not applicable to, adults with PID or PIMD.

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

The measure of quality of life for adults with PID or PIMD are ‘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 and Beadle-Brown 2012), and also referring to the Association for the Scientific Study of Intellectual Disabilities (IASSID). Despite the knowledge about that, activities and social relationships are crucial for quality of life 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), Wehmeyer (2015) writes that ‘small or large, self-determined actions contribute to one’s quality of life’ (p. 117). Even though self-determination is an important factor for quality of life, research has shown that adults

with PID or PIMD have the lowest levels of self-determination (Wehmeyer, Kelchner and Richards, 1996; Nota et al., 2007).

For adults with PID or PIMD, participation is achieved through the assistance of others, mostly from group home staff, personal assistants or family members (Johnson et al. 2012; Dolva, Kleiven, and Kollstad 2014; Dusseljee et al. 2011). 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. Typically, phenomenography is used to identify multiple conceptions, or meanings, that a particular group of people has about a specific phenomenon (Marton and Booth 2000). In phenomenography, the common collection of data is interviews. In this study, the first author conducted interviews from June 2015 to August 2015 with managers in a social care organisation and with staff that worked with adults with PID or PIMD in group homes or in private homes. All interviews were conducted in a medium-sized municipality in Sweden.

The social care organisation in this study was a division within a larger municipal organisation, consisting of a divisional manager, three regional managers and several unit managers that are responsible for different units, in this case, group homes and in-home personal assistants. The interviews included all the managers and a representative selection of staff that worked in the places 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, manager or staff, and a number instead of the informants' names.

Informants and data collection

It was not possible to interview adults with PID or PIMD about their participation to obtain their perspectives, partly due to their limited communication skills and partly due to the interviewers,

lack of special skills in alternative communication and knowledge about how these adults communicate. Participation for adults with PID or PIMD is mainly achieved through the assistance of others. For that reason, it was also considered important to capture staffs and managers' conceptions of participation for adults with PID or PIMD since they are the ones that facilitate participation for these adults. Therefore, informants consisted of staff and managers at a social care organisation. 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) where interviewed. Division manager, three regional manager and unit managers in the organisation where interviewed. Staff members were selected for interviews 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 - 65, and they had two to 35 years of professional experience in the field. The conceptualisations held by managers and staff were not compared because the study aimed to elucidate and describe organisational and operational variations in conceptions of the phenomenon participation.



Figure 1. Hierarchy in the social care organisation

The phenomenographic approach was used in interviews since the aim was to highlight organisational and operational variations of conceptions of the phenomenon participation. Thus, opening question in the interview guide was: *What does participation mean for adults with PID or PIMD?* Follow-up questions varied on basis of how each interview progressed. Examples of follow-up questions included: Can you give an example? What do you mean? The interviews were 10–30 minutes long, and were conducted at a location decided by the informant.

Data analysis

Interviews were transcribed verbatim, and then analysed based on phenomenographic techniques in order to describe the different ways that people conceptualise a phenomenon in their surroundings (Larsson 1986; Marton 1981; Marton and Booth 2000). The first and last author collaborated on the analysis and identification of categories and the so-called outcome space. Later, these were discussed with all co-authors until consensus was reached. To discern

variations in conceptions of the phenomenon, the seven steps of phenomenographic analysis suggested by Dahlgren and Fallsberg (1991) and Sjöström and Dahlgren (2002) were followed. In the first step (familiarisation), interviews were transcribed verbatim and, thereafter, repeatedly read so the analyst could become familiar with the material and establish an overall impression of the interviews. In the second step (compilation), 322 relevant statements were identified and carefully translated into English. In the third step (comparison), sources of variation or agreement within statements were identified in order to determine similarities and differences between them and to assess the meaning of the statements. The fourth step (grouping) entailed a preliminary grouping of similar statements, 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, for the seventh step (contrasting), categories were contrasted in order 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 (Larsson 1986; Marton and Booth 2000).

Variations of conceptions of participation

In general, the phenomenon of participation was abstract and difficult to conceptualise and verbalise for both managers and staff. For instance, Manager 4 was in 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 it according to Staff 8 was seen as individual '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 do not talk about the same thing when we discuss about it'. Moreover, the 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 works different.

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). When analysing the The results are illustrated in Figure 2.

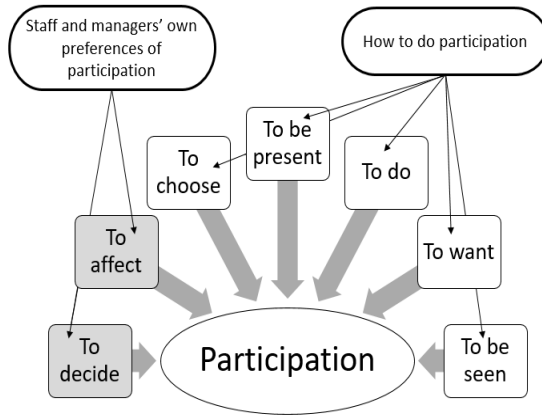


Figure 2. The outcome space

The managers’ and staff members’ conceptions of participation were divided into seven categories, the so-called outcome space, see Figure 2 (categories in grey squares refers to “Staff and managers’ own preferences of participation and categories in white squares refer to “How to do participation”). Participation was conceptualised as: *to be seen*, *to want*, *to choose*, *to be present* and *to do* (the white squares in Figure 2). These statements focused on *doing* participation 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 informants themselves within the categories: *to decide* and *to affect* (the grey squares in Figure 2). In the next section, these conceptions will be exemplified with quotations from the study informants.

Staff and managers’ own preferences of participation

The categories *to decide* and *to affect* (the grey squares in Figure 2) were about the managers and staffs’ own preferences of what participation entails for human beings. It was as if they were trying to define the phenomenon of participation without specifically connecting it to adults with PID or PIMD.

To decide

In general, 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’. It was also

according to Manager 5 considered 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. For instance, Staff 16 stated that

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 also made statements that seemed to be generally applicable to everyone. However, the ability to decide was dependent on whether or not an individual had the capability 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 had conceptions that were clearly about being able to make decisions about one's own life, they also stated that this was not possible for adults with PID or PIMD due to their disabilities. For instance, Manager 7 was in the opinion that '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 also connected to the informants rather than to the adults with PID or PIMD as Staff 5 express it 'Participation, for me, is to be able to affect the everyday life'. Exceptions arise when looking at participation from your own perspective and 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 that were taking place, because they needed to be there to feel something with their senses in order to participate. Moreover, when the staff members and managers addressed their own participation and the participation of adults with PID or PIMD, the degree of participation was always connected to a person's ability as Manager 6 describes below.

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 ability.

How to do participation

The categories *to be seen*, *to want*, *to choose*, *to be present* and *to do* (the white squares in Figure 2) 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, being respected as an individual, and being seen as a person beyond 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 members' 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 describes it 'Participation for adults with PID or PIMD are 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 also, in Staff 21 opinion be about feeling good or satisfied. '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 pointed out '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 the managers and staffs' 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 was 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 members' 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 explains 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. (Staff 14)

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 PID's and PIMDs' participation, it is according to Staff 24 important for staff to understand how they communicate their wants, wishes and what they like

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 express 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, since they did not think that adults with PID or PIMD were capable of interacting due to their profound disability 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 anywhere without getting 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. (Manager 9)

To be present also involved that the adult with PID or PIMD were 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, they need to experience the activities with their five senses and Staff 2 was in 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. (Staff 27)

Being the main character in ones' 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, so they can 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 and 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 points 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 of, 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, since they were seen as not being capable. Thus, they were reduced to helping out when others were managing the doing. For instance, Staff 12 was in 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. (Staff 12)

It could also be that the staff members 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.
(Manager 8)

Contextualisation of the variations of conceptions

The study results show that the outcome space could be divided into seven categories at two levels of abstraction. The two categories, *to affect* and *to decide* about one's own life were about staff 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 (2014) conclusion of what participation entails is similar since their result shows that participation is about *doing, feeling* and *being present*.

The results also show that participation was an abstract concept for managers and staff members, and they found it difficult to conceptualise and verbalise it. The municipal organisation also lacked a definition of what participation for adults with PID/PIMD entails. Moreover, the organisation did not have any guidelines for how participation should be achieved for adults with PID or PIMD. Staff and managers also talked about that participation were individual for each adult. This made it harder for managers and staff to describe what participation in general were for adults with PID or PIMD.

The aim was not to compare staff and managers conceptions, neither to compare if age or professional experience in the field affected them to respond in different ways. However, when analysing the interviews the result showed that there were no differences between how staff and managers conceptualised participation. Either the staff and managers' age and professional experience in the field had no impact on how they conceptualise, understand and experience participation. The only difference revealed was that managers often expressed themselves more properly political. This result is contradictory to the result of Furehed (1997) Johnson et al. (2012) and Mansell et al. (2008) research, which showed that professional qualifications was a facilitator for participation for adults with PID or PIMD.

Conceptions of participation were often connected to general daily activities (e.g. eating, getting dressed and cleaning the apartment), and, to a lesser extent, leisure activities. Dusseljee et al. (2011) reported that there is a higher risk of social exclusion when people have limited access to social contacts and leisure activities. The missing connection between participation and activities outside home makes it difficult to reach the Swedish disability goal (Government Bill 1999/2000:79; S2012.028) about facilitating the social participation of people with disabilities. Dolva, Kleiven, and Kollstad (2014) also pointed out that few social connections and/or leisure activities are organised specifically for 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 were often brought up in the interviews. While it was considered important to take a person's wants into account, staff members thought that they needed time to do so and that the degree of the impairment was an important factor when enabling participation of adults with PID or PIMD. Earlier research has also shown that the degree of the adults' disability is a predictor for the degree of self-determination (Wehmeyer, Kelchner and Richards, 1996; Nota et al., 2007). Swedish disability policy and the Convention on the Rights of Persons with Disabilities (Government Bill 1999/2000:79; S2012.028; SÖ 2008:26) states that participation and self-determination are legal rights for all citizens despite the degree of disability. Hence, it is troublesome when the informants express that profound intellectual disability is an important factor to limited participation and thereby self-determination for the adults with PID or PIMD.

Both managers and staff stated that an individual's capability was crucial in terms of how much the wants of the adult with PID or PIMD could be taken into account, as they thought that those adults did not have the ability to choose for themselves or to understand the consequences of their choices. This means that staff do not think that participation or self-determination on a higher level, such as decide about or affect one's own life is possible for adults with PID or PIMD due to their impairment. Bigby et al. (2009) and Clement and Bigby (2009) also noted that staff discuss this matter; this suggests that responsibility for participation of adults with PID or PIMD is, in some way, placed on the individual instead of being seen as the obligation of managers and staff.

Conceptions of participation varied among managers and staff. This could be challenging because it was not obvious that the informants were discussing the same phenomenon. The lack of consensus about the meaning of the phenomenon of participation, and how it should be achieved, is problematic as this suggests that it is both un-reflected and un-defined. The municipal social care organisation lacked a definition of participation, which made it more difficult because the way that managers and staff members defined and achieved that phenomenon in their daily work was probably subjective. That staff and managers definition of participation often rely on own values and life experiences is something that Dunn, Clare and Holland (2010) earlier has concluded. It is also 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 the meaning of participation themselves (Hammel et al. 2008). To achieve meaningful participation the subjective experience of participation is according to Maxwell, Augustine and Granlund (2012) very important and this experience can be lost if staff are the ones that defines participation. Research has also shown that adults with PID or PIMD can choose with whom they would like to interact if they are given the opportunities to do so

(Furenhed 1997; Johnson et al. 2012; Mansell et al. 2008) but it is not certain that they get the support needed (Qian et al. 2015)

The lack of a consensus on, and definition of, participation makes it difficult for staff to support adults with PID or PIMD; this leads to the 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 differ from day-to-day depending on the staff member that is working with them. This means that one day, participation for the adult is to do things by him or herself and another day participation for the adult is being there while staff do things. The different approach from staff regarding the adults participation might be one of the reasons to that Beadle-Brown et al. (2016) found that adults with PID or PIMD got low levels of support and often spend their days disengaged. To gain meaningful participation for adults with PID or PIMD, focus on the individuals' subjective experience of participation is needed and the adults need to participate in all decisions that directly affect them (Hammel et al., 2008; Maxwell, Augustine and Granlund, 2012). The challenge for staff to investigate the individuals' meaningful participation might be a trigger for increased personalized care and support founded in the conceptualisation of participation, as defined by the individual adult with PID or PIMD.

Limitations

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 for some of the informants 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. The focus on staffs' conceptions and not on higher educated professionals such as occupational therapists limited the result. On the other hand, the staff are the ones performing support in daily life, e.g. facilitating participation for adults with PID or PIMD therefore their conceptions were considered important for the study.

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, and Almqvist 2013). In this study, the interviewer lacked special skills in alternative communication. The lack of communication skills for the adults with PID or PIMD and the interviewer makes it difficult to determine what participation is from the perspective of the adults. Thus, interviewing staff and managers is a viable data collection choice since participation for adults with PID or PIMD is mainly achieved through the assistance of others. However, this can be problematic since it is not possible to determine if staff and managers' conceptions of participation are consistent with those of adults with PID or PIMD.

Validity and credibility of this study are in line with guidelines reported by Sjöström and Dahlgren (2002) and Marton and Booth (2000). This study provides knowledge about managers and staff members' 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 and Guba 1985). To enhance credibility of the current study, data was 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 the lack of consensus on the meaning of the phenomenon of participation. When consensus on the meaning of the phenomenon of participation is lacking, it can be difficult for staff members to facilitate daily life participation for adults with PID or PIMD, which can also affect their level of participation. Therefore, participation of adults with PID or PIMD can vary from day-to-day depending on the staff member that is working with them. Thus, it is important that the organisation have a common definition of participation so that staff members 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 a higher risk of social exclusion. The wide range of conceptions makes it difficult to fulfil the goal of supporting adults with PID or PIMD without a common understanding of the meaning of participation. In order to meet the participation goals, people at all levels of an organisation need to have a shared understanding of what participation of adults with PID or PIMD entails and a common definition of the phenomenon.

The wide range of conceptions among managers and staff of the meaning of participation is problematic and future research that problematize the differences of understanding in Swedish society and care is needed. Adaption of the concept meaningful participation can be a way to individualize participation, focusing on participation as defined by the individual adult with PID or PIMD. Other questions that need to be answered are if there are structural root causes, historical reasons or development differences that causes little 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.

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Competing interests

The authors declare that they have no competing interests.

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Staff members and managers' views of the conditions for the participation of adults with profound intellectual and multiple disabilities

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Abstract

Background: Participation is a central aspect of quality of life, and it is indicative of high-quality outcomes for people with intellectual disabilities. However, participation is difficult to achieve for adults with profound intellectual and multiple disabilities.

Aim: To describe staff members' perceptions of what participation means for adults with profound intellectual and multiple disabilities.

Method: Using a phenomenographic approach, 27 interviews were analysed resulting in variations in the conditions for participation.

Results: The interviews revealed conditions for participation at individual, staff and organisational levels.

Conclusion: Participation appears to be an un-reflected phenomenon, and several conditions must be met to achieve it. The conditions are experienced being fundamental for adults within the target group to achieve any kind of participation. The staff members and managers' perceptions of participation as conditional can make it more difficult for adults within the target group to achieve the Swedish disability policy goal of participation.

KEYWORDS

intellectual disability practice, participation, perceptions, phenomenography, profound intellectual and multiple disabilities

1 | INTRODUCTION

Participation is the overarching goal of the Swedish disability policy, which led the government to establish The Swedish Agency for Participation, 2015. The starting point for the Agency is the Swedish disability policy, as well as the United Nations Convention on the Rights of Persons with Disabilities. The Swedish Agency for Participation has the government's mandate to ensure that all people have the opportunity to participate in society (SFS 2014:134). According to Swedish Government Bill 1999/2000:79, entitled "From patient to citizen—a national action plan for disability policy," and the current disability strategy (S2012.028), society must enable participation for people with all types of disabilities.

Moreover, the Act Concerning Support and Service for Persons with Certain Functional Impairments (hereafter referred to as the law of support and service; SFS 1993:387) stipulates that participation is the key goal. The law specifies the rights for people with considerable and permanent physical or mental impairments functional impairments. The purpose of the law is to provide people with disabilities with "good living conditions" and opportunities to live their lives as fully as possible. To achieve the main goal of participation, all people with disabilities should receive the daily support and services they require. To ensure this, the individuals' wishes, their ability to participate in their daily lives and make decisions based on their needs and wishes and the actual opportunities they have to

participate must be accounted for Molin (2004). If not, the goals of the Swedish disability policy regarding participation for people with disabilities will not be fulfilled.

According to the World Health Organization (2001), participation is defined as an individual's engagement in a life situation. A life situation refers to what an individual does in his or her current environment (e.g., eating, cleaning or watching TV). However, the meanings and goals of participation vary in the current policies and laws. Similarly, research in the field provides numerous conceptualisations of these goals; sometimes, these are at odds with one another, sometimes they are complementary.

For instance, Gustavsson (2004) argued that participation entails three interrelated aspects: the individual's experience of participation, active participation and accessibility and interaction with one's environment. In addition to these aspects, Tideman (Gustavsson, 2004) suggested that participation is a synonym for equal living conditions for people with and without disabilities. Yet, participation should not be confused with the concept of "equal treatment," because support to facilitate participation must be adapted to address the unique needs of individuals. According to Hammel et al. (2008) participation is "personal" and needs to be meaningful for each individual. This means that individuals must be able to decide which aspects of participation they think are important and how participation should be supported. Thus, *meaningful* participation refers to an individual's right to participate in all decisions that directly affecting him or her.

As Maxwell, Augustine, and Granlund (2012) noted, the subjective experience of participation is crucial for an individual to achieve meaningful participation. As people with profound intellectual and multiple disabilities (PIMD) have limited resources/capabilities for independence and autonomy, and they are more prone to live in the "here and now", meaningful participation appears to be relevant when designing and providing care and support to them.

For the above reasons, participation is a focal aspect of quality of life for all people with intellectual disabilities (Clement & Bigby, 2010; Kozma, Mansell, & Beadle-Brown, 2009; Schalock et al., 2002). For adults with PIMD, participation is difficult to achieve; therefore, quality of life is often circumscribed (Beadle-Brown et al., 2015). An individual with PIMD has profound cognitive impairments (IQ < 25), motor impairments, sensory impairments, communication impairments and medical problems such as epilepsy (Nakken & Vlaskamp, 2007). Because adults with PIMD have a combination of disabilities, they are "hyper-dependent" on others for every aspect of their daily lives, and their possibilities to exercise self-determination and autonomy are much more limited than they are for people without disabilities (Granlund, Wilder, & Almqvist, 2013). Typically, adults with PIMD live in environments created and controlled by others (Blomberg, 2006; Felce & Perry, 1995; Ringsby Jansson, 2002; Tideman, 2000). In Sweden, adults with PIMD can live either in a group home or in their own home with personal assistants providing support and services.

As adults with PIMD are dependent on the support of society, many of them have fewer opportunities to pursue their wishes and

decide the course of their lives in comparison with other people without disabilities (Söder & Grönvik, 2008). This means that other people, often staff members, care for and control the possibilities for adults with PIMD to participate in making everyday life decisions.

The participation of adults with PIMD depends on other people's abilities and willingness to facilitate it (see Furenhed, 1997; Johnson, Douglas, Bigby, & Iacono, 2012; Mansell, Beadle-Brown, Whelton, Beckett, & Hutchinson, 2008). That participation depends on the nature and conditions for interaction and communication. In interviews with disability support workers about their experiences of interacting with people with profound intellectual disabilities, Forster and Iacono (2008) found that adaptive communication is essential. They also found that organisational policies emphasise age-appropriate interaction, yet the disability support workers stressed communication that stimulated an adult to respond. In another study, disability support workers stressed that getting to know the adults and the way they communicate is crucial for interacting with them (Goldbart, Chadwick, & Buell, 2014). Disability support workers need to possess contextual sensitivity and rely on prior knowledge to interpret communication with an adult with PIMD, as that communication is primarily non-verbal (Hostyn, Daelman, Janssen, & Maes, 2010).

Furthermore, there is research (Antaki, Finlay, & Walton, 2009; Bigby, Clement, Mansell, & Beadle-Brown, 2009; Clement & Bigby, 2009) indicating that the service and support staff that work with adults with PIMD stress the importance of the principles of choice, integration and participation, the underlying value is of which is that every human being should have the opportunity to make their own choices. However, often times, service and support staff do not think that adults with PIMD are able to make decisions or understand the consequences of their choices (Antaki et al., 2009; Bigby et al., 2009; Clement & Bigby, 2009).

Clement and Bigby (2009) reported that staffs disagree with the policies of inclusion. In that study, staffs thought that adults with PIMD were fundamentally different from the majority of the population; this makes complete societal inclusion impossible for adults with PIMD. Bigby et al. (2009) found that staff members believed that severe disability is connected to fewer possibilities for participation. Antaki et al. (2009) reported that although staff members tried to introduce choice for the residents' everyday activities, the policy goals on choice did not include options that were available for the residents.

Research shows that a staff's positive attitudes towards the capabilities of adults with PIMD facilitate their participation, whereas negative attitudes hinder participation (Bigby, Knox, Beadle-Brown, & Clement, 2015; Bigby, Knox, Beadle-Brown, Clement, & Mansell, 2012; Jones, Ouellette-Kuntz, Vilela, & Brown, 2008). Similarly, low-quality support for adults with PIMD leads to social isolation and disengagement (Beadle-Brown et al., 2015). In interviews with staff members about their views on what participation means for older people with intellectual disability, Kählin, Kjellberg, and Hagberg (2014) found that the

conditions for participation included resident-related factors, social and physical environmental factors and organisational and policy factors.

To summarise, participation is a moving target. A large portion of the research on the participation of people with intellectual disabilities has focused on *other* people's abilities, attitudes and willingness to facilitate participation. As we have seen, numerous attempts have been made to conceptualise participation; yet, there is a lack of relative agreement as to the meaning of the subjective experience of participation among persons with disabilities or with regard to how everyday staff practices facilitate that participation. In addition, and with appreciation for the difficulties in ensuring participation for adults with PIMD, there is an urgent need for more research that focuses on the conditions that facilitate or hinder participation of adults with PIMD.

1.1 | Aim

The present study aims to describe staffs members' and managers' perceptions of what participation means for adults with PIMD.

2 | METHOD

A phenomenological approach was used to explore the managers and staff members' perceptions of the meaning of participation in daily life for adults with PIMD. Data were collected by interviewing managers and staff members. The interviews were conducted in a social care organisation located in a medium-sized municipality in Sweden. The social care organisation was a division within a larger municipal organisation, consisting of a division manager, three regional managers and six unit managers that are responsible for group homes and in-home personal assistants. To determine the meaning of participation for adults with PIMD at all levels in the studied municipal organisation, it was important to interview managers and staff members. The interviews included all the managers ($n = 10$) and a representative selection of the direct support staff that worked with adults with PIMD, two or three staff from each of the six group homes and three staff that worked as personal assistants ($n = 17$). The managers and staff members ranged in age between 22 and 65, and the duration of their experience in the field ranged from 2 to 35 years. Phenomenography was the methodology that was used for the open interviews. This approach is used to identify a group's multiple perceptions about a specific phenomenon (Marton & Booth, 2000)—in this case, the managers and staff members' perceptions of the meaning of participation for adults with PIMD. The first author conducted interviews with the managers and staff members between June and August 2015. Each interview lasted between 10 and 30 min and was conducted in a place decided by the informant. Earlier, these interviews had been used to analyse and problematize the respondents' conceptions of what participation is for adults with PIMD (Talman, Wilder, Stier, & Gustafsson,

2017). In the interviews, the opening question was: What does participation mean for adults with PIMD? Depending on the answers, the follow-up questions varied. Examples of follow-up questions include: What do you mean? and Can you give an example? During the interviews, the staff members and managers talked a lot about the conditions they thought were needed in order for adults with PIMD to achieve participation.

2.1 | Data analysis

The interviews were transcribed verbatim; they were then analysed using phenomenographic techniques to describe the different ways that people conceptualise a phenomenon (Larsson, 1986; Marton, 1981; Marton & Booth, 2000). The first and last authors collaborated on identifying the categories and analysing the material. Later, the categorisation and analysis were discussed with the other co-authors until consensus was reached.

To discern variations in the perceptions of what participation means for people with PIMD, the seven steps of phenomenographic analysis proposed by Dahlgren and Fallsberg (1991) and Sjöström and Dahlgren (2002) were followed. In the first step (familiarisation), the interviews were transcribed verbatim. The authors then read the interviews repeatedly to become familiar with the data. In the second step (compilation), statements were identified. The statements were carefully translated from Swedish into English. In the third step (comparison), variations or agreements were identified to determine similarities and differences between the statements. In the fourth step (grouping), a preliminary grouping of statements was made and preliminary categories were created. In the fifth step (articulation), the preliminary categories were compared to verify that they were different from each other. In the sixth step (labelling), the categories were labelled to highlight their essence. In the seventh and last step (contrasting), the categories were contrasted to study the underlying structure (the outcome space) and to describe the variations in the conceptions. The outcome space is the main result of a phenomenographic study; it describes how the different conceptions relate to each other (Larsson, 1986; Marton & Booth, 2000).

2.2 | 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 members were informed about the aim of the study, that participation was voluntary and that they could withdraw their participation at any time. To ensure the informants' confidentiality, interview quotations refer to "manager" or "staff" and each participant is assigned a number instead of using their names.

3 | RESULTS

In the analysis following the phenomenographic approach, the informants' un-reflected perceptions of what participation means

were the phenomenon in focus. The analysis resulted in the essence of the phenomenon experienced as different variations of the conditions for participation. Therefore, the results are presented based on the categories of variations of the conditions that emerged in the interviews. The interview results show that participation for adults with PIMD was dependent upon conditions at three levels. The conditions for facilitating participation were found at the individual (*Degree of impairment and capability*), staff (*Knowledge, Learning from experienced staff, Communication skills, Time, Power and Being sensitive and aware*) and organisational (*The organisation*) levels, where the organisational level represents the conditions that the staff members thought they could not influence. The conditions describe what the managers and the staff think is needed to achieve participation for adults with PIMD. If the conditions are not fulfilled, to some extent, participation in daily life might be difficult or, in some cases, impossible to achieve.

3.1 | Degree of impairment and capability

At the individual level of an adult with PIMD, the degree of impairment was considered to be an important condition for participation. One staff member noted: "Well, it depends on what disabilities they have" (Staff 1). The capability of the adult with PIMD was also considered to be an important condition for participation. Another staff member noted: "But as I said, I do not think they always have the ability" (Staff 13). Severe impairment or lower capability was considered to limit the possibility for participation. One staff member said: "Yes, some are lower and some are higher, so it is. Some may of course decide for themselves and talk about what they want, but not all" (Staff 6). Apart from the capability connected to the degree of impairment, adults with PIMD were seen as lacking sufficient insight to make proper decisions. One of the managers noted: "Yes it depends much on, I think ... that you have to have the ability, and often they do not have the insight" (Manager 2).

3.2 | Knowledge

For the managers and staff members, the precondition for participation was knowledge, namely general knowledge about disabilities and special knowledge about the supported individual. Common knowledge pertained to routines—the daily work needed to ensure continuity for the adult with PIMD. Both the managers and staff members considered this to be important for adults with PIMD; otherwise, the daily activities could be confusing and create anxiety and fear. As one staff member noted:

The staff can do things a little bit differently, but overall, we will do the same thing. But, how we talk, how we joke with them and so on, it may be different, but some elements, they are just ... how we get to the bathroom, how we change, which

arm we start with, that we begin with changing diapers and then wash upper parts and then shave. There we are very structured, so it does not get too confusing. (Staff 14)

Special knowledge refers to knowing the adult with PIMD and trying to do things that he/she liked, or what the staff thought he/she liked to do. Special knowledge also refers to trying to understand what the adult with PIMD wants. This knowledge was thought to increase the more a staff member got to know the adult. Special knowledge made it easier to meet the adult's wishes:

We are trying to understand what the person really wants ... when you have known someone for a long time, you sort of learn that this person wants it in a particular way, and you try to do it the best you can, sort of. (Staff 13)

Staff members often talked about what the adult with PIMD wanted to do. It was difficult for them to figure out, so they often did things that they thought the adult with PIMD wanted to do:

We have been talking about what we think this person wants to do, so then you take that into account, and much of it is, in fact, what I feel and what I think this person would like to do. (Staff 14)

3.3 | Learning from experienced staff

New staff members learned from more senior and experienced staff members. As one staff member noted: "In the beginning, luckily, you work together with somebody and you learn from that person" (Staff 16). Staff members considered it important to listen to more experienced staff, to learn about their own small tricks and to overcome the fear of doing something wrong in the beginning.

I listen, of course, because many of the staff [members] have been working there for a long time, so I listen a lot about how they have done things so that I know what works; but, then you slowly find out small tricks and what they are capable of. And like I said, different staff members find out different things, and that can sometimes be very interesting because you see something that has not worked at all and suddenly someone else can make it work. It is really fun ... the longer you ... you get a bit tougher, and maybe at the beginning, I thought, "Oops, I hope it does not go wrong now; if only it won't go wrong now". Because I do not do things exactly as they used to be done, the towel right there or that box there. (Staff 5)

3.4 | Communication skills

Communication skills were considered crucial for either facilitating or hindering participation. The managers and staff members' communication skills enabled them to understand the different ways in which the adults with PIMD communicated (e.g., body language, signs or sounds). The managers and staff members had to be aware of the emotions triggered by different situations. The meaning of the communication was often not clearly expressed by the adults with PIMD.

Well, it is really about protesting against something that I [the adult with PIMD] do not like, and I think, I think I have noticed it and experienced it. To show in different ways that I do not want this or to show contentment when there is something I like; and it can be anything, glances or sounds. (Manager 1)

Understanding what the adult with PIMD is communicating was also much more difficult when forms of communication other than spoken language were used. When the adult with PIMD used body language, the staff had to focus on the person to read the small signs and cues.

It is always difficult when it comes to adults with PIMD, when they cannot speak and cannot ... some of them can show that, no, I do not want to do this ... and some of them cannot; so, you have to try to understand, and if something is interesting, you can see it in their eyes. (Staff 9)

It can be difficult to know what the adult with PIMD is expressing. Thus, the staff members or managers mostly interpreted what the adult wanted to say. As one manager noted: "Yes, I think you can see it in their eyes, but that is what I think, what I interpret, so it is hard to know" (Manager 4).

3.5 | Time

Working on ensuring the participation of adults with PIMD takes time. Lack of time was one of the topics discussed by the staff working at the group home: "Yes, and the fact that lack of time is always there, sometimes it is ... you must rush on because, well ... because there is so much more that also has to be done" (Staff 10). The staff also shared that there was less time now than before because the number of personnel had decreased.

You are always trying to slow down and really take the time and wait because you need to do that many times. ... But, I can add that I think it has become a bit more difficult because we were eight regular staff here; now it is six, but the same number of users ... you do not have the time anymore, as it was in the

past, and it affects them, of course, and I think that is not good. (Staff 12)

3.6 | Power

When the staff members and managers talked about power, they talked about how they had to be aware of their own power in any situation so that they did not miss involving the adult with PIMD in the decision-making process. At the same time, they explained that the adult with PIMD usually participated in the activity, but not when it came to making decisions about what activity to perform. One of the managers noted: "She is involved in the activity of walking ... she walks, but the decision that we should go for a walk every evening was more of our decision" (Manager 4). The staff members also used their power if they thought the adult was not capable of making the right decision.

When you go shopping, you get to choose ... but they might point to something totally crazy that we absolutely cannot buy ... it must of course be restricted ... we are professionals ... you control a bit, steering it a bit because perhaps they do not understand that I cannot buy that. (Staff 11)

3.7 | Being sensitive and aware

The study participants talked about being professional, which meant being empathetic and aware of the power advantage they had in their relationships with adults with PIMD. Being professional was a focal concern, and it was important for the managers and staff members to learn to stand back and let different activities unfold in due time.

I think that we, as staff, have to try to see, well, try to give them [the adults with PIMD] opportunities and try to see if you get a positive or negative reaction ... we simply must not give up. I think that is important because I think that ... well, that you do not take over as staff ... I do it myself because it goes faster, but as professionals, we have to stand back, stand a few feet away and let it [the activity] take its time. (Staff 4)

Being professional also meant being aware of what the adult with PIMD wanted or needed instead of just doing things with the best intentions.

We think a lot; I really want to say that we do this with the best of intentions, but sometimes we will take one-step too far. No, just because it is my attitude ... so we really need to be professional here. Yes, for me, it is incredibly important that the users are central. (Manager 6)

Being professional also meant being aware of the capabilities of the adult with PIMD's to increase his/her participation. As one manager noted: "My last thoughts about participation ... it is always possible to develop further. All adults have qualifications and different experiences, and you can always do things in different ways; otherwise, the problem lies with us." (Manager 8)

3.8 | The organisation

The staff members talked about the organisation's crucial role, especially in terms of opportunities for them to facilitate participation. The organisation lacked a common definition of participation. According to one staff member: "Yes, it is all about a group of staff members who have extremely different conceptions of participation, and then there will be problems in the workgroup" (Staff 7). The lack of personnel was another organisational problem that led the staff members to believe they could not always do a proper job.

It is, of course, a lack of personnel here and there, you could say. It is difficult to get temporary staff, and then one cannot do some things that you think they should do, but yes, so it is hard, it is a dilemma. You do want to feel that you are doing a good job, and sometimes you do not feel that because you do not think that you can do everything so well. (Staff 11)

With the staff shortage and with adults with different degrees of impairment living together in the same group home, it was considered difficult to facilitate participation. The staff saw this as a major obstacle:

You work alone at night, and then maybe it is hard to be out in the evening. It is good to have the same categories [of impairment]. If you are healthy enough to be out late in the evening, then maybe you should stay somewhere else to achieve participation. There may be times when we limit participation to those living in the wrong place—that is what I think about sometimes. (Staff 14)

Another possible barrier to participation is that the organisation does not provide the staff with the necessary equipment to facilitate participation: "I wish, for example, that we could have a car here ... yes, it would also make it possible for many to develop if you could get out of the house along with somebody" (Staff 15).

A positive aspect was that the group home had experienced staff, as many of the staff members had worked there for a long time. According to the staff members and managers, this made the adults with PIMD feel safe and secure, and it positively affected their opportunities to participate:

To feel safe and secure is important. Yes, it is absolutely true, and we have experienced staff around adults with

PIMD. There is not so much change in staff; we have staff who have worked here a long time. (Manager 3)

4 | DISCUSSION

Drawing on the qualitative methodology of phenomenography, this study aimed to describe managers and staff members' perceptions of what participation means for adults with PIMD. Interestingly, this un-reflected perception was not found. Rather, the informants predominantly expressed variations of the conditions needed to facilitate participation. This result means that, as a phenomenon for the group of adults with PIMD, participation is understood to be abstract and difficult to explicitly express. Thus, the meaning of participation is described in terms of surrounding aspects (conditions). The study results show that the most important conditions for meaningful participation are the capabilities and personality of the adult with PIMD, the staff's knowledge of the individual and target group, such as the time allocated by staff, and the staff's sensitivity and awareness. The individual characteristics that inhibit participation, as described by Kählin et al. (2014), were also found in the present study; however, Kählin et al.'s finding that an inhibiting factor for participation was limited social contacts outside the group home was not brought up by the managers or staff members in the interviews in the present study. According to Kählin et al. (2014), both personal and environmental factors are important preconditions for participation. In the present study, these factors were found to be influential, but in different ways, as the informants believed that environmental factors, as opposed to personal factors, are changeable. Another condition for participation that emerged in the interviews is that the organisation needs to be supportive and adequate, which is consistent with the findings reported by Kählin et al. (2014).

In the present study, staff members and managers frequently brought up the need to account for the individual's wishes, even though they had insufficient time to do so. This finding is in line with Molin (2004) model of participation. At the same time, the staff reported that it was not always easy to understand the wishes of adults with PIMD, and that getting to know those wishes was decisive for understanding them. This result is consistent with the findings reported by Goldbart et al. (2014) who noted that getting to know the adult and the ways he or she communicates is crucial for adult-staff interactions.

According to the staff members and managers, the degree of impairment of the adult with PIMD was a factor that influenced their participation and the extent to which their wishes could be met. This apparent in the findings in that staff views about the capabilities of the person with PIMD will influence whether or not the staff members involve the person to participate. Once again, this finding is in agreement with Molin (2004) model of participation; more specifically, an individual's capability is one of the three components needed for participation. The need to view participation in light of the degree of the impairment is also consistent with the findings

reported by Bigby et al. (2012) and Jones et al. (2008) The fact that the willingness to invite the adult to participate can decrease if staff members hold negative attitudes towards the adult's capacity and do not invite them to participate also supports Molin (2004) model of participation. However, the organisation does not always encourage or support staff members in doing things differently; thus, circumscribing their choices of actions is in line with Antaki et al. (2009), who found that participating in everyday life for people with intellectual disabilities must be seen in light of the choices available to them.

Adults with PIMD have limited communication skills; so, unsurprisingly, communication was viewed as an important condition for participation. The managers and staff members stated that it was important to understand the language of the adult with PIMD, regardless of whether that individual used spoken words, signs or body language. The managers and staff members stressed the importance of learning how to communicate with adults with PIMD in ways that they can understand. Forster and Iacono (2008) and Hostyn et al. (2010) came to the same conclusion, which is that knowing how an adult with PIMD communicates is crucial for interacting with him/her. Consequently, it impacts the adult's possibilities to participate in their daily lives.

The interviewees said that the degree to which the wishes of adults with PIMD could be fulfilled depended on their capabilities. They stated that adults with PIMD do not possess the ability to choose for themselves or to understand the consequences of their choices; this conclusion was also reached by Bigby et al. (2009) and Clement and Bigby (2009). This shows that the responsibility for participation (or non-participation) of the adult with PIMD is placed partly on the shoulders of the individual, not on the managers and staff members. Moreover, earlier research has shown that adults with PIMD spend much time isolated and disengaged due to low-quality support (Beadle-Brown et al., 2015), which could occur because managers and staff members place some of the responsibility for participation on the adult with PIMD.

The study results show that staff members often used their power if they did not think the adult with PIMD was capable of making the "right" decisions. The staff members also used their power when selecting activities, rather than allowing the adult with PIMD to choose them. The staff members claimed that these choices were made with good intentions, as the adult was not often able to initiate activities. This is consistent with Antaki et al. (2009) findings that staff often try to introduce choices for the residents' everyday activities.

The Swedish disability policy and the law of support and service state that society must enable participation for people with all types of disabilities, and adults with PIMD have limited participation in their everyday lives due to the lack of power. Antaki et al. (2009) found that policy goals for freedom of choice are often set at a level that is not available for these adults. Thus, staff members do not have an easy task, which they attribute to a lack of organisational support. Organisational difficulties, including the lack of a common definition of participation, the insufficient number of staff and the lack of necessary equipment, aids and tools, are challenging for staff. The absence

of a common definition of participation leaves staff members with the task of trying to define participation; consequently, it makes it difficult for them to live up to the mandate of the Swedish disability policy. Another problem is that, when managers and staff members talk about participation with each other, they talk about different things. An insufficient number of staff makes it difficult to consider the adults' wishes and to "do a proper job." Lack of equipment, such as a car to get around easier, also makes it harder for staff members to facilitate participation. The interviews also showed that the staff members want to elevate the level of participation as much as they can.

5 | METHODOLOGICAL DISCUSSION

It is common to use proxy interviews in research about adults with PIMD because they often have limited communication skills (Granlund et al., 2013). Therefore, interviewing staff members and managers is a suitable data collection method. It could be debated if we failed to present results corresponding to the study's aim; however, this was the result that emerged from the analysis of the interviews. Having the informants talk about the participation of adults with PIMD was difficult because it is an abstract and vaguely defined or reflected phenomenon for them. They predominantly expressed the conditions for participation. This was understood by expressing implied perceptions of their perceptions. As the informants lacked experiences of the meaning of perceptions for adults with PIMD, they expressed the conditions for their perceptions of the phenomenon under study. This is understood as the perceptions of what is unstated or what is not needed to be expressed because it has never been reflected. Marton and Svensson (1978) described this as the individuals' theoretical framework in which we collect our knowledge or the foundation upon which we build our understanding and reasoning. Therefore, the presented result is about the informants' perceptions of participation, although these are expressed in terms of the conditions for participation for adults with PIMD.

Credibility, transferability and confirmability are important for establishing trustworthiness in qualitative studies (Lincoln & Guba, 1985). The credibility of the study was ensured by taking both the content and context into account while carefully collecting and analysing the data. Transferability was achieved by providing a detailed description of the research process. As a group home or in-home service with personal assistance is a common accommodation for adults with PIMD, the results should be transferable to similar contexts.

6 | CONCLUSION

The study results showed that the managers and the staff members' perceptions of the participation of adults with PIMD were significantly dependent upon the conditions pertaining to the adult with PIMD, the perceptions of the managers and staff members and the organisation. The capability of adults with PIMD was the condition that the managers and staff members talked about the most.

Participation was often reduced, because the staff did not think that the adults with PIMD were capable enough of participating in their daily lives. The fact that the staff members decide on the adults' capability makes the power relationship even more uneven and reduces the opportunities for adults with PIMD to exercise self-determination and autonomy in their daily lives. However, some studies have reported that the staff's judgement could enable the self-determination of adults with PIMD, and many other studies have suggested that it is important for the staff to know the person well to facilitate participation (Forster & Iacono, 2008; Hostyn et al., 2010).

In the present study, the informants reported that the insufficient number of staff, the lack of time and the lack of a definition of participation also reduced the opportunities for adults with PIMD to participate. The organisation must provide staff members with the tools they need to facilitate participation for adults with PIMD. In addition to this essential organisational condition, the staff members' judgements of what an adult with PIMD can manage to do seem to be crucial for achieving the Swedish disability policy goal of participation.

COMPETING INTERESTS

The authors declare that they have no competing interests.

AUTHORS CONTRIBUTION

All authors designed the study. LT collected the data. LT and CG analysed the interviews and LT did the first analyse of the data collected at the observations. The analysis was discussed among the authors until consensus was reached. LT drafted the manuscript. All authors read, contributed to, and approved the final manuscript.

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Participation in daily life for adults with profound intellectual (and multiple) disabilities: How high do they climb on Shier's ladder of participation?

Participation is the goal of Swedish disability policy, but it is difficult to achieve for adults with profound intellectual (and multiple) disabilities. Since they are dependent on others for every aspect of their daily lives, others control their ability to participate in everyday life decisions. This study used observations analysed with Shier's ladder of participation to elucidate and describe participation in daily life for adults with profound intellectual (and multiple) disabilities living in a group home. Results showed that adults often reached the first three levels of the ladder. One adult reached the fourth level once, and no one reached the fifth level. Participation on a higher level, therefore, seems hard to reach for adults. Staff members' attitudes towards the adult's capability can also be a barrier to participation. Applying Shier's ladder of participation can provide valuable information that might lead to increased participation in daily life for the adults.

Keywords: group home, participation, profound intellectual (and multiple) disabilities, Shier's ladder of participation

Introduction

Participation is the overarching goal of the Swedish disability policy, which applies to people with a wide range of disabilities (Government Bill 1999/2000:79; S2012.028). For people with severe disabilities, there is also a Swedish law concerning their support and service. The law, which is called The Act Concerning Support and Service for Persons with Certain Functional Impairments (SFS 1993:387), specifies rights for people with considerable and permanent impairments. The purpose of the law is to ensure that people with disabilities have 'good living conditions' and opportunities to live as others do.

In Sweden, most adults with profound intellectual (and multiple) disabilities (PI(M)D) live in group homes where staff members carry out the needed support and service (The National Board of Health and Welfare, 2018). Given their dependence on others, adults with PI(M)D live in environments created by and controlled by others (Blomberg, 2006; Felce and Perry, 1995; Ringsby Jansson, 2002; Tideman, 2000).

Adults with PI(M)D depend on others to facilitate participation in many aspects of their daily lives (Granlund et al., 2013). Earlier studies (Furehed, 1997; Johnson et al., 2012; Mansell et al., 2008) on living conditions of adults with PI(M)D show that their participation largely depends on other people's capacity and willingness to facilitate their participation. Söder and

Grönvik (2008) have also shown that these adults have fewer opportunities to pursue their wishes and decide the course of their lives compared with other people.

Participation should be seen as a goal for support and service to people with PI(M)D (SFS 1993:387); therefore, the conceptualisation of participation for adults with PI(M)D is important. There are, however, different ways of conceptualising the meaning of participation. According to WHO (2001), participation is defined as an individual's engagement in the particular life situation, while Tideman (2004) considers participation as equal living conditions. Gustavsson (2004) claims that participation consists of three different dimensions: first, the individual needs to participate in the activity; secondly, the individual must experience participation; and thirdly, participation depends on the individual's interaction with and accessibility to his or her environment. Molin (2004) argues along the same lines as Gustavsson, stating that participation depends on whether the individual wants, can, and is offered the opportunity to participate. Hammel et al. (2008) present another variation on the meaning of participation: meaningful participation. Meaningful participation relates both to the individual's feeling of participation (that it feels meaningful to participate) and to the individual's right to participate in decisions affecting their own lives.

Shier has developed a model of participation known as the 'ladder of participation' (2001). Shier's ladder of participation was originally developed for children but is today also used for adults whose participation is dependent on support from the environment (Gullacksen and Hejdedal, 2014). The ladder is based on five levels of participation.

In Shier's original model, every level starts with the word, "children." Here, "children" has been replaced with the phrase, "Adults with PI(M)D," to fit the target group in this study:

1. Adults with PI(M)D are listened to.
2. Adults with PI(M)D are supported in expressing their views.
3. Adults with PI(M)D views are taken into account.
4. Adults with PI(M)D are involved in decision-making processes.
5. Adults with PI(M)D share power and responsibility for decision-making.

Connected to each of the five levels are three stages of commitment: 'openings', 'opportunities', and 'obligations'. Openings refer to the environment's capacity to facilitate listening to and supporting the adult with PI(M)D. The opening stage is, according to Shier, only an opening because it does not guarantee that the opportunity will come to fruition. Opportunities have to do with resources and the skills and knowledge that enable staff members to listen to and support these adults. Obligations, finally, refer to organisational policies and guidelines to increase the participation of adults with PI(M)D. To fully reach the last level, according to Shier, "requires an

explicit commitment on the part of adults (in this case staff members) to share their power; that is, to give some of it away” (p. 115).

Participation is considered a central aspect of quality of life for people with intellectual disabilities (Clement and Bigby 2010; Kozma et al., 2009; Schalock et al., 2002). According to Mansell and Beadle-Brown (2012), the key measure of quality of life for adults with PI(M)D is engagement in daily life activities and in social relationships. Despite this knowledge, research shows that adults with PI(M)D often spend their days disengaged and receiving low levels of support, and they are often left with simple activities such as watching television or eating (Beadle-Brown et al., 2016). It is also shown (see for example, Furehned, 1997; Bigby et al., 2009; Clement and Bigby, 2009; Jones et al., 2008) that support staff members should stress principles of choice, integration, and participation. However, sometimes they do not consider that adults with PI(M)D are able to make decisions or understand the consequences of their choices. Participation is therefore often difficult to achieve for adults with PI(M)D, and quality of life is considered relatively poor (Beadle-Brown et al., 2016).

Choice making is an aspect of participation. Burton Smith et al. (2005) show that choice making is connected to the degree of impairment rather than the individual’s age. Their research shows that daily choice making for adults with PI(M)D was significantly lower than for adults with milder or no intellectual disability. Further, they show that adults with PI(M)D “had the choice availability equivalent of non-disabled children aged 3 years and 10 months” (p. 234). Qian et al. (2015) have exposed that adults with PI(M)D have a low level of engagement in their daily lives: 21% in non-social activities and only 3% in social activities. Hanzen et al. (2017) also found that the engagement for these adults depends on how well their surroundings reflect an understanding of their needs.

For adults with PI(M)D, participation is achieved through the assistance of others (Johnson et al., 2012; Dolva et al., 2014; Dusseljee et al., 2011), and staff members often draw on their personal preferences when making decisions for adults with PI(M)D (Dunn et al., 2010). This is troublesome since their preferences may not necessarily coincide with those of the adult with PI(M)D. The fact that adults with PI(M)D must rely on others can also decrease their level of participation since staff members can choose such activities they themselves prefer rather than the ones the adult with PI(M)D prefers. In these circumstances, it is questionable whether the adult with PI(M)D obtains the support that they need (Qian et al., 2015).

Moreover, there is research indicating that staff members’ attitudes towards the capability of adults with PI(M)D affect their actual everyday life participation (Bigby et al., 2012; Bigby et al., 2015). In addition, low quality of support leads to social isolation and disengagement among adults with PI(M)D (Beadle-Brown et al., 2016). However, Talman et al. (2017) show that the

blame for the adult's lack of participation falls not only on staff members, but also on an inadequate definition of participation in the social care organisation and on a lack of support for staff members responsible for participation. From that perspective, it was considered important to observe how participation actually is conducted in PI(MD)s' daily lives. How do staff facilitate participation in PI(MD)s' daily lives without clear definitions and regulations supporting their work? The aim of the study was to elucidate and describe participation in daily life for adults with PI(M)D living in a group home.

Method

A qualitative deductive observation study approach was used, exploring Shier's (2001) model of participation in the circumstances of a group home in a middle-sized community in Sweden. Observations were used since they are helpful in contexts where little is known about a topic or where the phenomenon is complex (Creswell, 1998; Denzin and Lincoln, 2005). Close observations of the everyday life of the studied individuals facilitates an understanding both of the actions people take and of their conceptions of a given phenomenon. In this case, the phenomenon is how adults with PI(M)D participate in activities in their own daily lives.

Ethical considerations

Ethical approval for the study was obtained from the Regional Ethics Committee in Uppsala, Sweden (D.nr. 2013/375). The on-site observations were approved by the residents' legal guardians, who are responsible for making decisions on behalf of the adult with PI(M)D. To ensure confidentiality of the informants, names have been altered in citations drawn from the field notes.

Participants and data collection

Six apartments and a shared living/dining room with a small kitchen make up the group home being studied. In the group home, one woman and three men with PI(M)D, between 27 and 55 years of age, were observed with focus on the adults' participation in different activities. In the home, there are 12 ordinary and three extra staff members, between 27 and 63 years of age, with between three weeks and 29 years of experience working with the adults in the group home.

In this setting, the first author conducted observations on 13 occasions in October and November of 2016. The observations took place on all days of the week and lasted from 3.5-5.5 hours. To respect the residents' intimate morning and evening activities (e.g., dressing,

undressing, and taking showers), the observations were conducted between 10:00 and 19:00. In total, the first author spent 60 hours observing how the adults with PI(M)D were participating in daily life activities.

The first author acted as an observer as participant (Creswell, 1998). This meant being present in the same room as the observed individuals but keeping a distance by sitting or standing a bit away to avoid interrupting or disturbing the activity. The observer focused on how the adults participated in different activities in their daily lives. During the observations, extensive field notes were taken, with notes of a more synthesizing character completed afterwards. To supplement the observations, discussions with staff members on questions raised during the observations were also held. The field notes contained the observed activities, the researcher’s methodological and analytical reflections, and the researcher’s discussion with the staff members.

Data analysis

The field notes were retyped and further reflections from the observations were added. Field notes from the observations were deductively analysed using the methods of Elo and Kyngäs (2008). The field notes were read through several times and text that indicated participation or opportunities to participate for the adults with PI(M)D were marked. Using the analysis, a structured categorisation matrix based on Shier’s (2001) ladder of participation was developed (Table 1), and the annotations in the field notes were categorised according to Shier’s five levels of participation. The primary analysis was conducted by the first author and was thereafter discussed with the co-authors until a consensus on the structure was reached.

Table 1. Categorisation matrix of Shier’s (2001) ladder of participation

Adults with PI(M)D	Field notes indicating that
are listened to	The adult expressed a view that staff member(s) listened to.
are supported in expressing their views	Staff member(s) stimulated the adults to express their views or supported them when they did so.
views are taken into account	The adult’s views were taken into account/influenced the decision-making.
are involved in decision-making processes	The adult was directly involved when decisions were made.
share power and responsibility for decision-making	Staff member(s) shared their power and gave some of it away.

Results

The results are presented according to the five levels of participation in Shier's (2001) ladder of participation.

Adults with PI(M)D are listened to

The results show that the adults with PI(M)D often were listened to. In order to understand the adults with PI(M)D, staff tried to listen to the adults, no matter what kind of communication they used, which the following citations from the field notes highlight. When observing Peter shopping, the staff member showed him salami and asked if he wanted it. Peter reached for the salami and the staff member said, "He wants it," and put it in the basket. Another example of staff members listening to the adult with PI(M)D is described in the field notes below.

Simon and one of the staff members had gone to the shopping centre to do some shopping but first stopped at a hamburger restaurant to eat. The staff member asked Simon if he wanted a hamburger or French fries and waited for Simon to point out what he wanted before she put it into his mouth. Simon pointed at the coke when he wanted to drink, and the staff member fully concentrated on his wishes.

The adults with PI(M)D are also listened to despite the fact that they cannot communicate by speaking or protesting or pointing at things, as described in the following field notes of one of the discussions with a couple of staff members.

I talked to two of the staff members and asked them how they know what the adults like. The staff members said that the adults often show it by pointing or laughing, but that it is difficult to know when it comes to Emma. The staff members explained that they often react to things that she is looking at; for example, they told about their last visit to the city. In one of the stores, there was a big silver-plated animal and every time they went by it, Emma looked at it. Because she looked at the animal so many times, they decided to buy it and it is now standing in her apartment.

Another example of staff members listening to the adult's small signals was in one of the observations of Simon. Simon was sitting in his chair in his living room, and the staff member had just put on the television. The staff member saw that Simon was looking at the table next to his chair where he has a bowl with candy. The staff member immediately said, "I know what you want," and then she took two pieces of candy and put them into Simon's mouth. The staff

member also put a third piece of candy into his right hand and said, “You can take that one later.”

There were also several occasions when staff members did not listen to the adults with PI(M)D. William for instance is very fond of his toys and likes to play with them. He often invites others to play with him and the following field note describe staff members not listening to the adults with PI(M)D.

William likes to play with his toys, but I rarely/never see staff members playing with him. During the observations, I observed staff members playing with William on three occasions. A new staff member that was at the group home for the first time played with William for about five minutes at the third observation. One of the temporary staff members played for a short while with William during the seventh observation, and one of the new staff members (she had been working at the group home for six weeks) played with him for about five to ten minutes at the tenth observation. During the 60 hours of observation, none of the regular staff members who have worked there for a long time was observed playing with William.

Adults with PI(M)D are supported in expressing their views

The result shows that the adults often were able to express their own views in the activity. It seemed to be easy for all of the adults to express their views, and it seemed that the staff members supported the expressions, as the following field notes display.

After shopping for mugs with Simon, we popped into the store next door. It is a store combined with a daily activity centre, and the staff member knows the woman in the store and wanted to talk to her. After a little while, Simon became bored and started to sway back and forth in his wheelchair, and he threw his head toward the neck pillow. The staff member immediately said that it was not fun anymore, and we left the store.

While talking to the staff members about whether the adults have any assistive technology communication aids to help them express themselves, staff members said that the adults are not capable of using such aids. Yes and No cards have been recommended for use with Emma, but they told me that they did not believe that she was capable of using them. At one of the observations of Emma, the staff member working with her on that day decided to try to use the cards, and the field notes below show that they worked very well.

As I was sitting in a chair in Emma’s kitchen, the staff member (who was preparing Emma’s lunch) asked her if she wanted to have peppers filled with ground beef for lunch. The staff

member took out Emma's Yes and No cards. (The cards are quite big, about 10*15 cm.) The cards include text (Yes and No), and the Yes card is green while the No card is red. When the staff member asked once again if Emma wanted to have peppers filled with ground beef for lunch, Emma did not seem to know what to answer. The staff member said, "Peppers filled with ground beef, maybe you do not know what that is." Then she asked, "Do you want spaghetti and meat sauce?" Emma directly touched the No card. The staff member said, "Would you like Salisbury steak and potatoes?" Emma once again touched the No card. Then the staff member asked if Emma would like salmon and mashed potatoes. Emma selected the No card again, this time by instantly turning her head and directly looking at the No card. The staff member continued, asking if Emma wanted sausage stew and rice, and Emma said "no" by looking directly towards the No card. The staff member thought for a moment and then asked about the peppers filled with ground beef again, but this time she rephrased her question. The staff member put the Yes and No cards behind her back, and then she said very slowly, "Peppers filled with ground beef. Do you want to try?" While she posed the question, she showed Emma the Yes and No cards, and Emma turned her head and gazed directly at the Yes card. The staff member repeated the question. and Emma once again looked at the Yes card. The staff member replied by saying, "Ok, then we will take peppers filled with ground beef," and she started to prepare Emma's lunch.

After this observation, the staff member who had tried the cards told the other staff members how well they had worked. The staff members had a long discussion about how they might have been wrong in thinking that Emma was not capable of using them. They then decided that they should use the card as much as possible thereafter.

Adults with PI(M)D views are taken into account

That the views of the adults with PI(M)D were taken into account was observed as shown in the field notes below.

I knocked on Simon's door and asked if it was ok for me to come in, and the staff member said that it was ok. She spontaneously told me to watch how he chooses. Simon had a plate of food, a jar of salad, and a glass of water standing on the table in front of him. The staff member said, "What do you want?" Simon pointed at what he wanted. After a while, when there was only a little bit food left, Simon pushed the plate away. The staff member asked if he did not want anymore, and Simon pushed the plate further away. The staff member then took the plate and put it into the sink. She checked to see if he wanted more to drink. He did not, and she put the glass away. Then the staff member served him coffee, a cookie, and some candy, which he ate with good appetite.

Another example of the adult's views being taken into account happened while observing William at one of his home staying days, as described below.

At home staying days, William is supposed to clean his apartment and do the weekly shopping, but the staff members told me that William is not so fond of shopping. The staff members had therefore decided that it was better that they do the shopping in the afternoon while William went for a walk with his contact person, something he really likes to do. The staff members thought it best to clean the apartment before the contact person arrived, since William often is tired when he returns from the meetings with his contact person. One of the staff members went to William's apartment. She took out his vacuum cleaner and started to clean the floors. Before she went to his apartment, she had asked William if he should join her, but William preferred to play with his toys and did not pay any attention to the staff member. A second staff member stayed with William and moved towards his apartment. Since William is always seeking someone to play with, he followed her. When William noticed that someone (a staff member) was vacuuming in his apartment, he wanted to join in. He manoeuvred his wheelchair towards his couch and moved from the wheelchair to the couch. He sat down on the couch and the staff member handed him the vacuum cleaner, but William pushed it away. He threw himself down on the couch and laughed. He clearly showed that he wanted to be there, but did not want to do anything himself, so the staff member continued vacuuming while William lay on his couch.

During an observation of one of the common weekend dinners, Simon clearly showed that he did not want to participate any more. He showed this by pushing his wheelchair away from the table. The staff member sitting next to him asked him if he would have his coffee in his own apartment, and he responded by smiling. The staff member poured a cup of coffee, took a couple of cookies, and went with them to Simon's apartment. Then she came back to take Simon to his apartment.

There were also occasions observed where the adults' views were not taken into account, as the following field notes show.

In Peter's room, the staff member selected a music disc, without showing or letting Peter choose. She put on the music and set Peter's wheelchair beside his basket of toys. Peter took a toy and swayed to the music as he spun the toy, a kind of plastic ball with holes for fingers. The staff member went out for a few minutes and then returned to cook Peter's lunch. She turned off the music, removed the toy from Peter, and put it in the basket, while she told me that it was time to cook lunch, and that Peter shall participate and cannot be distracted. Then she turned Peter's wheelchair around so that he faced the sink, and she started to peel the potatoes with Peter sitting behind her. She did not ask Peter what he wanted to do.

Adults with PI(M)D are involved in decision-making processes

The results show that one of the four residents in the group home was observed as being involved in the decision-making processes, and this was observed at one single occasion, as described in the following field note.

The staff member was standing by the sink/stove and preparing the food, and Emma was standing behind her on her standing device. I sat at Emma's kitchen table to the left of them. I noticed quite soon that Emma was staring at me. She turned her head towards me and stared at me with a frown. It seemed as if she was annoyed that I was in the room. When she had stared at me a few times, I approached her and asked if she did not want me to be in her apartment. She stared at me (not looking happy). The staff member immediately asked if she wanted me to go out, and at the same time showed Emma her Yes and No cards. Emma immediately looked at the Yes card, and I said, "Ok, I will go out." When I got halfway out of the apartment, Emma started laughing, and both the staff member and I understood that we had probably interpreted the situation correctly. After a while (about 20 minutes), I went into her apartment again, and the staff member took her Yes and No cards and asked if I could be there when she ate? Emma immediately looked at the No card. The staff member took down the cards, placed them behind her back, and changed their position. Then she asked once again if I could be there while Emma was eating. When she asked the question, she held up the Yes and No cards. Emma looked immediately at the No card, and the staff member thought it was great to get feedback on the issue. The staff member later told me that she had not expected to get such clear answers.

The staff members rarely or never offer opportunities for the adults to make decisions. They know these particular adults, know what they like, and therefore often decide for them. That staff members tend to make decisions themselves seems partly due to time constraints and partly due to external circumstances, such as when transport is available to and from an activity. In discussion, staff members indicated that if all four adults with PI(M)D who live in the group home can choose between two things, they are allowed to do so. For example, the choice between apples and pears should not be a problem for any of the four adults, and the adults are allowed to make that choice. When asking why they get to choose so rarely if they can do it, staff members answered that there was not enough time. But during the 60 hours of observations in the group home, much time was spent sitting in the shared living/dining room talking to staff members while the adults were alone (watching TV or listening to music) in their apartments.

An example from the field notes that shows staff members deciding what to do and when is described below.

It was time to eat lunch. On the weekends, all residents ate together in the shared living/dining room. There were two staff members working. Simon and Emma needed to be fed, while Peter and William could eat by themselves if a staff member put the food on their spoon. One staff member was feeding Emma and supporting William, while the other staff member was feeding Simon and supporting Peter. Peter was hungry and took a bite of the food with his hand. William sometimes does the same thing, according to the staff member, so she put William's and Peter's food where they could not reach it and said, "You have to wait a bit." The staff member supporting Emma and William cut up William's food. It seemed to be difficult to assist both the adult to be fed and the one to be supported. William sat at the table with his head hanging and waited. 18 minutes after they had sat down at the table, he got the first bite. William was then waiting for the staff member to put more food on the spoon, and as soon as she did so he took the spoon and ate. He seemed to be very hungry. The staff members were talking to each other about how good the food looked. A question about who decides what to eat on the weekends was brought up, and the staff members replied that the decision was made by the staff members who worked that weekend.

Another example showing that staff members are the ones who decide the rules in the group home, and that they do so based in part on their working situation, is in the following field notes.

Williams's door to his apartment is closed in the afternoons. The reason for that, according to staff members, is that William likes to go into his room and lay down on his couch to rest. Staff members say that he is not allowed to do that because then he sleeps poorly in the night and disturbs the staff member who works at night. (The staff members at the group home have sleeping nights.) William therefore spends the afternoons (when he is not at his daily activity) in the shared living/dining room, where he goes around in his wheelchair and play with his toys. He often drives the wheelchair to his apartment door, but it is closed. He pushes the door to open it but without success, so he goes back to the shared living/dining room.

Adults with PI(M)D share power and responsibility for decision-making

The highest level of Shier's ladder of participation – sharing power and responsibility for decision-making – was not observed at any occasion of the 60 hours spent in the group home.

Openings, opportunities, and obligations connected to the five levels of participation

The study connected the five different levels of participation in Shier's (2001) ladder of

participation to the three stages of commitment: openings, opportunities, and obligations. Openings, which concern the environment's capacity to facilitate listening to and supporting the adult with PI(M)D, were often observed and there were many openings where the staff members could listen to the adults with PI(M)D. The staff members often took the opportunities to do so, but sometimes it was not possible because the opportunity to do so was limited by environmental circumstances, as the following field notes show.

When observing Simon's weekly shopping, the staff member often talked to Simon about what to buy, but she never asked him what he wanted. As an example, the staff member asked, "Should we take apples or pears?" However, she did not wait for an answer and chose pears.

In this example, the opportunity to let Simon choose was limited due to the arrival of the transportation back to the group home. Concerning the third stage, obligations, which addresses organisational policies and guidelines to increase the participation for the adults with PI(M)D, such policies and guidelines do exist. Nevertheless, staff members seem to pay no attention to them, and staff members usually determine for themselves whether it is possible or not for the adult with PI(M)D to participate.

Discussion

The aim of the study was to elucidate and describe participation in daily life for adults with PI(M)D living in a group home. This was done by drawing upon Shier's ladder of participation. The result shows that Shier's (2001) ladder of participation is useful in distinguishing the level of participation the adults with PI(M)D reach. The result shows that the adults with PI(M)D reached the first three levels in Shier's ladder of participation, but only one of the adults reached the fourth level, and none of them reached the fifth and last level.

Whereas the result from Talman et al. (2017) found a lack of definitions and support for staff members responsible for participation, this study demonstrated that the adults with PI(M)D reach the first three levels of participation. The result in this study also shows that staff members are working diligently, despite poor support from the organisation. Since the adults with PI(M)D reach the first three levels of participation with support from staff members, the adults might perhaps reach even higher levels with a more supportive organisation and drafted working methods. Also, the application of Shier's ladder of participation can shed light on the phenomenon, and through enhanced awareness stimulate staff improvements in their intellectual disability practice.

The staff members at the observed group home claim that they have good knowledge of what the adults with PI(M)D like and dislike, since they have supported them for many years. This confidence in their own knowledge limited their ability to invite the adults into the decision-making process since they thought they already knew the adults' preferences, which supports earlier research (e.g. Talman et al., 2017; Talman et al., 2018). Moreover, earlier studies for many years have shown that adults with PI(M)D seldom or never are invited to participate in decision-making (Furenhed, 1997; Johnson et al., 2012; Mansell et al., 2008). This means that the adults with PI(M)D have fewer opportunities to pursue their wishes and decide the course of their lives, as shown in a study by Söders and Grönviks (2008).

On the one hand, the lack of decision-making impedes progress towards the key goal of participation in the Swedish law about support and service for persons with certain functional impairments (SFS 1993:387). It is not certain that the staff members are able to ensure the adults with PI(M)D 'good living conditions' and opportunities to live as others do if they do not allow them to participate in the decision-making of their own lives. On the other hand, the result shows that the adults with PI(M)D were often listened to and that the staff members often took their views into account, although this was not true in all occasions. The result also shows that the observed adults with PI(M)D seldom were engaged in activities of their daily lives, and during the 60 hours of observations, only one of the adults had any social relationship at all with people other than staff members. (William spent one hour a week with his personal contact person.) Mansell and Beadle-Brown (2012) state that the key measure of quality of life for adults with PI(M)D is that they are engaged in the activities of their daily lives and that they have social relationships connected to their daily lives. This means that the result shows that the stated key measures were not reached for the adults observed.

Beadle-Brown et al. (2016) indicate that adults with PI(M)D often spend their days disengaged and that they get low levels of support, with much focus on simple activities (watching television or eating). The adults observed at the group home were often disengaged and they spent a great deal of time watching television or listening to music. At the same time, the staff members and I spent a lot of time in the shared living/dining room drinking coffee and talking instead of engaging the adults who lived in the group home. The adults with PI(M)D who lived in the group home seemed to have a low level of engagement in their daily lives, something that Qian et al. (2015) have exposed in their research. The result thereby shows that the low support from staff members was a barrier for participation for the adults with PI(M)D, and research by Hanzen et al. (2017) has shown that the engagement for these adults depends on surroundings that facilitate understanding of their needs.

The result from the observations also shows that staff members often draw on their own preferences when making decisions for adults with PI(M)D, which is consistent with the results of earlier research by Dunns et al. (2010) and Talman et al. (2017). The result shows that staff members did not think that the adults with PI(M)D were capable of making decisions, as they often made the decisions for them. This was shown by the observations of staff members not giving the adults the opportunities to choose (e.g., the adults were asked what they wanted but staff members did not wait for their decision). The lack of decision-making for the adults who lived in the group home may be connected to the premise that staff members do not think that these adults are capable of making decisions or understand the consequences of their choices (Furenhed, 1997; Bigby et al., 2009; Clement and Bigby, 2009; Jones et al., 2008). Earlier research also shows that low quality of support leads to social isolation and disengagement among adults with PI(M)D (Beadle-Brown et al., 2016), and the current result shows that the adults often spend their time alone and disengaged.

Methodological discussion

The aim to study participation by observations was both difficult and easy. The staff members were quite suspicious at the beginning, causing some loss of time as the purpose of the observations was explained. However, the staff soon became accustomed to the observing researcher and began to treat the observer as one of the staff members. Only the three first levels of Shier's (2001) ladder of participation were observed regularly. The fourth level was observed seldom, and the fifth level was not observed at all. The duration of time spent at the group home is a possible limitation of the observations, as a longer period of observations might have revealed activities where the fourth and fifth level were more common.

Transferability and credibility to receive trustworthiness is important in qualitative studies (Lincoln and Guba, 1985). Transferability was reached by a detailed description of the research process and credibility was attained by taking both content and context into account while collecting and analysing the data. Since group homes are a common accommodation for adults with PI(M)D, the result should be possible to transfer to similar contexts.

Conclusion

Generally, the results show that the studied adults with PI(M)D reach the first three levels. They are listened to, they are encouraged and supported in expressing their views, and their views are taken into account. One of the four adults reached the fourth level at one occasion. The fifth and

last level, where the staff members are supposed to share the power and responsibility for the decision-making, was not reached at any occasion during the observations. Participation on a higher level therefore seems difficult to reach for adults in these conditions. This means that staff members make more decisions about the adults' everyday lives than the adults themselves do. It also seems that the staff members' attitudes about the adults' capability is a barrier for participation (especially when it comes to the adults' opportunities to express themselves) and thereby a serious barrier for achieving the participation goals in the Swedish disability policy. By using Shier's (2001) ladder of participation in their daily work, staff members can be aware of the levels reached by the adults with PI(M)D. The ladder of participation can thereby be an instrument to increase participation in daily life for adults with PI(M)D.

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