LEENA BERLIN HALLRUP

Experiences Of Everyday Life And Participation For People With Intellectual Disabilities

From four perspectives

**EXPERIENCES OF EVERYDAY LIFE AND PARTICIPATION
FOR PEOPLE WITH INTELLECTUAL DISABILITIES**

Malmö University, Health and Society
Department of Care Science
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“The best way to find yourself is to lose yourself in the service of others”

Mahatma Gandhi

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ABSTRACT

People with intellectual disabilities are dependent in many ways on the support of others if they are to have access to social life, services and support in society. In order to participate in various activities, they need intellectual and social support. This means that participation for them, depends in several ways on other people's willingness to facilitate and promote participation. This imposes high demands on those professionals providing formal support for them. Hence, the overall aim of this thesis was to explore and describe from four perspectives the experiences of everyday life and participation for people with intellectual disabilities. The thesis contains four qualitatively oriented studies, which have evolved over time. Studies I-II, including participant observations and interviews, and were conducted in group homes with staff and adults with intellectual disabilities. Furthermore, it emerged that adults with intellectual disabilities experienced different limitations in their everyday life, which indicates a lack of opportunity for participation (Study II). From the findings of these two studies, it became clear that participation is a central focus and that leadership is of particular significance for how participation is implemented; therefore, interviews were conducted with service managers (Study III). Lastly, within the framework of this thesis, the aim was directed at focus groups with significant others as the fourth perspective to provide a broad framing of what participation can mean for people with intellectual disabilities. Despite the fact that the disability policy has contributed to improvements for this target group, there are currently extensive shortcomings. This study has revealed deficiencies such as the lack of working methods to help staff facilitate participation (Study I); the lack of care worker' continuity and the existence of many routines and rules in the group homes (Study II); more overarchingly, the financial situation was not adequate to promote participation (Studies III and IV). Consequently, there were also strengths and opportunities for a good everyday

life and for participation. All four perspectives are important as, together, they contribute with a deeper understanding of what participation is and is not, in relation to people with ID. From the findings presented in this thesis, it can be said that participation is double-edged as the four studies highlight both the absence and presence of participation.

ABBREVIATIONS

APA	American Psychiatric Association
CRPD	Convention on the Rights of Persons with Disabilities
DSM	DSM-5, Diagnostic and Statistical Manual of Mental Disorders
HSL	The Health and Medical Services (SFS 1982:763)
ICD	ICD-10, International Statistical Classification of Diseases
ICF	The International Classification of Functioning, Disability and Health
ID	Intellectual Disability
LSS	Act Concerning Support and Service for Persons with Certain Functional Impairments; Swedish Code of Statutes, Swedish Parliament (SFS 1993:387)
WHO	World Health Organization

LIST OF PUBLICATIONS

This thesis is based on the findings from the following papers which are referred to in the text by Roman numbers. The papers have been reprinted with permission from the publishers.

- I. Berlin Hallrup L, Heikkilä, K, Bengtsson-Tops A. (2010) Care Worker's Experiences of Working in a Swedish Institutional Care Setting. *Learning Disability Practice*.7, 21-25.
- II. Berlin Hallrup L. (2012) The Meaning of the Lived Experiences of Adults with Intellectual Disabilities in a Swedish Institutional Care Setting: a Reflective Lifeworld Approach. *Journal of Clinical Nursing*. 23, 1583-1592.
- III. Berlin Hallrup L., Kumlien, C., Carlson E. (2018) Service Managers' Experiences of How the Participation of People with Intellectual Disabilities can be Promoted in Swedish Group Homes. *Journal of Applied Research in Intellectual Disabilities*. 32, 427-434.
- IV. Berlin Hallrup L., Kumlien C., Carlson E. (2019) Participation in Everyday Life for People with Intellectual Disabilities in Sweden. The Experiences of Significant Others'. *Manuscript submitted to the Journal of Applied Research in Intellectual Disabilities*.

INTRODUCTION

During my education as a nurse, I was quite unaware that I later would be providing support to, caring for, and ensuring adequate health-oriented services for people with intellectual disabilities. Not least, because this vulnerable group was scarcely mentioned in the syllabus. Nonetheless, as a nurse in the municipal health care services, I met not only people with intellectual disabilities, their families and, significant others, but also staff members and managers in group homes. Initially, my focus was very much related to my own approach, building a trusting relationship, which became a mutual connection between me and the individual with an intellectual disability. To meet and care for people with intellectual disabilities was sometimes difficult, and I had ultimately to rely on their experiences of their illness or disease, if they did not have a disability, and if cognitive aids were lacking. Consequently, staff members, relatives and their social networks became important sources of information for understanding and being able to promote the individual towards wellbeing and health. Complex situations arose regularly that necessitated coordination with other actors, such as specialist health care or emergency care. On many occasions I experienced that I lacked knowledge, and I constantly had to challenge myself and learn more in order to be a better nurse for people with intellectual disabilities. One way for me to learn more about their rights and opportunities to live a life like all other community citizens, was to undertake research. This meant, gathering subjective experiences from the experts, the people with intellectual disabilities, staff members, managers and significant others. For this thesis, my research journey started by exploring what everyday life meant for people with intellectual disabilities so that I could eventually study what participation could potentially mean.

BACKGROUND

Everyday life in Sweden for people with intellectual disabilities (ID) has radically changed since the 1960s. Then they were labelled “idiots”, and were more or less invisible, living in sheltered institutions and lacking civil rights. However, societal changes and the development of disability policies have contributed to facilitating that people with ID can participate in society in the same way as other citizens. Not least, through the opportunities to live in group homes, to have access to employment and to participate in everyday life.

Intellectual Disability - Definition and Classification

An intellectual disability involves a limitation of the intellectual functional ability that a person needs to interpret, understand and adapt in his or her environment (WHO 2019). In the Convention on the Rights of Persons with Disabilities, CRPD (United Nations, 2007), people with ID are defined as persons with long-term, physical, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others. From a medical perspective, this limitation is in most caused by a brain injury that occurs in the fetal stage, in connection with childbirth, or before the age of eighteen (Schalock *et al.*, 2010; Grunewald, 2012). Such acquired brain damage entails a limited ability to understand and handle sensory impressions, thereby limiting abstract thinking and communication (Schalock & Luckasson, 2015). It is also common that people with ID have comorbidities, such as epilepsy, mobility impairment, cerebral palsy, autism, visual or hearing loss or other diagnoses (aa 2015). Although problematic to determine accurately, it is estimated that about 1 % of the population in Sweden have an intellectual disability with this definition (The National Board of Health and Welfare, 2017).

Two diagnostic systems are in use, DSM-5, Diagnostic and Statistical Manual of Mental Disorders, published by the American Psychiatric Association, APA (American Psychiatric Association, 2019) and ICD-10, International Classification of Diseases and Related Health Problems 10th Revision ICD-10, published by the World Health Organization, version 2016 (WHO, 2019). Both systems provide statistical classification of diseases into groups with associated diagnostic codes. There are several differences between these two systems. For example, the concept of intellectual disability is used in DSM 5 where developmental disorder is used in the Swedish translation of ICD-10. There are also differences relating to the definition of autism groups/diagnosis of autism.

ICD-10 classifies four degrees of intellectual disability, profound, severe, moderate and mild, which relate to the Intelligence Quotient (IQ). See Table 1.

Table 1. The WHO definition of intellectual disabilities by IQ (WHO, 2019).

Degree of ID	Profound	Severe	Moderate	Mild
IQ	> 20	20 - 34	35 - 49	50 - 69

In contrast to the WHO and ICD-10 definitions, intellectual disabilities in Sweden are divided into three levels, mild, moderate and severe developmental disorders, which entail different degrees of impairment (The National Board of Health and Welfare, 2017). Although, all people are unique, and there can be a large variation in regard to each person's unique abilities and limitations within the different levels. The National Board of Health and Welfare (2017) has provided a simplification of the descriptions of mild, moderate and severe as follows:

- A person with mild intellectual disability can imagine things that are not self-perceived and can learn to read, write and count. Thus, the person may have difficulty understanding abstract concepts and things that he or she cannot experience in concrete terms. For example, he or she may have difficulty understanding symbols for things, such as, for example, that a credit card corresponds to money as a means of payment.
- People who have a moderate disability may be able to read single, simple words and to write their own name. They can understand spoken language to a great extent and often they can communicate through speech, but they mainly understand things that they themselves experience.

- People with severe disability may not understand spoken language very well and can have difficulties speaking, instead they often communicate using body language and gestures. This person can learn to associate words with certain actions and situations.

The framework of the first three studies in this thesis includes, adult persons with mild and moderate levels of ID. Whereas the last study deals with descriptions by significant others' as to what participation means based on people with ID; this, gives a wider scope not defined by ID and age.

Models to define disability

Various models have been proposed to explain intellectual disability. Three models are usually used to describe how disability can be understood and constructed; the medical, the social and the relative model.

The medical model implies that people with ID have shortcomings which can be cured or remedied (Pfeiffer, 2002; Grönvik, 2007). The medical model views disability as an attribute of the individual, one that requires medical care (Renblad, 2003). In the medical model, appropriate treatments target the individual with a disability rather than targeting changes to the environment (Pfeiffer, 2002). The social model, emphasizes social and environmental conditions, rather than an individual's intellectual capacity, to explain negative outcomes (Mc Hugh, 2016). Intellectual disability is thereby constructed by social interactions between individuals (Kjellberg, 2002; Hammel *et al.* 2008; Hedlund, 2009). Disability is not solely an attribute of an individual, rather it is a complex combination of various conditions in the environment (Renblad, 2003; Kåhlin 2015). Notably, Hedlund (2009) points out that both the medical and social models have been criticized for associating limitations exclusively to either the individual's diagnosis or to the environment. Lastly, the relative model strives to combine the influence of the individual and the social environment, highlighting the influence of both individual characteristics and structural barriers in society, such as marginalization, stigmatization, and discrimination (Tideman, 2015). The relative model can be seen as congruent with the classification by WHO (2001), The International Classification of Functioning, Disability and Health (ICF). The ICF model is a conceptual framework, with a holistic and biopsychosocial view of disability, including functions, activities and participation. Within the framework of this ICF classification, the concept of participation is defined as "a person's involvement in a life situation" (WHO, 2001). In this thesis, according to WHO, participation can be understood that it is about people with ID and their involvement in a life situation.

People with Intellectual Disabilities – Historical Changes

People with ID have been treated differently in different eras, and how they have been labelled has also varied greatly. For example, idiot, feeble-minded and psychologically retarded are just some terms used in Sweden during the 20th century. Feeble-minded was the official term until 1955, and was replaced by psychologically retarded in 1968 (Grunewald, 2012); since 2007 the term “people with intellectual disabilities” has been used (The National Board of Health and Welfare, 2007). People with ID is now the common terminology that is used in disability research, disability policies and by the people who have disabilities (Bigby, Frawley, Ramcharan 2014; Kåhlin, 2015; Bigby & Beadle-Brown, 2016). Currently, there is an ongoing debate in Sweden on using the term “function variations” instead of people with ID. However, because The National Board of Health and Welfare since 2007 has used the term “people with intellectual disabilities” since 2007, and “intellectual disability” is the term used internationally, this thesis also uses “people with intellectual disabilities” (Bigby & Beadle-Brown, 2016). How, and in what way people with ID are termed should also have significance for their self-esteem, identity and the opportunity to participate in society.

Institutionalization

The arena in which everyday life for people with ID has been played out, has radically changed since the 1960s. Today’s disability policy is based on a struggle against exclusion and a quest for human and civil rights for people with ID (United Nations, 2007). This struggle arose because of a challenge to the beliefs and attitudes that had dominated care, support and services for people with ID until the 1960s. These had meant that during the first half of the 20th century, people with ID were not regarded as community citizens, but as “children” who needed education and training. This era was also dominated by a view that society should be protected from people with ID by institutionalization and sterilization, concepts which were motivated by racial biology ideas (Qvarsell 1991; Grunewald, 2012).

From a historical perspective, people with ID have for most of the 20th century been more or less confined to institutional care, and concomitantly, have been excluded from participation in society (Walmsley, 2006, Grunewald 2012). This approach was characterized by the idea that people with ID should be adapted to society and not vice versa. The institutions that existed until the 1960s varied greatly; adults with ID lived and worked in institutions together with others who had other disabilities (Grunewald 2012).

Deinstitutionalization and the principle of normalization

Of great importance for people with ID was the principle of normalization. This, is considered to be a paradigm shift both nationally and internationally for people with ID who were subjected to institutionalization (Nirje 1969; Wolfensberger, 1972). As a result of the deinstitutionalization in the 1960s, people with ID were to be integrated into society. Inclusion and participation now became a key goal within the disability policy. The principle meant that all people with ID would be given the opportunity to live as other people in society. Normalization meant that the approach to the “functional disability” changed as the medical model of disability was given a different definition. Disability was no longer linked to an individual deficit, instead disability was described in relation to deficiencies and barriers in the environment (Nirje, 1969; Wolfensberger 1972). One can assume, that as it is now several decades since the principle of normalization was set out in disability policies, inclusion and participation should be well known by today’s policymakers as well as other professionals.

The history of participation ideology in Sweden

Participation ideology emerged as part of a political effort during the 1990s on disability issues in Sweden. As part of this initiative, the National Action Plan, (Proposition 1999/2000:79), “From Patient to Citizen” was a significant contribution to the disability policy. It is a fundamental and important document describing the view of equality that people with ID should not be seen as objects needing support and care, but as citizens with equal rights and equal opportunities. The concept of participation is central to the National Action Plan (aa), which stipulates that people with ID of all ages should have full participation in society. Furthermore, it emphasizes that disability policy work should focus on identifying and removing obstacles to full participation in society for people with ID. Therefore, the disability perspective has been prioritized and should permeate all sectors of society, such as housing, education, health care, social policy etc, and these sectors should be designed so that unnecessary gaps between individuals can be bridged creating instead a society in which everyone can participate.

Moreover, The Convention on the Rights of Persons with Disabilities, CRPD (2007) states that people with ID must have the same rights as everyone in society, and that societies should facilitate their full participation in society. Sweden was one of the first countries to implement the CRPD in 2009, while some countries have not yet implemented it. Overall, this illustrates how changes in disability policy in recent decades have resulted in significant changes for people with ID

and their opportunity to live an everyday life similar to other people. However, the key goal of the disability policy is participation for people with ID (United Nations, 2007; The Swedish Agency for Participation, 2015). This means that their everyday life in society, whether in relation to accommodation, employment, need for health care or education, should empower participation.

Community Service and Organization

Municipalities' responsibilities

People with ID have differing needs for support. Social service for people with ID in Sweden is funded by taxes and regulated by the LSS Act (SFS 1993:387). Sweden has 290 politically driven and self-governing municipalities that are responsible for providing support in accordance with the Act. The Act describes which persons are covered by the law.

People with ID are categorised into three groups based on a number of assessment criteria. People can apply for support if they meet some of the criteria.

1. Developmental disorder, autism or autism-like condition.
2. Significant and permanent mental disability following a brain injury in adulthood caused by external violence or bodily disease.
3. Other major, lasting physical or mental disabilities that are not the result of normal aging and which cause great difficulty in coping with daily life such as dressing, cooking, moving or communicating with the environment.

Inclusion of people with ID who meet the above criteria have the right to good living conditions, to be supported in their everyday life and to have participatory involvement how the support is provided. A person with ID continues to develop throughout their whole life, therefore the care and social support given must be monitored regularly (The National Board of Health and Welfare, 2017).

In total, there are 10 different services stipulated by the Act. Common support for people with ID who are covered by the Act include, some of them follow below:

- Daily activity centre with activities which should offer the individual stimuli, development, meaningfulness and community according to the person's wishes. The daily activity can include activities with habilitating focus and more production-oriented tasks.

- Group home care in fully-fledged home with common areas where support, service and care can be provided around the clock.
- Companion service meaning that a companion facilitates the participation of people with ID in a social life. The intervention should have the character of personal service and be adapted to the individual needs.
- A contact person who can help with social contact, participate in leisure activities and give advice and support in everyday life.

Anyway, the most common support for people with ID are daily activity centre and group homes (The National Board of Health and Welfare, 2017). According to the National Board of Health and Welfare (2019), the number of adults with various disabilities who need support or service in accordance with the Act has increased from 2007 to 2019. Group homes for adults with ID have increased from about 21, 600 to 27, 800 and daily activities from about 27, 000 to 37, 500. Group homes in Sweden are regulated to a maximum of six residents in each group home (The National Board of Health and Welfare, 2018). As the responsibility for providing support is decentralized to the municipalities, there may be some differences between them.

Service managers are directly responsible for implementing the intentions of the legislation on participation and for ensuring that it is followed by all staff employed in group homes (The National Board of Health and Welfare, 2017). Moreover, the Act stipulates that participation is the key ambition and states that service managers in group homes should work closely with the staff in order to better support and guide them in daily work. Service manager leadership in Sweden can thus be described as corresponding to that described by Deveau & McGill (2016) as frontline managers, which means coaching, counselling and supporting staff members in daily service delivery. Section 5 of the LSS Act, state that services shall promote equality in living conditions and full participation in society. This imposes high demands on those professionals providing formal support to increase opportunities for people with ID to participate in everyday life.

The framework of the first study of this thesis includes staff members and how they provide support and service to adult persons with mild and moderate levels of ID in group homes. The third study include service managers who are directly responsible for implementing the intentions of the legislation on participation and for ensuring that it is followed by all staff members employed in group homes.

Participation

Participation as a concept is multifaceted, and can be viewed as multidimensional because it can be described in different ways depending on the context. According to the Swedish National Encyclopaedia, participation is defined as “active participation”, meaning that a person takes part in, and participates in a specific situation. Participation can also be lexically defined as “the active involvement of members of a community or organization in decisions that affect their lives and work” (Simpson & Weiner, 1989, p.268).

The WHO (2001) defines participation as a person’s involvement in a life situation in accordance with ICF. According to, the ICF, participation is categorized into domains such as: learning and applying knowledge; communication; domestic life; interpersonal interactions and relationships; life areas such as work, school and community, social, and civic life. Other definitions of participation in the health care and disability context include service user participation, service user influence and patient participation which emphasise that decisions are made in consultation with the service user or patient (The National Board of Health and Welfare, 2018). Thus, participation is a fundamental aspect of health and social care, and is included in the Health and Medical Services Act care (HSL 1982:763) and the Act Concerning Support and Service for Persons with Certain Functional Impairments (LSS 1993:387). These laws form the foundation and describe how participation should be guaranteed in a care or social context. In a healthcare context, participation means the patient is involved in various types of decision-making, for example by, having access to information about their treatment (Cahill, 1996; Eldh, 2006). For people with ID, participation is also about being involved in various types of decision-making, having information and being involved in everyday life and “living in the same way as other people” in society (The LSS Act).

Previous research on participation

Molin (2004) defines what participation means for young people with ID through a conceptual analysis of the ICF definition. Which involves an interaction between an individual and his or her social and physical environment. According to Molin (aa), participation can be described by internal and external conditions for participation. Internal conditions relate to the individual’s interest in, will, and ability to be involved (*capacity*). Internal conditions are thus to some extent necessary but not a sufficient condition for participation. However, individual conditions also require accessibility in the physical and social sense, including the

provision of opportunities for participation (*opportunities*). These opportunities may include rules, procedures and standards that enable participation. Molin (aa) notes that the definition of participation is complex and that participation appear to have different meanings for different constellations of people with ID depending on the contexts.

Another study, by Verdonshot *et al.* (2009, p.304), drawing on the ICF, defined participation for people with ID as “the performance of people in actual activities in social life domains through interaction with others in the context in which they live”. Tideman (2015) states that the ICF has played a major role in defining the Swedish participation ideology, but that this definition is not sufficient to achieve a more complete understanding of the concept participation. This is mainly because the ICF does not take into account the subjective experience of what participation is or is not (aa).

Hammel *et al.* (2008) state that participation is a subjective experience for adults with ID. Furthermore, (aa) describes participation as inclusion in an active and meaningful commitment, both on a personal level and in society. Thus, participation can be achieved by providing opportunity to influence, support and interact with other individuals in society, and opportunity to be able to choose and control. Further, Craig & Bigby (2015) defines participation as *active participation*, when people with ID are present in community groups and have equal membership status with other members without ID.

Overall, there are different interpretations of the meaning of participation. The way in which a person is involved can be different, ranging from the fact that the person makes the decision about a treatment in health care or social care support, and that the professional makes the decision about the treatment or support after negotiation and discussion with the person. Anyone who is dependent on health care treatment, social support has the right to be well informed and have a real influence over the process (Sandman & Munthe, 2009).

In Sweden, the majority of studies and evaluations that have been carried out on participation concern patients in the health care (The National Board of Health and Welfare 2014). In addition, the term participation is frequently used in caring. In caring practice, patient participation is described as involvement in decision-making and collaboration (Cahill, 1998), and as sharing information based on the experiences of the patients-as-partners (Eldh, Ekman & Ehnfors 2010). Sahlsten,

Larsson, Sjöström & Plos (2008) describe patient participation to be characterized by four elements. First, there must be an established relationship based on trust, respect and positive emotions between the health care professional and the patient. Second, the professional assigns some power or control to the patient. Such participation is supported by the fact that health care professionals facilitate patients taking responsibility for certain activities in their care. The third element concerns the sharing of information in the relationship. This, means that the professionals should collect information about the patient's needs and preferences, in order to adjust the information for the patient. The fourth element concerns a mutual commitment in the relationship, which is expressed in conversations or activities that they do together. In addition to these four elements, patient participation, is also affected by the patient's own strength, health and abilities. With this emphasis, Sahlsten *et al.* (2008) describe participation as a balance of power between two different actors, the nurse and the patient. Furthermore, within caring science there is a holistic view of the concept of patient participation, and thus includes and embraces the voices of the patients (Sahlsten *et al.* 2008; Eldh *et al.* 2010; Ringdal, Chaboyer, Ulin, Bucknall & Oxelmark (2017). An interesting aspect highlighted by Eldh (2006) is that early research from the beginning of the 1990s (Cahill, 1996, 1998) on patient participation was based on what nurses experienced as patient participation, i.e. the voices of patients were not heard. Eldh (aa) has instead included the patients' experiences in studies on what patient participation is and is not. One can assume that the definitions of patient participation and non-patient participation may be transposed from the health care context to the disability context to enable a broader understanding of the concept. All in all, in nursing, participation is considered to be relational taking place in the care between the patient and health professionals. At the same time as Eldh (aa) highlights and emphasizes that it is necessary for participation to be included in governing documents that cover the entire care process.

The disability policy, highlights broad opportunities to create and promote participation for the target group. Participation is the cornerstone in Swedish disability policies, and must be present at all stages: both for the individual in their daily life; when living in a group home; and to enable full participation in social life. Against the background that I have chosen to highlight what participation is and is not from the viewpoint of the health care sector, it shows that the concept relates to all potential patients, also people with ID. The fact that participation is central to health and medical care bodes well and is an opportunity for this target group to be involved and participate in their own care. In theory, there are many different approaches to the concept of participation.

Challenges for participation

People with ID are, dependent in many ways on the support of others if they are to have access to social life, services and support in society. In order to participate in various activities, they need intellectual and social support. This means that participation for people with ID, depends in several ways on other people's willingness to facilitate and promote participation (Clement & Bigby, 2009; Johnson, Douglas, Bigby & Iacono, 2012; Craig & Bigby, 2015). Participation for people with ID cannot be taken for granted as for most other people in society. Despite the disability policies, it has been shown that barriers to participation in everyday life still exist for people with ID. Such barriers may exist due to the approach and attitudes of professionals (Bigby, Knox, Beadle-Brown, Clement & Mansell, 2012; Deveau & McGill 2014) as well as to the delivery of support and care by staff members in group homes (Bigby, Frawley, & Ramcharan, 2014; Mansell & Beadle-Brown, 2012; Deveau & McGill, 2016).

Further aspects that can constitute limitations for participation are the staff values and existing cultures in group homes (Bigby *et al.* 2012; Bigby & Beadle-Brown, 2016). There may also be structural barriers related to how top management and the organization support the service managers, who are directly responsible in group homes, and who work with the staff in group homes (Beadle-Brown *et al.* 2014; Bigby & Beadle-Brown, 2016; Deveau & McGill, 2016). This may relate to the fact that participation is a central concept at an overarching disability level, but how it is put into practice at a local level is dependent on the approach of professionals or organizations. A recent study has also shown that before participation can be created, a trustful relationship must be established between the professionals and people with ID (Collings, Dew & Dowse, 2018). Thus, professional providers of support can face a challenge in enabling participation.

Taken together, it can be concluded that the definitions of participation are complex, and that participation is dependent on the social and physical context, i.e. what internal and external conditions are offered to people with ID (compare Molin 2004). Against this background, which highlights the importance of taking into account subjective experiences of what participation is (compare with Eldh 2006; Eldh *et al.* 2010; Hammel *et al.* 2008; Tideman 2015), it is important to find out what and how participation is described from various perspectives.

AIM

The overall aim of this thesis was to explore and describe from four perspectives the experiences of everyday life and participation for people with intellectual disabilities (ID).

Specific aims

- I) The aim was to describe the meaning of care workers everyday work with adults with intellectual disabilities in a Swedish institutional care setting.
- II) The aim was to describe the meaning of the lived experiences of adults with intellectual disabilities in a Swedish institutional care setting.
- III) The aim was to explore service managers' experiences of how participation of adults with intellectual disabilities can be promoted in Swedish group homes.
- IV) The aim was to explore significant others' experiences of participation in everyday life for people with intellectual disabilities.

METHOD

Methodology

The studies in this thesis have a qualitative and inductive design with the aim to explore experiences of everyday life and participation for people with ID. The thesis contains four qualitatively oriented studies. Studies I-IV, which have evolved over time. Initially, participant observations and interviews were conducted in group homes, and including staff members and adults with ID (Studies I and II). Furthermore, it emerged that adults with ID experienced different limitations in their everyday life, which indicates a lack of opportunity for participation (Study II). From the findings of these two studies, it became clear that participation is a central focus and that leadership is of particular significance for how participation is implemented; therefore, interviews were conducted with service managers (Study III). Finally, within the framework of this thesis, the aim was directed at focus groups with significant others as the fourth perspective to provide a broad framing of what participation can mean for people with ID (see Table 2).

Setting

All field work, including participant observations and interviews, was carried out in group homes owned by a private company (Studies I+II). The mission for the private company was to provide support, service and care for adults with ID over the age of 20, in accordance with the LSS Act. A total of 249 employees worked either part-time or full-time at the setting, and 77 adults with ID, lived in group homes for one to four persons. The adults with ID were classified as having mild to moderate intellectual disabilities and some had additional diagnoses. The about 20 group homes were scattered in clusters within the same geographical area. In addition to accommodation, there were facilities for daily activity centre and socialisation opportunities for adults with ID. Having several group homes in the same geographical area as daily activity centres differs from how group homes are organized in the municipalities.

Table 2. Inclusion criteria for the included studies, empirical materials and method of analysis.

Study	Inclusion criteria	Data collection	Analysis
I	Staff members were selected by age, gender, length of employment, form of employment and work tasks.	Participant observations and interviews, with staff members (n=18). September 2006 to December 2007	Thematic analysis (Taylor & Bogdan, 1998)
II	Informants with ID were selected by age, gender and how long they had been residents in the setting.	Participant observations and interviews with adults with ID (n=12). September 2006 to June 2009	Phenomenological reflective life-world analysis (Dahlberg, Drew & Nyström (2008).
III	Service managers directly responsible for managing and supporting staff in group homes for adults with ID.	Interviews with service managers (n=14). August 2016 to November 2016	Thematic analysis (Braun & Clarke, 2006)
IV	Informants from interest groups, with personal experience of being a significant other to a person with ID.	Five focus group interviews with significant others	Thematic analysis (Braun & Clarke, 2006)

The setting in Study III included service managers of group homes for adults older than 20, with ID who were classified as having moderate intellectual disabilities. The service managers were all responsible for at least one group home with a maximum of six residents and some were responsible for up to five group homes, which meant approximately six to 35 residents and 20 to 60 part-time and permanent employees. While for some group homes the residents were more or less independent, those included in the present study are staffed on a 24 hour basis. The setting for Study IV included informants from various interest groups in the field of disability.

Sample

Studies I and II

The field work studies started by an invitation from the private company, in order to describe staff and adults with ID experiences about their work and everyday life in the setting. Thus, this invitation allowed access to a site with potentially informants who had both knowledge and experiences.

In order to obtain a strategic sample, (Study I) informants were selected by age, gender, length of employment, form of employment and work tasks (Patton, 2002).

One inclusion criterion was that informants who were selected for interviews also participated in observations. Informants with part-time employment were excluded from participation interviews. Of the staff, 47 participated in participant observations, of these 31 were women and 16 men. They were aged between 20 and 64 and had an average of about 35 years' work experience. Experience in the group home setting varied from one to 28 years. Of those a strategic sample were performed, which resulted in interviewed (12 women and six men), all were full-time employees and had occupational experience of between four and 28 years working with adults with ID. Informants with ID (Study II) were selected by age, gender and how long they had been residents in the setting. Of the residents, 55 (37 men and 18 woman) were included in the participant observations. Informants were aged between 20 and 67 and had an average age of about 36 years; they had lived in the setting for one to 56 years. A total of 12 residents (seven men and five woman) who had participated in various observations were also interviewed. The inclusion criterion for the 12 participants was that they had been present at different observations. Residents were excluded from participating in the study if, in addition to intellectual disability, they had a psychiatric diagnosis, poor general health or lacked verbal skills.

Study III

During the planning for interviews with service managers, strategic sampling was performed (Patton, 2002). Strategic sampling was employed to select 20 different municipalities representing large cities, small towns and rural areas. One service manager in each municipality was contacted by e-mail with information about the study and that one criterion for participation was at least one year's experience as a service manager of a group home for adults with ID. They were also informed that participation was voluntary and were requested to reply to the e-mail within two months. Six informants declined participation, three due to lack of time while three gave no reason. Thus, 14 informants (13 women and one man) agreed to participate. Their work experience ranged from four to 35 years.

Study IV

Initially, in order to get in contact with potential informants, a convenience sampling was employed to select informants from various Swedish interest

groups in the disability area. The inclusion criterion for this study was informants from interest groups, with a personal experience of being a significant other to a person with ID. In this study, significant other is defined as a friend, relative or legal representative who in some way is important and provide support for a person with ID (Mead, 1976). A letter containing information about the study was sent by e-mail to 10 interest groups in the disability area. After receiving the study information, five contacted the researcher by e-mail and invited the researcher to a pre-meeting with members of the association to allow questions and to provide a forum for information about the study. After that first meeting, the five associations contacted the researcher and suggested a location, time and date to conduct the focus group interviews. In total, 34 informants of whom 24 were female and 10 male, agreed to participate. Of those who participated, 18 were parents, six were legal representatives, five were friends and five were other relatives (three siblings, one cousin and one grandmother).

Data Collection

Data collection involved a variety of methods such as participant observations, (Studies I + II), in-depth interviews (Studies I + II + III), and focus groups (Study IV).

Participant observations

Fieldwork for Studies I and II, including participant observations with staff members and adults with ID, was carried out from September 2006 to June 2009 December. Initially, short visits were made to the setting to make contact with the informants and to explore the available activities, resources and facilities. One way to make contact with informants was by getting to know gate-keepers (Atkinson, Coffey, Delamont, Lofland & Lofland 2001/2010); these were key persons with lengthy experience of the setting and thus well socialised. Gate-keepers could therefore assist with access to other individuals and places in the setting. The observations were conducted one or two days a week. The aim during the first ten months of observations, was to acquire an overall picture by observing many different places and situations. The observation sessions took place at various times and on different days and lasted approximately five hours each time. Field notes including participant observations, informal interviews and memos were transcribed immediately after each observation. The notes provided a framework for future observations, which focused more on specific aspects to clarify any elements.

Interviews

To give informants further opportunities to reflect on their work, 18 individual in-depth interviews were conducted with staff members (Study I), 12 with adults with ID (Study II). For study III, individual interviews were held with 14 service managers. Individual interviews were used to gain an understanding of informants subjective experiences and a deeper understanding of the studied phenomenon. Individual interviewing is an approach in which the informant and the interviewer interact, and co-construct knowledge based on their experiences (Lincoln, Lynham & Guba, 2018). This implies that the interviewer participated in the interview process with the subjects in producing knowledge that reflect the informants reality (Lincoln, Lynham & Guba, 2018).

Focus group interviews

Five focus group interviews (Study IV) were conducted from March 2017 to January 2018 and consisted of six to 11 informants per/group and in total In total, 34 informants. Each focus group session was conducted in a secluded room and digitally recorded. Focus group interviews were conducted to gain an understanding of significant others' experiences of participation in everyday life for people with ID. Focus groups are suitable as they enable individuals to interact, discuss and share experiences about a common theme (Kitzinger, 1994). In this study, focus group interviews allowed significant others', to discuss, interact and share common beliefs about what participation in everyday life is for people with ID in a relaxed setting with other informants.

Data analysis

The analysis in Study I, was based on the thematic analysis procedures presented by Taylor and Bogdan (1998). Thematic analysis was found suitable for inductive analysis of themes from data, and was an ongoing process as data collection and analysis went hand in hand as the study progressed. All field notes and interviews were transcribed into text and then analysed independently by members of the research team. The analysis used in Study II was based on the phenomenological reflective lifeworld approach as described by Dahlberg *et al.* (2008). The analysis aimed to describe the essence of the phenomenon "adults with intellectual disabilities lived experience in an institutional care setting". Such analysis is a fluid flexible movement between whole-parts-whole. Importantly, each part is understood in terms of the whole and vice versa. Sensitivity to this subtle and pervasive relationship reveals the inherent ambiguities of the phenomena. In addition to the aim of illustrating essential meanings, the analysis emphasises

various everyday life experiences in relation to the aim, revealing unique meanings embedded in the descriptions of these experiences.

For Studies III and IV, analysis was performed in accordance with thematic analysis by Braun and Clarke (2006). Thematic analysis is a progressive and iterative process rather than linear (Braun & Clarke, 2006), and is useful when collecting and describing subjective perceptions in qualitative studies. Data were analysed inductively to elucidate the naturally arising themes in the data itself, comprising the informants experiences. Initially, the interview texts were transcribed, then the empirical material was independently read several times. Next, each researcher identified and generated descriptive codes that grouped data based on similar experiences and topics. The next stage of analysis included all authors, coding and sorting the transcripts in order to organize them into patterns that highlighted meaningful sub-themes. Further, the analysis continued by identifying important themes and collating all data extracts that had been coded. Once completed, the analysis provided repeated opportunities to cross-check raw data against emergent themes, thus ensuring credibility and trustworthiness.

ETHICAL CONSIDERATIONS

All four studies adhere to the principles outlined in the Helsinki Declaration (1964) and were approved by The Swedish Regional Ethical Review Board in Linköping (Reg. No.208-06, Studies I and II) and Lund, Sweden (Reg. No. 2016-712 , Studies III and IV). Ethical considerations are of particular importance in regard to research involving vulnerable groups (Barron 2001; Swedish Research Council, 2017). To observe and interview people with ID as well as staff who deliver their care and support requires reflection based on the research ethical principles of justice, autonomy and doing good (Helsinki Declaration 1964; Brodin & Renblad 2000; Barron 2001). From a justice perspective, it was important to make their voices heard, particularly people with ID, who are a vulnerable group in society. Particular attention was paid to autonomy, and the fact that participating in the research should be voluntary and that the informants should not be identified. Another aspect, ensuring ethical research and minimizing the risk of discomfort associated with participating in observations and interviews, was that all the studies were conducted by a nurse who had worked for many years in municipality and private home care. Thus, my occupation as a nurse mean that I had knowledge and experience of how to interact and communicate with people with ID.

Initially, all informants were informed of the purpose of the Studies (I-IV) at pre-meetings, so that they could discuss and ask questions, and establish a trustful relationship with the researcher. For Studies I-III, consent was initially obtained from the top management for the group homes because I would be visiting the informants home or workplace and with regard to the volunteer participation. Relatives and legal representatives were also informed of the study. In Study IV, consent was obtained directly in connection with the data collection after the first pre-meeting. Prospective informants in all studies received written and oral information regarding voluntary participation, consent, information,

confidentiality about how the empirical material would be used. For informants with intellectual disabilities (Study II), the written and oral information was adjusted to their cognitive ability. Only informants with ID who could give their consent and voluntarily participate in the data collection were included in the studies. Consent and volunteering were particularly important to consider for informants with ID, and prior to various participant observation occasions with follow-up short conversations and to the individual interviews. Written and oral information were repeated, and continuous consent was obtained from informants with ID. Respecting personal integrity, I chose not to participate in situations that I considered to be sensitive, such as personal hygiene, showering and bathing. I was also aware of reactions by the staff (Studies I and II) that indicated that my presence cause unease. In those instances, I left. However, I have not been aware that participation in the studies gave any negative reactions, not for staff or informants with ID in the group homes (Studies I and II), or for service managers and significant others (Studies III and IV). There was no dependency relationship between the researcher and the informants in any of the studies.

Findings

Study I

Three main themes emerge from the thematic analysis: staff members were engaged in creating a family-like atmosphere; they were engaged in making the everyday ordered and structured; and they were also exposed to stress factors.

Creating a family-like atmosphere meant that informants (staff members) regarded the institutional care setting as a home for the residents and therefore endeavoured to create a family-like atmosphere. Informants described that many of the residents had not experienced what it is like to be part of a family so they wanted to create an atmosphere that would provide them with the sense of security found in families. The informants felt connected to the residents as though they were all members of the same family. Sometimes the boundaries between the informant's private life and work were removed. For example, in their spare time, informants invited residents to their own homes to meet their family or to go shopping. Indeed, some of the informants thought of the workplace as their home, too. One informant said: "I have a home, not a job. I live here during my working, day or evening, or on the weekend. When I am here, my job becomes my home. This home has become like a family to me; we are all one family, both staff and those who live here. We are together all the time and even though it is their home, that feeling is erased when we are together."

Making the everyday ordered and structured meant that informants planned and scheduled each day. By scheduling the days, routines developed: for example, routines for morning assembly, daily work, smoking, leisure time and socialisation were organized to a timetable. Setting the routines helped to make the days more predictable and functioned as positive and negative reinforcements for the residents; for example, exclusion from the day activity centre or weekend trips if residents did not behave as expected. Therefore, routines are tools for gaining stabilisation, prediction and for motivating good behaviour. The following excerpt from an interview with an informant illustrates this. “Anna used to wet herself in order to avoid work. She did this because she enjoyed going home to shower and change clothes during working hours. When we realised this we made her sit the whole day on the chair that she had urinated on, not allowing her to leave. This made her stop.” Supervising the residents was a feature of the everyday work, and the order and structure helped staff to be alert to situations that arose, such as conflicts among the residents, aggressive behaviour and escape attempts, and enabled them to tackle them promptly. “We have to check what they are doing at all times. We can’t go on a break together; we have to go separately as one of us has to be inside, watching them.” Structuring and given order to everyday meant limiting the residents’ freedom, since certain rules had to be set, such as locking refrigerators to prevent obsessive behaviour with regard to eating. Some rules were written down as agreements between staff and residents.

Exposure to stress factors in the course of their work included verbal and physical abuse by residents, which sometimes resulted in injury requiring medical treatment and sick leave. The informants found the violence difficult to cope with. “It really isn’t any fun getting beaten up at work. It occurs occasionally, I don’t know how many times I’ve been hit at work”. Witnessing incidents could lead to feelings of guilt because they had not managed to prevent them. “A resident hit her (staff member) many times...I feel guilty every time she hits somebody, I feel like I should be able to stop it”. Sometimes informants verbally abused each other, for example, when they thought a colleague had acted incorrectly in a volatile situation. Newly employed staff were often accused of causing aggressive behaviour in residents. The working conditions were also stressful. At the time of this study, the number of residents increased from 67 to 77 at the institution, which further amplified the stressful working conditions.

Study II

The essential picture of the phenomenon was experienced “as a meaningful and meaningless existence” and was reflected in informants’ (adults with ID) descriptions of their everyday life in the setting. A meaningful and meaningless existence revealed itself as an ambivalent dependency, implying that informants accepted their dependency in relation to their disability, at the same time, their dependency meant that they had no other choices than being reliant on the care workers. A meaningful and meaningless existence in everyday life involved social interactions with other residents and staff, which on the one hand gave meaning in having a social network and on the other feelings of insecurity. The overall everyday life in the setting was described as a meaningless experience as it meant living in a reduced “life space”. The feeling of living a restricted life overshadowing the whole of their existence made it, on occasion, hard to endure. The essence of their experience can be described by the three following constituents: ambivalent dependency; social interactions and everyday life in a restricted area.

An ambivalent dependency meant being dependent on staff and the restricted environment. On the one hand, dependency showed itself as something vital as it was related to the informant’s perception of their own disability. Informants perceived their situations as needing a great deal of help from staff to manage their everyday lives. The need of staff was experienced by the informants with ID as meaningful because it directly related to their own life situation, giving them a feeling of acceptance. On the other hand, informants were forced to conform to this everyday life, having no other choices. Informants said that they had not chosen to be dependent on support and care, in the first place. They thought that life in their situation was simply that way based on an understanding that their relocation was related to having no one else to care for them at their original home. Further, the informants pointed out that their stay was only temporary as they had no idea how long they were to stay in the group home.

Another aspect of their ambivalent dependency was characterised by having trust in staff. For example, knowing that staff were available in their immediate vicinity 24 hours a day gave them feelings of safety. At the same time, they experienced feelings of vulnerability, insecurity and loneliness in not knowing whether or not staff would come or who would take care of them. In addition, ambivalent dependency was strengthened by how informants were treated and met by staff. Staff members who listened and had the ability to respond to them with respect gave them a feeling of being valued and understood on their own terms, thus creating a meaningful encounter.

A meaningful and meaningless existence in everyday life involved socialising with other residents and staff, social interaction was meaningful in the sense that it created an opportunity for informants to establish social contact, yet at the same time meaningless as feelings of insecurity could arise in meeting other people. Social wellbeing, that is, feeling secure in a social environment, increased when informants felt a bond between themselves and a certain staff member. This connection created a sense of having special access to a particular care worker and a feeling of commitment towards that person emerged. Concomitantly, because that staff gave them permanent feelings of security, it was the same staff member who could unexpectedly give rise to a sense of loss. Social interaction gave a sense of meaninglessness in relation to the staff lack of continuity. The informants experienced a sense of vulnerability when supported by staff who were strangers to them and who did not know how to meet their individual needs. Occasionally, social relationships between informants with ID led to friendships and even love affairs and engagements. Over time, a solidarity developed between the residents, meaning that they protected and helped each other.

Everyday life in the setting was described by informants as living everyday life in a restricted area. It involved a reduced “life space” and emerged around routines and rules. Daily life in a restricted area included following various rules. For example, the ‘house rule’, which meant that the residents were forced to adapt to certain restrictions such as those in communal areas that required that refrigerators and closets were kept locked. Another “house rule” stipulated that that residents were to follow specific meal orders, shower times and various rules of conduct. One rule of conduct was seclusion and meant that residents had to go to their rooms immediately after returning home from daily occupation. The staff decided when residents were allowed to leave their rooms.

Study III

The informants’ (service managers) experiences of how participation can be promoted in group homes for adults with ID consisted of two main themes; “Creating preconditions for participation” and “Barriers to promoting participation”. In the Findings section, the term service user will be used as a synonym for adults with ID.

Creating preconditions for participation was described by informants as always putting the service users first, and they applied various organizational structures and approaches to encourage staff to support and work in a way that increased service user participation. In order to find ways of creating preconditions for

participation they created structures to facilitate a trusting relationship between staff and service users by ensuring that staff had certain responsibilities and enough time to get to know the service users. To further fulfil the participation ideology, the informants provided supervision, used a reflective approach in day-to-day work with staff, and applied structural strategies such as the participation model.

Facilitating participation meant that the informants assumed that staff initially needed to develop a trusting relationship with each service user. According to the informants, trust was crucial for the service users' feelings of confidence. They believed that a trusting relationship was necessary and something that service users could benefit from when developing their own individual strategies for participating in everyday life. The informants explained that staff were given a certain responsibility in the group home, which meant that one staff member was a so-called "contact person" for a new resident. The contact-person had the responsibility for gaining a deeper understanding of the individual's needs and formulating a personalised "implementation plan". This gave the service user an opportunity to be involved in how service and support were to be provided by staff and what such service and support should entail. The informants expressed that facilitating a trusting relationship was an ongoing process that was constantly developing as they tested new strategies and ways of working.

The informants needed to support the staff in their everyday work by means of various strategies in order to successfully create preconditions for service user participation. One of the strategies was to be consistent present in the group homes and immediately assist staff members in organizing their daily work as a means of increasing the focus on participation. Another important strategy for supporting staff in their efforts to increase participation was supervision. The informants sometimes provided one-to-one and group supervision themselves or in collaboration with professional supervisors.

Although the informants described opportunities for participation, they also expressed that from time to time they experienced barriers that prevented them from promoting increased participation. The barriers led to a tension between trying to enable participation in accordance with disability legislation and adapting to existing conditions and restrictions that limited their opportunity to do so. They described that there are still restrictions that hinder participation such as the attitudes of staff or next of kin, or a lack of physical space in the group home. Informants also stated that they felt that they lacked necessary support from top management, due to financial or political decisions.

Study IV

“Double-edged participation” emerged as the maintheme from the analysis and was interpreted from two sub-themes, which were based on the informants (significant others) experiences: *opportunities to achieve empowerment* and *fighting against marginalization*. The maintheme attempts to illustrate the ambiguity of informants’ experiences of participation in everyday life for people with ID. Participation is experienced as double-edged since it is perceived, on the one hand as an ongoing and positive development in society where people with ID are presented with opportunities to achieve empowerment, and on the other as a continuous fight against marginalization, which could jeopardize opportunities for participation. Informants described opportunities to gain empowerment as a process of important changes in society that enable participation in various life situations for people with ID. This was the result of changes in legislation by the government and the municipalities, resulting in further inclusion, equality and increased empowerment. Furthermore, informants described that such empowering processes of change also meant that people with ID were given new opportunities for participation in society. For example, when they turned 18, and became eligible to vote, they could participate in politics and democratic processes. Another aspect of participation put forward by the informants were opportunities for community participation such as being members of interest groups for people with ID and those without ID.

Informants described that the opportunity for people with ID to live more independently in group homes or own apartments also largely depended on their own attitude. For example, informants who were parents experienced an existential dilemma when an individual with ID was in the transition of moving out from the parents’ home. Being able to let go of their adult child as a parent also meant an opportunity for the individual to be more empowered. conditions for participation, as they could share their knowledge on the individual’s preferences with staff. They believed that such individual knowledge could contribute to a broader understanding of the individual’s needs and better treatment as a resident in a group home.

Informants described that they were fighting against marginalization and limited opportunities for a vulnerable group. Instead of empowering people with ID to have the ability to make their own choices and have control, participation was sometimes perceived as a chimera. Informants related that it was the professionals, for example social administrators, staff and managers on all levels, who had the

power and the preferential rights to interpret the preferences of people with ID. Informants related that they as members of an interest group wanted to be invited to forums where disability issues could be discussed with representatives from the municipality. However, what they experienced was a sense of marginalization that affect themselves and people with ID because they felt excluded from information meetings, concerning disability policy issues and decisions at a municipal level. The municipalities' financial circumstances was another factor that created a risk of marginalization for people with ID, and thus diminishing opportunities for participation.

METHODOLOGICAL CONSIDERATIONS

Methodology, refers to the way in which I approached the empirical arena in order to seek answers to the aim of this thesis. Taylor & Bogdan (1998), state that to be a qualitative researcher you have to go to the people and ask them. And so, I did. In the qualitative research process, the researcher is often regarded as an active co-creator by planning, leading and giving meaning to what is being studied (Taylor & Bogdan, 1998; Patton, 2002; Atkinson *et al.* 2001/2010).

In order to produce trustworthiness (Lincoln & Guba, 1985). Credibility involved giving informants a subjective voice through a description of their unique experiences (Studies I-IV). In order to produce a valid description, method triangulation including informal interviews were conducted in association with participant observations (Studies I and II), for example, informants with ID or staff were asked to explain the reasons for their behaviour in specific situations during an observation or directly after an observation. This, decreased the bias that could occur if the researcher only interpreted the studied situation. Further, the individual interviews were open (Studies I-III), e.g. that no structured interview guide was used, which made it possible for the informants to describe and reflect, during the interviews. Follow-up questions were used to gain more in-depth descriptions and to obtain confirmation that I had understood them correctly.

In addition, prolonged engagement in data collection can increase the opportunities to build a trustful relationship between the informants and the researcher (aa). In this thesis, prolonged engagement enabled the researcher to gain the informant's trust and the opportunity to acquire a deeper understanding of their experiences, thereby increasing credibility. At the same time, prolonged engagement can also mean that my own pre-understanding could be a drawback because I could have found certain phenomena to be obvious and therefore did not ask follow-up questions in connection with them.

The dependability of the study depends on how the empirical material is obtained (aa). The initial participant observations made it possible to get to know potential informants for interviews and were a prerequisite for gaining access to the disability field and prospective and knowledgeable informants for the interviews. This may help to strengthen the dependability of the studies. Participant observation is an useful method because it enables one to study aspects that can be difficult for the participants to put into words, such as tacit knowledge. Participant observation is therefore well suited to explore contexts where individuals in some way may have difficulty in making their voices heard (Leininger, 2001; Taylor & Bogdan, 1998). To increase the dependability of the analysis phase and the trustworthiness of the findings, all authors had an active role in the analysis work.

The studies have also been conducted with a quest for confirmability in order to be able to reproduce the structure and development of the dissertation as the studies progressed. To limit any influence of my own values, quotes and field notes have been used to demonstrate the confirmability of the analysis. Instead of starting from a predefined model or theory, the research for this study started in everyday life as it is experienced by informants. The intention has been to meet the subject and his or her image of the world openly, without prejudice, by adopting a reflective attitude (Atkinson *et al.* 2001/2010). My endeavour in this thesis has been to let the informants' voices be louder than my own, and my approach reflects that all people have the right to define and describe their world of life as they perceive it.

The studies transferability relates to reproducing a clear context (aa), such as all four studies focus on persons with ID. The first three studies also included group homes and adult persons with ID. The contextual description in each sub-study can strengthen the transferability in an international perspective, as there are similarities with for example, group homes in other countries.

DISCUSSION OF THE FINDINGS

The studies illustrate experiences of everyday life and participation from four perspectives. At the forefront of this thesis, are people with ID and how their everyday life and opportunity for participation can be experienced, by them, their professional providers and their significant others.

An overall goal for the Swedish disability policy is to promote equality and participation in everyday life for people with ID. People with ID should have opportunities to live as others and be fully involved and participate in society. This can pose a challenge for society as a whole; for professionals such as frontline staff members and service managers in group homes; other professionals; and other members of society who meet people with ID. But, if it pose a major challenge for those professionals without ID to achieve this goal of full participation, it is an even greater challenge for the people with ID. Participation is sometimes difficult to achieve for adults with ID as shown in this thesis, but even more difficult for persons with profound intellectual and multiple disabilities (Talman, Wilder, Stier & Gustafsson, 2018).

Despite the fact that the disability policy has contributed to improvements for this target group, there are currently extensive shortcomings. This study has revealed deficiencies such as the lack of working methods to support staff to facilitate participation (Study I); the lack of staff members' continuity and the existence of many routines and rules in the group homes (Study II); more overarchingly, the financial situation was not adequate to promote participation (Study III); a continuous fighting against marginalization and limited opportunities for this vulnerable group in society (Study IV). Consequently, there were also strengths and opportunities for a good everyday life and for participation. All four perspectives are important as, together, they contribute with a deeper understanding of what

participation is and is not, in relation to people with ID. From the findings presented in this thesis it can be said that participation is double-edged. All four studies in this thesis highlight both the absence and presence of participation. Participation as a concept is multifaceted, and can be seen as multidimensional because it can be described in different ways depending on the context (Molin 2004; Tideman 2015; Talman *et al.* 2018). In this thesis participation can be illustrated in a SWOT matrix, i.e. describing *Strengths*, *Weaknesses*, *Opportunities* and *Threats* to participation (See Figure 1).

Figure 1: Strengths, Weaknesses, Opportunities and Threats to Participation

All in all, the studies in the thesis reveals numerous strengths and opportunities for participation. Not least through the staff's commitment to creating trusting relationships for people with ID. This is constituent with the findings of Collings *et al.* (2018), that planning practioners need to build a partnership based on mutual trust and respect with a person with ID to respond to individual support needs. The study involving service managers reveals that they may be seen as a

strength and opportunity to increase participation because they feel they have the ultimate responsibility to promote participation for adults with ID living in group homes. Service managers' emphasis coaching and supervising staff to promote participation. Which is confirmed by Deveau & McGill (2016), as frontline managers improving staff performance in daily work by practice leadership. Similar findings state that complex environment such as a group home with persons with ID and challenging behaviour, needs managing e.g. seeing beyond the behaviour, constant awareness of the manager to allow staff to explore and develop trust (Olivier-Pijpers, Cram & Nieboer, 2018).

Significant others should also be perceived as an opportunity for developing participation since they increase the possibility for people with ID to develop as individuals. Findings reveal that significant others saw themselves as important facilitators for increased participation at an individual level (compare with Larsson *et al.* 2017) as well as in interest groups both for people with ID and without ID. Which can be linked to what Bigby, Anderson & Cameron (2017) describe as, community participation as a valued sense of belonging and identity for people with ID and consequential opportunities for social interactions with peers as well as people without disability who may have similar interests.

Perhaps the most important opportunities for participation have arisen as result of changes in society, which have played a major role historically and continue to do so in the present day. Not least, in this thesis it was related by giving people with ID the opportunity to be included in the democratic and political arena by participating and voting. This can be understood as a reconceptualization of people with ID as worthy of social and political belonging and is what Altermark (2016) state as "the politics of inclusion". Hence, there has been processes of deinstitutionalisation, socially integrated accommodations, legal frameworks such as the LSS Act, UN and WHO granting individual rights. As the closure of institutions has progressed, group homes have been mainstay in community care with their increase paralleling the closure of institutional settings (Clement & Bigby, 2010; Clement & Bigby, 2016). Clement & Bigby (2010), state that it may be variation in quality of outcomes for people with ID living in group homes and currently there is no model of best practice. At the same time, a group home can also be more or less institutionalized, if, for example when it exist a paternalistic culture (Bigby *et al.* 2012; Jormfeldt, 2016). Concomitantly, the results of inclusion are far less good than the stated ambitions: it seems that people with ID are far from the self-determined citizens, participating and fully

included, that the new disability politics stipulate (Altermark, 2016; Bigby, 2012; Bigby *et al.* 2017).

This thesis also reveal weaknesses and threats to increased participation for people with ID. Particularly apparent is the absence of participation that occurs when staff lack working methods to enable participation. This was also shown in similar studies, concerning staff working with older people with ID in group homes (Kåhlin, 2015; Jormfeldt, 2016; Johansson, 2017). Absence of participation, due to a lack of working methods and, not least, a lack of evidence-based working methods can be perceived as a threat to participation (National Board of Health and Welfare, 2019). Instead frontline staff members were motivated to use rules and routines as a way of creating stability and predictability, aspects considered to be important for the wellbeing of adults with ID. It may be argued that staff were sometimes unreflective about their everyday work with adults with ID. It also reflect what Clement & Bigby (2010) stated, that group homes are only as good as the staff who run them. Staff seemed to be entrenched in the culture that routines and rules had become taken for granted resulting in neglect of the adults with ID. Jenkins (2000) added that routines and rules are potent ways to put – and keep people in their place. Living in a group home as an adult with ID and being dependent on staff and limited by the “house rules” can clearly give a sense of meaninglessness. Studies have shown when residents living in group homes are subject to control and restraint, it is more likely it is also a trigger for develop challenging behaviour (Deveau & McGill, 2016). Challenging behaviour doesn't belong to the individual, rather it occurs in contexts of immediate support in group homes (Deveau & McGill (2016). Such rules, procedures and regulations, maintained by the staff in this thesis, can erode the opportunity for participation. According to Goffman (1961), such treatment is often used to reinforce rituals of dispossession, and everyday activities often required permission from staff. Furthermore, adults with ID commonly experienced that they were not able to influence their life situation. According to Eldh (2006), this can be interpreted as a lack of control, non-participation, and a lack of respect for the individual as a human being.

These rules and routines to some extent indicate a non-individualized care. Indeed, previous research has shown that staff in institutional care settings have difficulty in providing individualized care (Kim, Larson & Lakin, 2001). Such non-individualized care can be understood to be the non-patient participation described by Eldh (2006) because it also significantly lack a relationship. Being

told what to do without further explanations, indicate that one is regarded as not being accountable to choose adequate actions appropriate to one's situation. Deely (2002), points out that the manner in which staff behave towards people with ID is crucial in affecting whether or not they can participate and influence their life situation. This aspect is also emphasised by service managers. Participation risks being lost if service managers are not involved directly by coaching and supervising the staff in their everyday work in group homes. The service managers' conscious presence and assumption of responsibility, will likely create better conditions for participation in group homes. Not least because they are present in the daily work and can observe any situations that do not promote participation. Through reflective practice and questioning, they can motivate and guide the staff to support participation. These findings are similar to what Deveau & McGill (2014; 2016) describe as practice leadership which include that service managers need to immediate support, training, monitoring and give feed back in daily practice. Further, they state that the manager need to train each staff member in the group home, but that is also hard to implement such managing, when staff working 24-7 (aa). Significant others also emphasize the importance of the staff having a good and individual approach to the needs of adults with ID, when promoting opportunities for participation.

Notwithstanding, people with ID are, dependent in many ways on the support of others people if they are to have access to a social life, services and support in society. Despite the disability policies, it has been shown that barriers to participating in everyday life still exist for people with ID. Such barriers to participation were found in this thesis and persisted as result of the approach and attitudes of staff. Further aspects that can constitute limitations for participation are staff values and existing cultures in group homes (Bigby & Beadle-Brown, 2016), and a lack of leadership (Deveau & McGill 2016). To minimize such risks, it is important that the service managers are present in everyday work and that there are financial conditions for competence development and support for staff.

In this study, service managers in group homes struggled and managed alone with their mission, and they experience a lack of support due to local or financial decisions. They felt that they underperformed in regard to promoting participation for adults with ID and one can assume that these circumstances also posed a risk of non-participation for adults with ID. Structural barriers similar to those emphasised by the service managers were also found in the study involving significant others. Significant others' state that people with ID are not are given enough opportunities

to participate on similar terms to other citizens. For example, the municipality's financial circumstances impacted negatively on the staff approach and on lack of leisure activities. Instead, significant others felt a responsibility to compensate for some activities that the municipalities did not cover.

CONCLUSIONS

Despite the fact that the disability policy has contributed to improvements for this target group, there are currently extensive shortcomings. This study has revealed deficiencies such as the lack of working methods to support staff facilitate participation (Study I); the lack of staffs' continuity and the existence of many routines and rules in the group homes (Study II); more overarchingly, the financial situation was not adequate to promote participation (Studies III+IV).

To avoid the risk of establishing a culture of non-participation in group homes for people with ID, staff in group homes should receive clear directives from service managers and top management on objectives, as well as guidelines on how to promote participation based on the ideology of participation. This can be achieved through a present leadership such as the practice leadership, that coaches and guides the staff's often complex work in everyday life. By guiding and showing staff the right way in promoting participation in daily practice. Consequently, it will be better lives for people with ID in for example participating in a meaningful activity, and better working quality for staff. Top management and financial structures are of importance to facilitate service managers to support staff in daily practice in promoting participation for people with ID Staff need support and skills development in working methods and, not least, evidence-based methods to support development of participation in the everyday work with people with ID.

CLINICAL IMPLICATIONS AND FUTURE RESEARCH

The findings in this thesis contribute to valuable insights and deeper understanding and knowledge that can enhance staff members' efforts to promote participation for people with ID. This can be achieved by changing the staffs' attitudes and reducing the use of rules and routines when working with people with ID. The findings in this thesis have revealed that staff lacked formal training, which can lead to limitations in daily life and participation for people with ID. Thus, it indicates that formal training and education of staff are important. Such formal training and education should include necessary knowledge about the intellectual disability and the best method for providing support and opportunities to promote participation. Staff themselves need support and supervision from a present and local leadership, similar to practice leadership in their often complex everyday work. Staff need training in working methods and not least evidence-based methods to promote participation in group homes for people with ID. The findings also show that significant others must be included more by the municipality's representatives as they strive to enable participation in society with and for people with ID.

- Service managers often perceive the organizational structures as ineffective, therefore the whole organization must make it possible for service managers to be working in the front-line. Thus, meaning that they achieve sufficient support from top management because this local leadership such as practice leadership can make a difference in the outcome in supporting staff to promote participation.

- It is scarcely satisfactory that people with ID experience dependency of on staff or that they do not have control or participate in everyday life issues. Therefore, it is important to continue to listen to and to conduct further research with and on this vulnerable group – a group that is risk of marginalization not only in society in general but also when living in group homes.
- The findings can also contribute to reflection and feedback for staff, managers and other professionals working in the field of disability and other professionals who meet this vulnerable group. Future research can also explore other arenas that, for example, how opportunities for participation are promoted for people with ID in health care, education or workplaces.

POPULÄRVETENSKAPLIG SAMMANFATTNING

Jag har valt att skriva på lättläst svenska för att personer med intellektuell funktionsnedsättning kan läsa vad avhandlingen handlar om¹.

Därför har jag gjort avhandlingen

Avhandlingen handlar om hur en vanlig dag och vad delaktighet är för personer med intellektuell funktionsnedsättning.

Mitt intresse började.

När jag arbetade som sjuksköterska i kommunen.

Arbetet handlade om att stödja hälsa och välbefinnande till personer med intellektuell funktionsnedsättning.

För att underlätta för dem att vara delaktiga.

Jag visste lite om funktionshinderspolitik

och hur en vanlig dag är för personer med intellektuell funktionsnedsättning.

Jag ville lära mig mera.

Jag började forska för att ta reda på mer

om personer med intellektuell funktionsnedsättning.

¹ Jag har blivit inspirerad av att skriva på lättläst svenska genom b.la Kählin (2015).

Funktionshinderspolitiken säger att alla människor med funktionsnedsättning i alla åldrar ska vara fullt delaktiga i samhället.

Det finns höga krav på samhällets stöd, omvårdnad och service för personer med intellektuell funktionsnedsättning i Sverige. Detta skapar förväntningar på personal och chefer som arbetar med att ge stöd. Stödet ska bidra till ett självständigt liv och delaktighet.

Detta ville jag veta

I arbetet med avhandlingen har jag fyra frågor:

1. Hur upplever personalen sitt arbete med personer med intellektuell funktionsnedsättning i gruppboenden?
2. Hur upplever personer med intellektuell funktionsnedsättning en vanlig dag i gruppboendet?
3. Hur kan chefer i gruppboende underlätta delaktighet?
4. Hur beskriver anhöriga, vänner eller gode män delaktighet?

Detta har jag kommit fram till

Personalen saknar möjlighet att ge stöd som underlättar delaktighet. Det beror på att personal saknar arbetsmetoder och stöd av chefer.

Personer med intellektuell funktionsnedsättning upplever att det finns för många regler och rutiner i en gruppboende. Det ger en känsla av att vara beroende av personal.

Chefer är viktiga för att ge stöd till personal i gruppboende. Chefer som handleder och ger stöd till personal gör att personal kan underlätta delaktighet.

Anhöriga, vänner och gode män till personer med intellektuell funktionsnedsättning vill känna sig välkomna med sin kunskap till personal, chefer och myndigheter. De vill att fler personer med intellektuell funktionsnedsättning är delaktiga i samhället.

Så här kan forskningen användas

Personal och personer med intellektuell funktionsnedsättning kan diskutera resultaten,
är det så här i denna gruppbostad?
Får personal stöd, utbildning och
handledning av närmaste chef?
Vad är delaktighet för mig?

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In fear of leaving someone out, I will not list the name of all of those who helped me learn about qualitative research. To all of those who have supported me and my work, thank you.

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ORIGINAL PAPERS I-V

I

Care workers' experiences of working in a Swedish institutional care setting

Observing staff during their interactions with residents enabled Leena Berlin Hallrup and colleagues to build up a picture of how they operate in a complex and stressful work environment

Summary

Despite the general move to support people with learning disabilities in their own homes or in home-like settings, many institutional settings still exist and little research has been carried out on the role of the care workers who work in them. In this study, participant observations over a 16-month period describe care workers' experiences of working in an institutional care setting in Sweden, and 18 care workers were interviewed. The three main themes to emerge from the thematic analysis were: care workers were engaged in creating a family-like atmosphere; they were engaged in making the everyday ordered and structured; and they were exposed to stress factors.

It became evident that care workers need additional support, training and opportunities for reflection to handle their complex work situation.

Keywords

Care workers, interviews, institutional setting, participant observations, Sweden

IDEALLY, PEOPLE with learning disabilities should be offered support in their homes or in home-like settings in their own community (United Nations 2006), but the number of institutional settings is increasing internationally and there is a growing body of care workers employed in them (Jordahl 2002, Braddock and Hemp 2006, Mansell *et al* 2007). A reason for this may be that some people do not benefit from the support offered in home-like settings because of their complex needs and therefore need assistance in the areas of daily living, work, leisure time and socialisation (Slevin *et al* 2008).

Studies have mainly focused on care workers in small-scale living arrangements in the community. Previous research has shown that care workers are often subjected to threats and violence by clients

(Durnin and Freeman 2005, Lundström *et al* 2005) and frequently witness self-injurious behaviour (McKenzie *et al* 2000), which can lead to feelings of powerlessness and symptoms of burnout (Dennis and Leach 2007). However, there are few recent studies investigating care workers' experiences in institutional settings for people with learning disabilities. According to Goffman's seminal work (1961) institutional settings are residential establishments in which boundaries that normally separate the three life spheres (living, working and leisure) do not exist. Following the trend towards deinstitutionalisation, research concerning care workers' work in institutional care settings is lacking. The present study aimed to describe the meaning of their everyday work.

Sample and methods

A qualitative approach with participant observations and in-depth interviews was chosen to develop an understanding of how care workers think and act in the institutional care setting. Participant observations enable the researcher to listen and see what is happening and later to ask those involved in the situation how they experienced what happened (Taylor and Bogdan 1998).

Setting

The study was carried out in an institutional setting in Sweden for people with learning disabilities. Housing, daily occupation and socialisation opportunities were all offered on a campus. A total of 77 residents lived in homes for one to four people. The residents were classified

Table 1 Characteristics of residents (*n*=77)

Male	Female	Age range	Accommodation (yrs)	Additional diagnosis
45	32	20 to 67	0 to 56	Asperger syndrome (20) Autism (12) Psychosis (seven) Forensic history crimes (six)

as having moderate learning disabilities and some had an additional diagnosis (Table 1).

A total of 249 employees worked at the institution. Care workers (*n*=228) were employed either in the group homes (*n*=208), which were staffed 24 hours a day, or in a day centre (*n*=20) (Table 2).

Procedure

There were 47 care workers present on the days when observations were performed (Table 3). In-depth interviews were conducted with 18 of these care workers. For variety the interviewees were selected with regard to gender, age and length of employment, and working tasks such as in the group homes, day centre or as teachers.

About 400 hours of participant observations were carried out over 16 months (September 2006 to December 2007). Residents and employees were informed about the purpose of the researcher's presence. Initially, short visits were made to the setting to make contact with the participants and to explore the available activities, resources and facilities. The observations were made one or two days a week by the first author. During the first ten months of observations, the researcher tried to get an overall picture of the care workers' duties by observing many different places and situations. The observation sessions took place at different times and on different days and lasted approximately five hours each time. While being observed, the care workers were asked for explanations of their behaviour through informal interviews. Field notes including participant observations, informal interviews and the researcher's memos were

transcribed immediately after every observation. The notes provided a framework for future observations, which became more focused on certain aspects to clarify what was going on.

To give care workers further opportunities to reflect on their work, in-depth interviews were performed. They were asked to describe their work with the residents more comprehensively. Follow-up questions were asked when needed such as 'what do you mean?' or 'can you tell me more about that?'. The interviews, which lasted between 35 and 75 minutes, were undertaken in a private room and tape recorded for verbatim transcription by the first author.

Ethical considerations

Written informed consent was obtained from residents and care workers who were involved in participant observations and in-depth interviews. The study was approved by the regional ethics committee in Linköping, Sweden.

Data analysis

The analysis, which was based on the thematic analysis procedures presented by Taylor and Bogdan (1998) and found suitable for inductive analysis of themes from data, was an ongoing process since data collection and analysis went hand in hand as the study progressed. All field notes and interviews were transcribed into text by the researcher and were analysed independently by members of the research team. Initially, all text from the data was read and re-read, and text or statements that captured the meaning of experiences of working with people with learning disabilities in an institutional care setting were given a code. Codes with similar meanings were gathered and used to create categories. Categories were compared for similarities and differences to discern the underlying meaning and patterns leading to themes, an example of which is shown in Table 4.

Rigour

The researcher's involvement in gathering the data may pose a risk for subjective bias, so to minimise this possibility field work was carried out over 16 months. Conducting observations for an extended period enabled the researcher to gain participants' trust and the chance to obtain a deep understanding of care workers' experiences. Informal interviews were carried out to verify interpretations of different situations. Throughout the field work a reflective diary was kept and used when sharing reflections with the other researchers. Reflections allowed researchers to verify and

Table 2 Characteristics of employees at the setting (*n*=249)

Work occupation	Age range	Gender male/female	Post-secondary health education
Care workers (228)	16 to 64	162f/66m	2
Management (10)	38 to 56	3f/7m	1
Others (11)	35 to 55	2f/9m	–

match their own interpretations (Hammersley and Atkinson 2007). The preliminary data analysis was validated at a staff meeting and by care workers who had participated. Furthermore, the study's results are generalisable in the sense that other carers with the same professional background in a similar context may recognise the findings.

Findings

Creating a family-like atmosphere The care workers regarded the institutional care setting as a home for the residents and therefore endeavoured to create a family-like atmosphere. Many of the residents had not experienced what it is like to be part of a family so the staff wanted to create an atmosphere that would provide them with the sense of security found in families. The care workers felt connected to the residents as though they were all members of the same family. Sometimes the boundaries between the carer's private life and work were removed. For example, in their spare time, care workers invited residents to their own homes to meet their family or to go shopping. Indeed, some of the care workers thought of the workplace as their home, too.

One respondent said: 'I have a home, not a job. I live here during (my working) day or evening, or on the weekend. When I am here, my job becomes my home. This home has become like a family to me; we are all one family, both care workers and those who live here. We are together all the time and even though it is "their" home, that feeling is erased when we are together.'

The care workers developed a particular kind of togetherness with the residents, involving what they experienced as intimate relations built on confidence, closeness and confirmation. Staff became 'living aids', compensating for the residents' disabilities. For example, when the residents dressed, made telephone calls or did laundry, the carers were close behind, guiding them just by being there without saying or doing anything.

Staff always made an effort to listen to residents' problems, irrespective of how busy they were. The following part of an observation, taken during a computer lesson with six residents, illustrates this.

'Lars is sitting in front of the computer. Suddenly he gets up and walks over to the teacher who is busy sorting notebooks and says that he needs to talk. The teacher puts her work to the side and says: "Let's go and sit down in the little room". Together they go to the room, closing the door behind them.'

Creating a family-like atmosphere meant that care workers took on specific traditional family roles: the men had a fatherly role, while the women had a more motherly one. For example, whereas, the male

Table 3 Characteristics of participants included in the study ($n=47$)

Care workers	Total	Age range (yrs)	Gender (male/female)	Length of employment
Observations	47	20 to 64	16m/31f	1 to 28 yrs
Interviews	18	24 to 64	6m/12f	4 to 28 yrs

care workers tended to be more involved in violent situations, the function of the female care worker was to be emotional. They had also taken on roles as parents, seeing the residents as children, and siblings of each other. The following text is an excerpt from the field notes taken during a civic lesson in school.

'One of the residents starts suddenly a discussion with another resident about which one of them is right regarding school... Suddenly they start to push each other. The teacher tells them in a calm voice, "calm down, the both of you, you two are like family, you shouldn't fight".'

Making the everyday ordered and structured

The staff planned and scheduled each day. By scheduling the days, routines developed: for example, routines for morning assembly, daily work, smoking, leisure time and socialisation were organised to a timetable. Setting routines helped to make the days more predictable and functioned as positive and negative reinforcements in relation to the residents; for example, the exclusion from daily occupation or weekend trips if residents did not behave as expected. Therefore, routines are tools for gaining stabilisation, prediction and for motivating good behaviour. The following excerpt from an interview with a care worker illustrates this.

'Anna used to wet herself in order to avoid work. She did this because she enjoyed going home to shower and change clothes during working hours. When we realised she did this we made her sit the whole day long on the chair that she had urinated on, not allowing her to leave. This made her stop.'

Table 4 Example of the analysis process

Text of meanings	Code	Category	Theme
1:1 Every house has its own rules	Rules	Needing rules	
15:3 Routines make things work out properly	Routines	Making routines	Making the everyday ordered and structured
2:5 Residents must follow the 'straight square' – clear rules	Control	Controlling residents	

Supervising the residents was a feature of the everyday work, and the order and structure helped care workers to be alert to situations arising, such as conflicts among the residents, aggressive behaviour and escape attempts, and enabled them to tackle them promptly.

'We have to check what they are doing at all times. We can't go on a break together; we have to go separately as one of us has to be inside, watching them.'

Making the everyday ordered and structured meant limiting the residents' freedom, since certain rules were set; for example, locking refrigerators to prevent obsessive behaviour with regard to eating. Some rules were written down as agreements between care workers and residents.

Being exposed to stress factors In the course of their work, staff experience verbal and physical abuse by residents, which sometimes results in injury requiring medical treatment and sick leave. The care workers found the violence difficult to cope with.

'It really isn't any fun to get beaten up at work. It occurs off and on, I don't know how many times I've been hit at work.'

Witnessing incidents could lead to feelings of guilt because they had not managed to prevent them.

'A resident hit her (care worker) many times... I feel guilty every time she hits somebody, I feel like I should be able to stop it.'

Sometimes care workers verbally abused each other; when, for example, they thought a colleague had acted incorrectly in a volatile situation, and newly employed care workers were often accused of causing aggressive behaviour in residents.

The working conditions were also stressful. At the time of this study, the number of residents increased from 67 to 77 at the institution, which created stressful working conditions. This meant that care workers had to make more effort to make time for new residents and at the same time maintain business production in the residents' workshop. Periodically, sub-contracted work increased which meant the pace of work in the sheltered workshop needed to speed up to fulfil a commitment.

When this happened the care workers had to work under pressure, and led unintentionally to forcing the residents to work extra hard. 'We are often in a hurry because industry demands that a certain amount of products are produced daily. Sometimes we have to push them, or we feel that we have to push them even though this feeling shouldn't exist.'

Witnessing a resident's pain due to illness was another stress factor for staff. When, for example, making visits to healthcare services with a resident the carer needed to argue for the resident's right to treatment. 'One resident was not hospitalised two times despite his pneumonia. When finally he was allowed into the hospital his pneumonia had spread to both lungs.'

Discussion

The main objective of care workers was to create a home-like atmosphere in an institutional environment. This might occur in response to the care workers' untrained status; they did not have the knowledge or skills to offer specialised care, so they mirrored the care found in their own family life. In everyday work the care workers used their natural ability and disposition to care. According to Noddings (2003), caring does not need any formal training; it comes naturally from experiences or perceptions of close relationships in a family. Natural care is learned in real life and in good relationships. The natural care observed in the present study became legitimised by care workers' unreflective feelings of doing good work.

The natural care involved the traditional perception of roles inherent in a family. It followed stereotypical gender roles, based on how men and women tend to act and, in doing so, the care workers organised gender according to what Butler (1999) called the heteronormative matrix. Butler explained that gender roles are manifested by performance acts, in other words, actions that are repeated in social relations; in this study care workers assumed that the male staff would intervene in violent incidents. In addition, care workers performed gender roles within the hierarchical parent-child relationship with residents.

However, care workers were also schooled by each other to use methods such as rules and routines that were aimed at creating a functional everyday life. Goffman (1961) stated that routines are a way for staff to uphold social control over deviant behaviour. Jenkins (2000) added that routines and rules are 'potent ways to put - and keep - people in their place'. Care workers were motivated to use rules and routines in the present study as a way of creating stability and predictability, aspects considered to be important for residents' wellbeing.

Rules also functioned as a means of decreasing the risk of being exposed to violence. Rules and routines to some extent indicate non-individualised care. Indeed, previous research has shown that care workers in institutional settings have difficulties in providing individualised care (Kim *et al* 2001).

It may be argued that care workers were unreflective about their everyday work with the residents. For example, they used their private experiences when developing relationships with residents, and caring actions and strategies were usually learned from colleagues or previous practical learning. Kayser-Jones *et al* (2003) found that uneducated care workers in long-term care for older people were not aware of how their attitudes influenced residents' dependency.

The fact that care workers forced a resident to sit in urine-soaked clothes violates the resident's right to be treated with dignity. This is maltreatment and against Swedish law (Rattsstatet 1982). It also shows that care workers adopted an unethical approach.

On the one hand, care workers were exposed to various forms of stress, such as threats, violence and workload, and also in contacts with the outside world, while on the other, care workers seemed so entrenched by the care culture that routines and rules had become taken for granted in a way that brought about neglect of the residents. This neglect became evident in unequal relationships, for example, when residents were treated like children.

Bengtsson Tops (2005) found that incidents of violence against staff who work in nursing homes for individuals with long-term mental illness often lead to symptoms of burnout. According

to Durnin and Freeman (2005) such symptoms could be avoided by giving staff the opportunity for training and mentorship, which would also give them increased self-confidence in their work. Care workers in the present study were not offered mentorship or supervision by the care institution management.

Conclusion

It may be argued that care workers in their everyday work with people with learning disabilities in an institutional care setting used private experiences when they lacked formal caring training. Such experiences help to create meaningfulness but risk preserving inequality and gender stereotyping. To avoid these risks care workers should receive clear directives from management about objectives, and guidelines about how best to care for the residents and offer them individualised care. Furthermore, all care workers should be supported with appropriate training and supervision.

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III

ORIGINAL ARTICLE

The meaning of the lived experiences of adults with intellectual disabilities in a Swedish institutional care setting: a reflective lifeworld approach

Leena Berlin Hallrup

Aims and objectives. This study describes the meaning of the lived experiences of adults with intellectual disabilities in a Swedish institutional care setting.

Background. Despite the general intention of the Swedish law to give care and support for adults with intellectual disabilities in small settings in the community, large institutional care settings exist in Sweden. It is also known that adults with intellectual disabilities have more influence over their care and support when living in small settings than in large institutions. There is a dearth research in regard to studies that focus on how adults with intellectual disabilities experiences their everyday life in such settings.

Design. A qualitative design was used to gain a deeper understanding of the lived experiences of adults with intellectual disabilities in an institutional care setting in Sweden.

Methods. Fieldwork from September 2006 to June 2009 in an institutional care setting including participant observation and in-depth interviews with 12 residents was used. Verbatim-transcribed text was analysed using a phenomenological reflective lifeworld approach.

Results. The essential picture of the phenomenon was experienced 'as a meaningful and meaningless existence' and was reflected in residents' descriptions of their everyday life in the setting. It was characterised by the constituents: ambiguous dependency, social interactions and everyday life in a restricted area.

Conclusion. The results reveal the importance of paying close attention to what adults with intellectual disabilities have to say about their everyday life when living in an institutional care setting. For caring practices of people with intellectual disabilities, it is scarcely satisfactory that residents experience an ambivalent dependency and of having to live in a restricted area.

Relevance to clinical practice. The results of this study contribute to better insight and deeper knowledge of the lived experiences of adults with intellectual disabilities, enabling the staff and management to further enhance the well-being for residents. In addition, the findings provide feedback to staff, managers and researchers working in the intellectual disabilities field.

Key words: adults with intellectual disabilities, institutional care setting, lived experiences, Sweden

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Introduction

Intellectual disability involves a reduction in the person's ability to meet culturally marked age-appropriate standards when it comes to communication, social relationships, use

of community resources, education, work, leisure, health care and personal safety (World Health Organization 2010). Approximately 0.5% of the world population is characterised as intellectually disabled, and in Sweden, approximately

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0.4% of the population is intellectually disabled (The National Board of Health and Welfare 2010a).

Swedish disability policies are based on The United Nations Convention's Rights of Persons with Disabilities (United Nations 2006), which states that adults with intellectual disabilities should have the opportunities to live under as equal conditions as possible as that of other persons in the society. Furthermore, care must be provided with respect for autonomy and be responsive to the individual's needs, abilities and preferences over time (The National Board of Health and Welfare 2010a). Another important policy in Sweden is the Support and Service Act for Persons with Certain Functional Impairments (The Ministry of Health and Social Affairs 2006), which states that large institutional settings for people with intellectual disabilities are to be closed and replaced with integrated housing. The National Board of Health and Welfare (2006, p.7) maintain that 'large institutional settings have closed and people with intellectual disabilities now live in small group homes or in their own homes with varying degrees of support'. Given that large institutional settings are not to exist for adults with intellectual disabilities living in Sweden, they paradoxically still do. These institutional settings are often operated by private companies that offer all care and support covered by the law (Brink *et al.* 2009). According to Statistic Sweden report (2009), this form of institutional care settings is on the rise and more and more people with intellectual disabilities being placed in such settings. One reason that can explain this is that the municipalities, which have the main responsibility to manage care and support for people with intellectual disabilities, lack the resources to meet those needs (The National Board of Health and Welfare 2010b). Another reason is that some individuals do not benefit from the support offered in small settings because of the complex nature of their needs and therefore need assistance in the areas of daily living, work, leisure time and socialisation (Slevin *et al.* 2008). Approximately 23,000 people with intellectual disabilities residing in small community-based settings in Sweden and 596 individuals (336 men and 260 women) are living in institutional settings (The National Board of Health and Welfare 2010a).

It has been shown that adults with intellectual disabilities are better equipped to exert influence over their own care and support and participate in society when living in group homes in the municipality and other forms of independent living as opposed to large institutional settings (Duvdedany *et al.* 2002, Mansell & Beadle-Brown 2010). Previous studies have concerned themselves mainly with examining how life is in small group homes for adults with intellectual disabilities and highlight obstacles that prevent such adults from participat-

ing in society, such as various forms of victimisation by other citizens and care providers (Manners & Carruthers 2006), powerlessness and dependence on formal and informal carers (Manners *et al.* 2006). Umb-Carlsson and Sonnander (2005) argue that persons with intellectual disabilities are a silent group in society and that they have difficulty making their voices heard, and therefore, it may be difficult for various care providers to offer support and care based on the intentions stated in the law. Deely (2002) points out that the manner in which carers work and behave towards people with intellectual disabilities is crucial in affecting whether or not they can participate and influence their life situation.

According to Goffman (1961), institutional settings are residential establishments in which boundaries that normally separate the three life spheres (living, working and leisure) do not exist. An institutional care setting can as in this study be described using Goffman's (1961) definition, that is, that it meets all the criteria of what characterises a total institution as it offers accommodation, school, employment and social activities on a campus.

However, few recent studies have focused on adults with intellectual disabilities lived experiences in large institutional care settings. This is due in part to the political process of deinstitutionalisation, which has created a greater interest in how adults with intellectual disabilities experience life in small group homes in the community. According to Swedish law, large institutional care settings should no longer exist and, as has been pointed out in earlier studies, they limit and even hinder the opportunity for people with intellectual disabilities to exert influence (Mansell & Beadle-Brown 2010). Despite these findings, they continue to exist on a limited scale. As little research is available regarding this phenomenon, it will be the aim of this study to describe the meaning of the lived experiences of adults with intellectual disabilities in a Swedish institutional care setting.

Methods

Design

A qualitative research design was used, involving fieldwork from September 2006 to June 2009 including participant observation and in-depth interviews with 12 residents to gain a deep understanding of the lived experiences of adults with intellectual disabilities in a Swedish institutional care setting.

Approach and method

Understanding adults with intellectual disabilities lived experiences in an institutional care setting requires an ability

to openly meet their lifeworlds. Therefore, a phenomenological reflective lifeworld approach was chosen (Dahlberg *et al.* 2008). Life manifests itself in experience, and each lifeworld shows structures or styles that need to be studied so that care providers may understand the needs of adults with intellectual disabilities. From this point of view, everyday life in an institutional care setting must be understood as an embodied experience, including adults with intellectual disabilities lifeworlds. Reflective lifeworld research illustrates the world experienced prior to any theories devised to explain it (Dahlberg *et al.* 2008). The lifeworld is to be investigated in its own terms, without reference to any external criteria of 'how it is' (Ashworth 1996).

A principle of matter in all phenomenological approaches is openness towards the phenomenon in focus, and researchers must therefore learn how to 'bridle' their evolving understanding of the phenomenon and its meanings (Dahlberg *et al.* 2008). The aim of 'bridling' attention, experience and understanding is to be as aware as possible of the concrete instance of the phenomenon as it exists and presents itself in the research.

Openness and sensitivity towards, and thus a nearness to, the phenomenon being studied characterise the lifeworld approach. This means that the research method and the questions that are asked can never be decided beforehand. Sensitivity to 'the things themselves' demands that the 'nature of things' influences the design of the research questions and choice of methods (Dahlberg *et al.* 2008).

Participant observation was chosen to establish close contact with the field and develop a deep understanding of how residents' think and act in everyday life in an institutional care setting. Participant observation provides an interior perspective where the researcher can see and come to understand a phenomenon in its natural setting. Interviewing gives a sense of the milieu, through observation as well doing informal interviews directly in various interactions and situations the researcher is privy to information that may not have been revealed in the course of a singular interview. Using various methods to collect data such as participant observation, informal interviews and in-depth interviews aids in strengthening the objectivity of the study (Dahlberg *et al.* 2008). To give residents further opportunities to reflect on their everyday life, phenomenological in-depth interviews were performed (Dahlberg *et al.* 2008).

Research setting

The study was carried out in a Swedish institutional care setting for adults with intellectual disabilities or as they shall henceforth be referred to residents. Housing, schooling, daily

occupation and socialisation were all offered on a campus. The setting was located in a rural area and consisted of various buildings: (1) 10 training apartments in which residents were given the opportunity to try to live independently under round-the-clock supervision, (2) 20 group homes in which three to five residents had private bedrooms and shared a kitchen, toilets and living room, (3) a main building for the management offices where ten administrators were employed, (4) premises for daily occupation, such as a textile workshop and an assembly plant for work that was subcontracted by different companies, in which twenty staff members were employed, and (5) one school building consisting of one classroom staffed by temporary teachers.

A total of 77 residents (45 men and 32 women) lived in the setting. Their ages ranged from 20–67 years and they had lived there one month to 56 years. They were diagnosed as intellectually disabled, and some had additional diagnoses such as psychosis ($n = 20$), autism ($n = 12$) and Asperger's syndrome ($n = 7$).

The setting had a total of 249 employees (167 women and 82 men). Of these, 228 worked as care workers and 21 as administrators, kitchen staff, teachers, cleaners/porters and psychologist. The care workers were deployed either in the group homes that were staffed 24 hours a day ($n = 208$) or on premises for daily occupation ($n = 20$).

Participants

A total of 55 residents (37 men and 18 women) participated in the study on occasions when and at places where the participant observations were performed. They had a median age of 36 years, ranging from 20–67 years and had lived in the setting for one month to 56 years. Some of those who participated in the observations also took part in in-depth interviews. Twelve residents (7 men and 5 women) were purposively selected on the basis of gender, age and years of residence. Their median age was 35 years, ranging from 23–66 years, and they had resided in the setting between 3 and 36 years.

Data collection

Initially, the first four months of field work were all about making contact with the participants and to explore available activities, resources and facilities. One way to learn even more about them was by getting to know the so called gatekeepers, who were key persons with lengthy experience in living in the setting and thus well socialised in relation to other residents and staff. Gate-keepers could therefore assist with access to other individuals and other places in the

institutional setting. Field work was performed one or two days per week. During the next 18 months, the researcher tried to obtain an overall picture of the residents' everyday life by visiting various settings and observing different situations. The participant observation took place at various times of the day, on different weekdays and lasted approximately five hours on each occasion. While being observed, residents were asked for explanations of their behaviour through informal interviews without tape recording. As the fieldwork progressed, the remaining months of participant observation became more focused on certain aspects to clarify what was going on in different situations. Field notes comprising of participant observation and informal interviews were transcribed immediately after each observation.

At the end of the field work, to give residents further opportunities to reflect on their lived experience, phenomenological in-depth interviews were performed (Dahlberg *et al.* 2008). The interviews focused on the phenomenon 'adults with intellectual disabilities lived experience of an institutional care setting'. All interviews started with the question 'can you tell me about how an ordinary day is for you?' The main purpose of this question was to be open and to get a background to the phenomenon. Thereafter, during the interview, further questions were posed that focused on what the residents themselves had chosen to talk about. Follow-up questions such as 'what do you mean by that?' or 'can you tell me more about that?' were posed to increase the information by letting the participant reflect over the phenomenon. The interviews lasted 45–75 minutes and were performed in a secluded room chosen by the resident and tape recorded for verbatim transcription.

Ethical considerations

Residents and staff were informed about the purpose of the researcher's presence. Written informed consent was obtained from both the staff and the residents who were involved in the participant observation and interviews. Relatives or legal representatives gave their permission for those residents who were judged by the owner of the setting and by the author as having difficulty in giving such consent. The study was approved by the Regional Ethics Committee in Linköping, Sweden (Reg. No. 208-06).

Rigour

The researcher's involvement in the world of the participants may pose a risk for subjective bias, so to mitigate this possibility, field work was carried out for an extended period (Ashworth 1996, Dahlberg *et al.* 2008). A prolonged engagement in the field enabled the researcher to gain participant's

trust and the possibility to obtain a deep understanding of residents' lived experiences. From the start of the process until the final analysis, the researcher 'bridled' the preunderstanding of the material under consideration and to encounter it in an open manner and make unprejudiced generalisations about it (Ashworth 1996, Dahlberg *et al.* 2008). To produce a valid description, informal interviews were carried out to verify the researcher's interpretations of different situations (van Manen 1990). For example, during or directly after an observation, the residents were asked to explain the reasons for their behaviour, that is, informal interviews. Thus, the phenomenon could be studied as it was experienced by the residents. Validity checks were ensured by making the field notes and interview transcripts that justified the claims available to research colleagues. A triangulation of various sources such as participant observation, informal interviews and in-depth interviews can enhanced the objectivity of the study (Ashworth 1996, Dahlberg *et al.* 2008). The findings can be generalised in the sense that other residents and care providers in a similar context can recognise the findings, which can thus be deemed theoretically transferable to comparable contexts.

Data analysis

The analysis was based on the phenomenological reflective lifeworld approach as described by Dahlberg *et al.* (2008) and aimed at describing the essence of the phenomenon 'adults with intellectual disabilities lived experiences in an institutional care setting'. Such analysis is a fluid flexible movement between whole-parts-whole. Importantly, each part is understood in terms of the whole and vice versa. Sensitivity to this subtle and pervasive relationship reveals the inherent ambiguities of the phenomena. In addition to the aim of illustrating essential meanings, the analysis emphasises various everyday life experiences in relation to the aim, revealing unique meanings embedded in the descriptions of these experiences. Initially, all field notes and interviews were transcribed and read through several times to get a sense of the whole and to get familiar with the data. After focusing on the phenomenon under study, the text was divided into smaller parts called meaning units. Next, statements pertaining to words or phrases that captured various meanings of the phenomenon were identified and grouped together. In distinguishing the cluster of meaning units, the everyday language of the participants was used to avoid the influence of theoretical explanations. Then, the concrete data were transformed into abstract scientific language, organising the parts into patterns that generated a general structure that is the phenomenon's essence and its constituents.

Results

The essential picture of the phenomenon was experienced 'as a meaningful and meaningless existence' and was reflected in residents' descriptions of their everyday life in an institutional care setting. A meaningful and meaningless existence revealed itself as an ambivalent dependency, implying that residents accepted their dependency in relation to their disability, yet at the same time their dependency meant that they had no other choices than being reliant on institutional care. A meaningful and meaningless existence in everyday life involved social interactions with other residents and staff, which on the one hand gave meaning in having a social network and on the other feelings of insecurity. The overall everyday life in an institutional care setting was described as a meaningless experience as it meant living in a reduced 'life space'. The feeling of living a restricted life overshadowing the whole of their existence and made it, on occasion, hard to endure. The essence of their experience can be described in the three constituents as follows: ambivalent dependency, social interactions and everyday life in a restricted area.

Ambivalent dependency

Everyday life for the residents meant being dependent on institutional care. Residents were forced to conform to this everyday life, having no other choices. Residents meant that they had not chosen to be dependent on institutional care, in the first place. They thought that life in their situation was simply that way based on an understanding that their relocation was related to having no one else to care for them at home. Further, the residents pointed out that their stay was only temporary as they had no idea how long the duration of their stay was. For example, one resident said:

I moved here because my mom couldn't take care of me any longer...we fought a lot...and the municipality had no apartment for me...I'd love to come home as soon as they have arranged a home for me. I have lived long enough here...(Interviewer; how do you mean?) I've been here about eight years...it's enough.

Dependency also showed itself as something vital as it was related to the residents' perception of their own disability. Residents perceived their situations as needing a great deal of help from staff to manage their every day lives. One resident said: 'The staff is very important for me in managing my daily life here'. The need of staff was experienced by residents as meaningful because it directly related to their own life situation, giving them a feeling of acceptance, which to some extent is expressed in following quotation:

I am thirty three years old...and I have an intellectual disability since I fell down from a tree when I was five years old. Now,... I am like an old man who needs help every day. I need staff to remind me to wake up, go to work, school and do laundry...//...the staff is great here. I can not live without the help from staff.

Another aspect of their ambivalent dependency was characterised by having trust in staff. For example, knowing that staff was available in their immediate vicinity 24 hours a day gave them feelings of safety. At the same time, they experienced feelings of vulnerability, insecurity and loneliness in not knowing whether or not staff would come or who would take care of them:

One night there were no ordinary staff in my house...they was just vicar here...and everyone had gone away to another house. I rang and rang for the staff...I was worried...I wished that they would come...I needed their help because I felt bad and wanted to cut myself.

In addition, ambivalent dependency was strengthened by how residents were treated and encountered by staff. Staff who listened and had the ability to respond to them with respect gave them a feeling of being valued and understood on their own terms, thus creating a meaningful encounter, which, to some extent, is expressed in the following quotation by one resident:

He (staff) is always friendly and talks to me in a nice manner...if I do not understand at once what he means he repeats it until I understand...he never gets mad at me...sometimes when I'm tired, he lets me rest... He is calm, whatever happens down here in daily activities.

At the same time, staff could destroy residents' feelings of meaningfulness by showing them a negative attitude and/or brusque behaviour in their encounters. One resident said: 'one of the staff is always yelling at me...he totally dictates my life with his angry attitude'. Such dependency was described by residents as feeling exposed and having nowhere else to go, which is evident in the following field note from one of the group homes where four residents lived:

After a weekend meal when the residents were permitted to drink Saturday Soda, one of the residents was assigned to clear the table. He forgets to remove the empty cans from the table and suddenly one of the personnel raises her voice and tells the resident "how many times do I have to tell you that you must learn to set the empty can at the right place. You know as well as I do that it is important to follow the rules of the house, everyone does that!". Later in an informal conversation the resident describes his feelings, saying that he has nowhere else to go...he has to stay as much as possible in his room, especially when that staff is working.

Social interaction

A meaningful and meaningless existence in everyday life involved socialising with other residents and staff, and social interaction was meaningful in the sense that it created an opportunity for residents to establish social contact yet at the same time meaningless as feelings of insecurity could arise in meeting other people. Social well-being, that is, feeling secure in a social environment, increased when residents felt a bond between themselves and a certain member of staff. This connection created a sense of having special access to a particular staff member and a feeling of commitment towards that person emerged.

For example, upon arrival, residents were given a 'contact person' who they perceived as being especially focused and responsive to their individual needs and who they felt took them seriously, which is evident in the following excerpt from an interview:

Anna (staff) took care of me the first day when I moved in here. I was very anxious...I was afraid... Anna listened to me....and showed me where to live and work. Anna is my contact person...(Interviewer: can you please tell me what a contact person is?). Anna is helping me with many things...she is buying clothes for me and to my child in Africa...Anna has helped me to sponsor a child in Ghana. Anna is helping me writing letters in English on the computer...to the child in Ghana.

At the same time, as the contact person was the one who gave them permanent feelings of security, it was the same staff who could unexpectedly give rise to a sense of loss. Social interaction gave a sense of meaninglessness in relation to the staff's lack of continuity. The residents experienced a sense of vulnerability when in the care of staff members who were strangers to them and who did not know how to meet their individual needs:

I miss Maria (staff) very much. Maria meant everything to me and we did fun things together, we went to movies and we bought clothes to me, then one day she said that she was forced by the management to work in another house. I do not really understand why it had to be so. I have difficulty with the new guy (staff) who started working here, he does not understand me as good as Maria...(Interviewer: how do you mean?...He forget important things...he is not as careful as Maria when he help me with the shower, it is too hot water and I get shampoo in my eyes).

Social interaction gave residents the opportunity to establish durable social networks with each other. Over time, they developed social relationships with each other, and to some extent, they also learned to understand each other's ways of expression. Residents learned to interpret each others facial

expressions, sounds and body language. It meant that they could predict other residents' reactions and having control over their situation, which is evident in the following field note from one of the group homes where four residents lived:

Two female residents were sitting next to each other watching TV in the group room. Suddenly one of them starts to swing back and forth with her body. The other resident gets up and goes immediately to her room. I follow her and ask her why she left. She says that "She (the other resident) usually gets like that when she is anxious and when she is, she can start to fight! In that case it is better to leave."

Occasionally, social relationships led to friendships and even love affairs and engagements between residents occurred. Over time, a solidarity developed between the residents, meaning that they protected and helped each other. It was particularly noticeable between residents who were less disabled than those who were more disabled and meant that residents helped each other whenever they could. The residents explained that offering support to others was a source of joy. The following field note describes how one of the residents takes care of another resident:

There are four houses in a row on the side of a road. A resident living in a house situated farthest away makes a practice of collecting another resident on his way to work since it is difficult for him to get to work due to a stroke. Both of them walk together arm in arm on the snowy and slippery path. Later, when I ask him "why he picks him up every morning" he answers that he thinks it is good to do something for someone else and that his job is even more fun when Mats comes with him.

Social interaction also meant being in a social environment 24 hours a day with individuals who residents themselves had not chosen to live with. It meant that residents had to encounter daily aggressive and self-destructive residents and that they were on occasion prey to bullying by other residents. The residents said that it was difficult to avoid such experiences as they happened sporadically. During the fieldwork and when questioning residents about their feelings during such incidents, one of the residents said:

It's very hard, I am always terrified when he is around...once he hit me very hard...I happened to come to close to him and no staff were nearby and could help me.

The residents also expressed feelings of anxiety when being in a noisy environment, experiencing it as though it were a permanent situation and something that they had to become accustomed to. At the same time, they expressed uncertainty as to how staff could cope:

The new guy that moved in screams all night and cuts himself with CDs. The personnel can't seem to control him. It's really difficult. The new people that come here feel bad and it just gets worse and worse.

Uncertainty and lack of confidence in the staff's ability to contend with the situation resulted in residents developing their own coping strategies, as one resident said: 'When my neighbour screams and pounding his head into the wall...I can't sleep...I listen to loud music through my headphones.'

Everyday life in a restricted area

Everyday life in an institutional care setting was described by residents as living every day life in a restricted area. It involved a reduced 'life space' and emerged around staff routines. For example, night staff was instructed by management to get residents out of bed just before they went off duty at 7 A.M. Day staff were then to get residents washed, dressed and to breakfast before 7:30 A.M. After that, residents walked with the staff to their work a few hundred yards from home and worked between 8 A.M. and 16 A.M. Their evening routines were regulated similarly and most residents were in their rooms before the day staff went off duty at 9 P.M. The residents were allowed little choice in the matter and were to keep to the routine.

Everyday life in a restricted area meant that the residents had a structured lifestyle in relation to social activities. One of the residents said: 'living here means doing the same thing over and over again...day after day'. For example, residents were given various work assignments that were limited to doing miscellaneous contract work in the sewing work shop, machinery or assembly hall:

It is quite a monotonous job...doing the same thing every day...before I had another job, a real job...I worked as an assistant in a butcher shop...here, you can't choose what you want to do...it is very noisy too...I am so tired of everyone yelling down here...I would like to change work tasks, but the staff says there are no other jobs...and outside there are no jobs and a lot of people are unemployed so for a guy like me it is difficult to find a real job.

Daily life in a restricted area included also following various rules. For example, the 'house rule', which meant that the residents were forced to adapt to certain restrictions such as those in communal areas that required that refrigerators and closets were kept locked. Another 'house rule' stipulated that that residents were to follow specific meal orders, shower times and various rules of conduct. One rule of conduct was seclusion and meant that residents had to remain in their rooms directly after returning home from daily occupation.

The staff decided when residents were allowed to leave their rooms:

The staff told me to stay in my room. They decide when I should have time-out (Interviewer: what does time-out means?). It means that when I am calm I am allowed to come out and eat dinner. It's the staff who decides.

The restricted area affected the staff's behaviour negatively towards residents. Residents were used to being threatened and punished when the rules and regulations were broken, and as a result, they had learned how to behave towards staff. For example, residents 'knew' how to respond in relation to certain staff members.

When Karin is at work you have to watch out (Interviewer: what do you mean?) She gets really mad at me when I embroider and sing. She starts to tell me off. She threatens me and says that if I don't stop she'll turn off the radio. But if I am quiet she let's me listen. That's why I am quiet at work.

Discussion

The focus of this study has been to gain a better understanding of how adults with intellectual disabilities experience their lives in an institutionalised care setting. A lifeworld approach was used to gain deeper insight into residents' thoughts and feelings regarding their daily life. The residents' experiences within this setting are the basis for which meaning can be derived and is defined here using two categories: meaningful existence and meaningless existence. Furthermore, the descriptions that residents gave of their daily lives allowed access into their human needs and what constitutes a meaningful and/or meaningless existence.

Residents explicitly expressed ambivalence when describing their dependency on staff in everyday life. Dependency can be understood in this context as follows 'one does not saw off the branch one is sitting on'. Being dependent on institutional care and facing the inevitability of not being able to manage everyday life by one self is problematic and at times dehumanising. Residents were forced to rely on the staff giving them the care that they are dependent on. This study maintains that it is better for residents to receive care than not to receive it at all. The ambivalent situation of dependency is in itself not something that residents are able to do something about, they can only accept it. To adapt, residents try to find meaning in what they experience, choosing to view as 'acceptable' dependency. The residents' descriptions reveal that they are emotionally and physically attached to the staff and bound to the care they offer. Residents' everyday life can be understood as synonymous

with being tormented by ambivalent feelings of being trapped in the care situation. This can clearly be seen in their relationships with other residents the staff and their environment.

This type of dependency can be illustrated with the help of Noddings' care theory. According to Noddings (2002), care theory emphasises caring as an attribute of certain relationships. Care theory is needs based, that is, a carer responds to the needs of the cared for and, when that response is received as caring, the relation between carer and cared for is rightly recognised as a caring relation (Noddings 2002, p.442). In this study, such care relation was experienced by residents as being dependent and or attached to certain staff and bound to the care they offered. It can be understood that the meaning of dependency on care is embedded within the staff-residents relationship. The residents valued opportunities that were given for social interaction with the staff, that is, the 'contact person'. Such a relationship can be understood in terms of the staff providing care and support with respect for individual autonomy (MacDonald 2002), which is also emphasised in The National Board of Health and Welfare (2010b) which highlights that people with intellectual disabilities should have access to a 'contact person' as it results in feelings of well-being and maintains the opportunities to exercise participation and influence over daily lives. Seemingly, the management and staff in this study have succeeded in following the Swedish law in this area.

Deely (2002) points out that the manner in which carers work and behave towards people with intellectual disabilities is crucial in affecting whether or not they can participate and influence their life situation. Noddings (2002) argues that the love and trust offered by those carers who listen may have a strong therapeutic effect. It can be argued that such relationships as Deely and Noddings describe contribute to a sense of well-being. Well-being can be characterised as a subjective impression associated with an individual's inner experiences and is therefore unique and individual (Eriksson 1994). In this study, well-being seemed to be linked to an individual experience of receiving care and support, provided by a certain staff member, that is, 'contact person'.

Various aspects gave rise to feelings of a meaningless existence for the residents in the institutional care setting. One aspect was that routines and rituals overwhelmed everyday life, which means that residents lost much of their freedom of choice in everyday life. For example, rules for seclusion existed forcing the residents to stay in their rooms when returning from work and the need for permission of staff to leave their room. According to Goffman (1961), treatment in institutional care is often used to reinforced

rituals of dispossession, and everyday activities often require permission from staff. Jenkins (2000) added that 'routines and rules are potent ways to put – keep – people in their place'. In this study, residents had to live in a reduced 'life space'. Previous research has shown that carers in institutional care settings have difficulties in providing individualised care (Kim *et al.* 2001). In a study by Kayser-Jones *et al.* (2003), it was found that uneducated carers in long-term care for older people were not aware of how their attitudes influenced residents' dependency. It may be argued that staff in this study were unreflective about their everyday work with the residents.

The fact that residents had become used to being threatened and punished by staff when rules and regulations were violated, also violates the residents' right to be treated with dignity. In this study, this violation on an individual's dignity can be understood by Goffman (1961) as the institutional care effort to transform the resident's identity with regular rules and routines.

Further, residents commonly experienced that they were not being able to influence their life situation in full. Here, it can be understood as a frustration because of a lack of control. According to Hauge and Heggen (2008), a lack of control over the situation constitutes an enforced relationship, as the residents in institutional care cannot escape from the situation. Goffman (1961) takes up the impact of institutional care on its residents maintaining that it can transform resident's identity and self-esteem and describes the subtle way that this system is maintained under the rationale of the person's best interest. There is therefore a need for further research in exploring the experiences of staff working for adults with intellectual disabilities in institutional care settings.

Conclusions

The lived experiences collected for this study reveal the importance of paying close attention to what adults with intellectual disabilities have to say about the present conditions of their everyday life when living in an institutional care setting. For caring practices of people with intellectual disabilities, it is scarcely satisfactory that residents experience an ambivalent dependency and of having to live everyday life in a restricted area. It could be understood that the meaning of dependency on care is embedded within the staff-residents relationship. Therefore, it would be interesting in further research to disclose the staff's perspectives on the phenomenon of giving care for adults with intellectual disabilities in an institutional care setting.

Relevance to clinical practice

The results of this study contribute to insights and deeper knowledge that can significantly enhance staff and an organisation's ability to question its taken-for-granted practices. The results can provide feedback to staff, managers and researchers working in the intellectual disabilities field. However, it is crucial that further studies are undertaken to try to understand the feelings and perceptions of staff who, until recently, now have worked in the context of long-term institutional care. It may then be possible to find effective ways to provide support for staff and management.

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Contributions

Study design: LBH; data collection and analysis: LBH and manuscript preparation: LBH.

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III

Service managers' experiences of how the participation of people with intellectual disabilities can be promoted in Swedish group homes

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Abstract

Background: People with intellectual disabilities in staffed group homes often need lifelong support and dependency on others. Thereby, special demands are placed on staff and service managers to ensure opportunities for participation in everyday life. This study aims to explore how service managers promote participation in Swedish group homes for adults with intellectual disabilities.

Method: A qualitative research design involving individual interviews with 14 service managers was used to gain an understanding of how the participation of adults with intellectual disabilities can be promoted in Swedish group homes.

Results: The results comprise two main themes; Creating preconditions for participation and Barriers for promotion of participation.

Conclusions: Service managers experienced that promoting service user participation in group homes was an important part of their responsibility. The findings indicate that structural strategies such as coaching, supervision and reflection are important and should be further developed.

KEYWORDS

experiences, group home, participation, people with intellectual disabilities, service manager

1 | INTRODUCTION

The ideological disability policy emphasizes that people with intellectual disabilities should be given the opportunity to participate in society (United Nations, 2006) and also when residing in group homes (The Swedish Agency for Participation, 2015; The National Board of Health and Welfare, 2017). Participation is defined as a person's involvement in a life situation (World Health Organization, 2001). The definition of participation in the present study originates from active support, described as the relationship between staff and the people they support that provides assistance to enable a person to successfully participate in meaningful activities and social relationships (Bigby, Bould, & Beadle-Brown, 2017; Mansell & Beadle-Brown, 2012). A recent study has also shown that before participation can be created, a trustful relationship must be established between the professionals and people with intellectual

disabilities (Collings, Dew, & Dowse, 2018). However, in what way adults with intellectual disabilities can be involved and participate in everyday life, when residing in group homes, may also depend on how that support is organized by service managers. Service managers are responsible for developing and promoting the support provided by frontline staff (Deveau & McGill, 2016). The current study focuses upon the experiences of service managers who are directly responsible for managing and supporting staff in group homes for adults with intellectual disabilities.

People with intellectual disabilities in staffed group homes often need lifelong support and are inadvertently put in a position of dependency on others (Bailey, Doody, & Lyons, 2016). Thereby, special demands are placed on staff, service managers and the organization to ensure that people with intellectual disabilities have the opportunity to participate in everyday life. Previous studies have revealed that support to staff from their immediate manager may be

an important factor for development and improvement of necessary staff skills (Deveau & McGill, 2016). Studies have also shown that managers' leadership and way of motivating staff can result in better outcomes for residents in group homes in terms of participation and increased independence (Bigby, Knox, Beadle-Brown, & Clement, 2015; Deveau & McGill, 2014; Jackson, 2011). Beadle-Brown et al. (2014) state that practice leadership provided by the service manager is of importance when supporting staff to pay close attention to the provision of active support. The concept of practice leadership is defined as the development and maintenance of good staff support for residents, for example by service managers observing how staff members work and act as well as providing immediate feedback and supervision in everyday practice (Deveau & McGill, 2016; Mansell & Beadle-Brown, 2012). Moreover, practice leadership also involves staff working in accordance with the active support evidence-based model, which facilitates autonomy in daily life for people with intellectual disabilities (Beadle-Brown et al., 2014; Deveau & McGill, 2014; Mansell & Beadle-Brown, 2012). This combination of practice leadership and active support provides enhanced support for staff as well as a better outcome for people with intellectual disabilities (Beadle-Brown et al., 2014; Mansell & Beadle-Brown, 2012). Bigby and Beadle-Brown (2016a) also noted that the challenges facing by service managers concern not only how to provide the necessary skills for working according to the active support model but also how to motivate staff members to employ the model in a consistent and systematic way to promote participation.

The evidence-based models such as active support and practice leadership are not yet implemented in Sweden (The National Board of Health and Welfare, 2017). However, a non-evidence-based model which is used in some organizations is the participation model. The participation model aims to provide opportunities for service users to participate in formally organized activities in group homes. The model is based on dialogue discussions, conducted in smaller groups of residents led by a supervisor. The dialogue discussion is evaluated by the service manager in order to enable residents' opinions and interests to be taken serious and implemented in the everyday practice (Gullacksen & Hejdedal, 2014). Further, the model of participation is a framework that can support service managers when creating an organizational structure that promotes opportunities for participation and social inclusion at a micro level such as a group home. Consequently, the model of participation may be an important part of organizational strategies to be used by the service manager to achieve and ensure participation, rather than being synonymous to practice leadership. Moreover, the participation model by Gullacksen and Hejdedal (2014) is not empirically tested in research but can be seen as a first step in strengthening empowerment for service users in order to facilitate participation in social activities in a broader community in the society as described by Bigby, Andersson, and Cameron (2017).

However, previous research shows that barriers for participation in everyday life for people with intellectual disabilities residing in group homes still exist. Such barriers may occur due to the approach and attitudes of staff (Bigby, Knox, Beadle-Brown, Clement,

& Mansell, 2012; Deveau & McGill, 2014) and to the delivery of support and care (Bigby, Frawley, & Ramcharan, 2014; Mansell & Beadle-Brown, 2012). Further aspects that can constitute limitations for participation are staff values and existing cultures in group homes (Bigby & Beadle-Brown, 2016b; Clement & Bigby, 2010) as well as structural barriers related to how the overall management and the organization support service managers in their everyday work (Beadle-Brown et al., 2014; Berlin Hallrup, 2012; Bigby & Beadle-Brown, 2016b).

Social service for people with intellectual disabilities in Sweden is funded by taxes and regulated by the Act concerning support for persons with certain functional impairments (SFS 1993:387). Sweden has 290 politically driven and self-governing municipalities that are responsible for providing support in accordance with the Act. Service managers are responsible for implementing the intentions of the legislation on participation and ensuring that it is followed by all staff employed in group homes (The National Board of Health and Welfare, 2017). Moreover, the Act stipulates that participation is the key goal and describes that service managers in group homes should work closely with the staff in order to better support and guide them in daily work. Service manager's leadership in Sweden can thus be described in line with what Deveau and McGill (2016) describe as frontline managers, which means coaching, counselling and supporting staff in daily service delivery.

The most common support for people with intellectual disabilities is day care activities and group homes (The National Board of Health and Welfare, 2018). There are approximately 27,000 people with intellectual disabilities residing in staffed group homes in Sweden, and it is regulated that a maximum of six residents reside in each group home (The National Board of Health and Welfare, 2018). Concurrently, considering that the responsibility for providing support is decentralized to the municipalities it can be some differences between them.

Despite previous research, how service managers create opportunities for participation for adults with intellectual disabilities in Sweden as well as in other countries remains relatively unknown (Beadle-Brown et al., 2014; Bigby & Beadle-Brown, 2016a; Deveau & McGill, 2016; Jackson, 2011). Service managers who are responsible for the day-to-day care of adults with intellectual disabilities in staffed group homes can be assumed to be in a position to improve staff performance which may increase opportunities for participation for residents in group homes. Therefore, the aim of the present study was to explore service managers' experiences of how the participation of adults with intellectual disabilities can be promoted in Swedish group homes.

2 | METHOD

2.1 | Methodology and design

This is a qualitative explorative study underpinned by a constructivist epistemological lens. The qualitative design was used to gain

an understanding of service managers everyday experiences of how the participation of adults with intellectual disabilities can be promoted in Swedish group homes. The constructivist epistemological lens allowed an approach where the researchers and informants interacted and co-constructed knowledge based on their experiences. This implies that the researchers participated in the research process with the subjects in producing knowledge that is reflective to the informants reality (Lincoln, Lynham, & Guba, 2018). Thus, the epistemological assumption is that participation for adults with intellectual disabilities and how that can be promoted by service managers is inherent in their experiences.

2.2 | Informants

In this study, service managers are directly responsible for managing and supporting staff in group homes for adults with intellectual disabilities. Strategic sampling was employed to select 20 different municipalities representing large cities, small towns and rural areas. One service manager in each municipality was contacted by e-mail with information about the study and that a criterion for participation was at least one year's experience as a service manager of a group home for adults with intellectual disabilities. They were also informed that participation was voluntary and requested to reply to the e-mail within 2 months. Six informants declined participation, three due to lack of time while three gave no reason. Thus, 14 informants (13 women and 1 man) agreed to participate. Their work experience ranged from 4 to 35 years. Ethical approval for the study was granted by The Swedish Regional Ethical Review Board (Reg. No. 2016-712).

2.3 | Setting

The informants were service managers of group homes for adults over the age of 20, with intellectual disabilities who were autistic or had a condition resembling autism. They were all responsible for at least one group home with a maximum of six residents and some for up to five group homes, which meant approximately 6–35 residents and 20–60 part-time and permanent employees. While in some group homes the residents lived more or less independently, those included in the present study are staffed on a 24 hr basis.

2.4 | Data collection

Individual interviews with 14 service managers were used to gain an understanding of their experiences of how the participation of adults with intellectual disabilities can be promoted in Swedish group homes. The time and place for each interview were agreed by the informants and the first author. The interviews were conducted between August and November 2016. Each interview started with the opening question "Can you please describe what participation for adults with intellectual disabilities means to you?", followed by "How do you promote participation for adults with intellectual disabilities in a group home?". Probing questions such as "What do you mean?" or "Can you tell me more about that?" were posed in order to facilitate deeper reflection on the part of the informants. The interviews lasted between 60 and 80 min, were performed in a secluded room, digitally recorded and transcribed verbatim by the first author.

2.5 | Data analysis

The data analysis was conducted in accordance with thematic content analysis by Braun and Clarke (2006). Initially, the first author transcribed the recorded interviews, and then, all authors independently read the interviews several times. Each author identified and generated descriptive codes that grouped data based on similar experiences and topics. The next stage of analysis included all authors, coding and sorting the transcripts in order to organize them into patterns highlighting meaningful subthemes. Further, the analysis continued by identifying important themes collating all data extracts that had been coded. Once completed, the analysis provided repeated opportunities to cross-check raw data against emergent themes, thus ensuring credibility and trustworthy. Table 1 provides an example of the analysis process from data to codes to identify the main themes "Creating preconditions for participation" and "Barriers for promotion of participation" (Table 1).

3 | FINDINGS

The informants' experiences of how participation can be promoted in group homes for adults with intellectual disabilities consisted of

TABLE 1 Development of codes and subthemes from data for the main themes "Creating preconditions for participation" and "Barriers for promotion of participation"

Quotes	Codes	Subthemes	Themes
"First, staff must create a relation-ship built on trust...//"	Build trust	Facilitating a trusting relationship	Creating preconditions for participation
"In addition to my support, I arrange supervision...//"	Arrange supervision	Supporting staff to increase participation	Creating preconditions for participation
"Sometimes both staff and users wishes are overuled by next of kin...//"	Restrictions	Restrictions that hinder participation	Barriers for promotion of participation
"I miss the occupational therapist...//"	Lack of support	Managing while experiencing a lack of support	Barriers for promotion of participation

FIGURE 1 Thematic map of the two main themes and subthemes relating to service managers' experiences of how the participation of people with intellectual disabilities can be promoted in Swedish group homes

two main themes: "Creating preconditions for participation" and "Barriers for promotion of participation." Creating preconditions for participation comprised the following subthemes: *Facilitating a trusting relationship* and *Supporting staff to increase participation*. The second main theme, Barriers for promotion of participation, included two subthemes: *Restrictions that hinder participation* and *Managing while experiencing a lack of support* (Figure 1). In the findings section, the term service user will be employed as a synonym for adults with intellectual disabilities.

3.1 | Creating preconditions for participation

The informants described always putting the service users first and used various organizational structures and approaches to encourage staff to support and work in a way that increased service user participation. In order to find ways of creating preconditions for participation, they created structures to facilitate a trusting relationship between staff and service users by ensuring that staff had certain responsibilities and enough time to get to know the service users. Another important aspect was using individualized implementation plans based on the needs of service users. To further fulfil the participation ideology, the informants provided supervision, used a reflected approach in day-to-day work with staff and applied strategies such as the participation model.

3.1.1 | Facilitating a trusting relationship

Facilitating participation meant that the informants assumed that staff initially needed to develop a trusting relationship with each service user. According to the informants, trust was crucial for service users' feelings of confidence. They believed that a trusting relationship was necessary and something that service users could benefit from when developing their own individual strategies for participating in everyday life. The following statement exemplifies this belief:

First, staff must create a relationship built on trust with the service users. It is important. If they have no relationship with the individual, nothing will work.

(Informant 9)

In order to facilitate a trusting relationship, the informants provided their employees with sufficient time to get to know

each service user. The informants explained that staff were given a certain responsibility in the group home, which meant that one staff member was a so-called "contact person" for a new resident. The contact person had the responsibility for gaining a deeper understanding of the individual's needs and formulating an individually based "implementation plan." This gave the service user an opportunity to be involved in how service and support were to be provided by staff and what such service and support should entail.

The implementation plan should be formulated without delay. When someone moves in here, she/he receives a contact person and then the formulation of the implementation plan starts immediately.

(Informant 1)

The informants expressed that facilitating a trusting relationship was an ongoing process that was constantly developing as they tested new strategies and ways of working. This could involve the introduction of new activities to empower service users to further express their opinions.

We have taken it a step further....//...as we have a coordinator for participation, she ensures that service users receive assistance with communication tools so that they have a better opportunity to express themselves at meetings.

(Informant 10)

The informants also expressed that facilitating a trusting relationship to increase participation, meant encouraging and challenging service users to become even more active and visible, such as participating in the recruitment of new staff.

3.1.2 | Supporting staff to increase participation

The informants also needed to support the staff in their everyday work by means of various strategies in order to successfully create preconditions for service user participation. One of the strategies for them was to be present in the group homes and assist staff members in organizing their daily work as means of increasing the focus on participation. Another important strategy for supporting staff in their efforts to increase participation was supervision. The

informants sometimes provided one-to-one and group supervision themselves or in collaboration with professional supervisors.

In addition to my support, I arrange supervision for staff, which is necessary. For one group we have supervision regarding work place meetings and we also have individual supervision where the supervisor has been involved in the whole process.

(Informant 2)

The informants described having a reflective approach and challenging the staff members' assumptions and prejudices, such as when various ethical dilemmas arose, for example involving a service user with no verbal skills.

How can we find out what he wants? The staff came up with the idea of showing him pictures of various dishes and suddenly he pointed to the food he wanted or did not want. It is important to constantly challenge staff and give them the opportunity to reflect on what other options that are available for service users.

(Informant 13)

The informants also highlighted the importance of continuous staff education. They were convinced that the staff members needed in-depth knowledge and education about, for example, disabilities and pedagogical approaches.

It is important for the staff to have knowledge of disability legislation, but also about pedagogical approaches...in this municipality we have invested a lot in various forms of staff training.

(Informant 8)

The informants described the necessity of ensuring that staffing and schedules were based on when and how service users needed assistance and support. They also strived to stimulate that regular and recurring structures for participation were embedded in daily work. One such structure included to create a forum for dialogue such as the participation model between service users and a certain employee with responsibility as a supervisor. This model was considered as a necessary strategy not only to address the wishes and needs of service users, but also as a means to develop the staff's knowledge of the users' wishes and needs.

We call it the participation model, we have trained an employee with a certain responsibility who does not work in that specific group home who has meetings four times a year with service users. The model is based on the assumption that service users should express their preferences and opinions in relation to their accommodation in the group home.

(Informant 11)

3.2 | Barriers for promotion of participation

Although the informants described opportunities for participation, they also expressed that from time to time they experienced barriers that prevented them from promoting increased participation. The barriers led to a tension between trying to enable participation in accordance with disability legislation and adapting to existing conditions and restrictions that limited their opportunity to do so. They described that there still exist restrictions that hinder participation such as attitudes by staff or next of kin and a lack of physical space in the group home. Informants also stated that managing was a sense of lacking necessary support by the overall management, due to financial or political decisions.

3.2.1 | Restrictions that hinder participation

According to the informants, restrictions that hinder participation could be due to low staff turnover and the fact that employees had worked in the same group home for too long. The informants reported that staff members who had worked in the same place for many years found it more difficult to change their approach encouraging and promoting service user participation.

A few days ago I asked staff member in one of my group homes about what service users want and the answer I received was, What? What do you mean?

(Informant 6)

The attitudes of next of kin also contributed to restrictions in enabling participation, especially when they lacked knowledge about disability legislation and service users' right to influence and participate in daily life.

Next of kin have very strong opinions. Often the residents tell the staff what they would like, but their next of kin object. Sometimes both staff members' and service users' wishes are overruled by next of kin.

(Informant 12)

According to the informants, there were also physical restrictions in the group homes, such as a lack of space enabling social interaction between service users, staff and visitors. Hence, service users had to stay in their apartments.

There is no real community room for service users, when you enter you go straight into the TV room. It is more like a giant hall or corridor. It is difficult for visitors and service users to meet socially, so instead service users stay in their own apartments.

(Informant 12)

3.2.2 | Managing while experiencing a lack of support

The informants were aware of the structural strategies, necessary for creating and increasing successful service user participation. At the same time, they felt limited by various aspects, such as the overall management, the organization or political directives that prioritized the need to adhere to the budget in the municipality. Such directives made the informants feel that they lacked necessary support from allied health professionals and instead they had to manage by themselves.

I miss the occupational therapist as that profession is important for making staff members understand at what level they should communicate and what communication service users might need. (Informant 7)

The informants described that they sometimes felt lonely and lacked time, which led to a sense of resignation about developing the necessary improvements for staff.

I am alone and responsible for five group homes right now...//...the development ideas that I had, such as implementing the participation model, have grounded to a halt. I have no time to follow things up, it is not worth starting something new when I do not have enough time to make staff members familiar with it... or follow it up...right now it is sort of work done in vain. (Informant 13)

Managing while experiencing a lack of support meant that the informants missed a clear vision on the part of the overall management which led to feelings of frustration, especially, when there was a high turnover among top-line and administrative managers. The informants described an occasional lack of understanding support from the overall management. The informants expressed that they felt overruled due to political decisions as well as governed by overarching systems, making them unable to influence and promote participation.

We are also governed by policies and union interests; for example, we must endeavor to ensure the right of all employees to work full-time...even if I do not need so many full-time employees. I prefer to focus instead on promoting and starting...such as the participation model for service users. (Informant 1)

4 | DISCUSSION

Our study illustrates the significance service managers place on their responsibility for the promotion of service users opportunities for active participation. For this work, they describe the various

strategies used to fulfil the intentions of the Swedish disability participation policy.

One such prominent strategy described in this study was to be present as a leader providing support and instant feedback to the staff in their efforts to include service users' needs and perspectives. Thus, the informants regarded themselves as role models and interacted in day-to-day practice by observing and providing supervision to staff. This strategy indicates that daily support to staff is important in order to enable conditions for participation for service users in group homes. Based on these findings, we argue that the service manager leadership described by the informants as being attentive to staff providing instant feedback and supervision may be compared to what earlier research define as practice leadership (Deveau & McGill, 2016; Mansell & Beadle-Brown, 2012).

Another strategy stated by the informants was to establish a trusting relationship between staff and service users. The informants assumed that a trusting relationship was necessary to develop at an early stage in order to establish sustainable opportunities for participation. Similar findings have been reported by Collings et al. (2018) who highlight person-centred approaches, which describes that the relationship between practitioners and people with intellectual disabilities should be based on trust and to get to know the person before engaging them in further activities.

Furthermore, the participation model was put forward by the informants as a strategy that provided a structure for how participation for service users could be organized and as such it was considered an asset in achieving necessary quality goals. The model provided ways for the service managers how to create social and including arenas where service users and staff could meet. Our findings thereby contribute to previous research by Gullacksen and Hejdedal (2014) who states that the initial purpose of the participation model was to empower people with intellectual disabilities to be engaged in meaningful activities as well as in relationships with others. According to Gullacksen and Hejdedal (2014), the participation model can contribute to greater influence and participation as it allows an open space where service users can feel comfortable sharing their views in a group home. However, the model may also exclude people with severe and profound intellectual disabilities because they sometimes lack communication skills. Therefore, we suggest that future studies explore how the model can be developed to better suit the needs of this vulnerable group.

The informants described the occasional lack of support from overall management, which limited their efforts to promote participation and the implementation of the participation model. This can be seen as a serious shortcoming as a prerequisite for the participation model to lead to successful results is that the entire organization is willing to integrate the model (Gullacksen & Hejdedal, 2014). This suggests that it is important that the overall management ensure that service managers have enough resources to properly implement the participation model. Therefore, we suggest that the participation model is implemented and systematically tested in future studies.

The informant's experienced several barriers that limited their opportunity to enhance participation. Sometimes they felt abandoned

as they lacked necessary support from other professionals such as occupational therapists due to financial directives. Further, service managers described that staff who had worked for longer periods in group homes were less inclined to change their attitude to enable participation. In other words, it may mean that low staff turnover could contribute to a culture that is less likely to promote participation for service users. Similar findings were reported by Bigby (2012), that on the one hand, staff longevity may help to shape the culture of a group home, and on the other hand, it can perpetuate a culture where residents are regarded as "others."

Findings in this study showed that service managers attempted to promote staff to deliver better disability practice based on the disability ideology of participation. Having the responsibility as a service manager and providing policies at a local level can be understood in the light of the concept of "street-level bureaucracy" described by Lipsky (1980). Lipsky (1980) argued that "decisions of street-level bureaucrats, the routines they establish and the devices they invent to cope with uncertainty and work pressures, effectively become the public policies they carry out" (p.xiii). In this study, service managers can be described as street-level practitioners trying to adapt and transform the national disability policy to professional values and local strategies. At the same time, a lack of support due to local political or financial decisions gave the service managers a sense of underperforming in their daily mission to promote participation. It may also imply that service managers struggle and manage alone while experiencing a lack of support for making good disability practice even better.

5 | STRENGTHS AND LIMITATIONS

The present study focused primarily on a strategic sample of 14 service managers' experiences of how participation in daily life can be promoted for adults with intellectual disabilities in Swedish staffed group homes. Thus, a limitation of the study is that only a small number of service managers participated and the staff to service users ratio was not collected.

Several criterias were used to increase trustworthiness (Lincoln & Guba, 1985). Credibility involves giving the informants a voice through a description of their individual experiences. The emerging themes were discussed among the authors until consensus was achieved, thus ensuring credibility. Moreover, to enhance dependability, the first author conducted all the interviews using an open and inductive approach. Confirmability was strengthened by illustrating the themes using quotations from the informants. Taken together, this means that the findings may be transferable to similar contexts.

6 | CONCLUSIONS

The findings contribute to an understanding of how service managers promote participation for adults with intellectual disabilities

in Swedish staffed group homes. All service managers experienced that promoting participation in everyday life for service users was an important part of their mission and professional role. In parallel with how the service managers provided support for their staff, they also needed support themselves from various key actors within the organization in order to introduce structures aimed at increasing participation. Based on the outcome of this study, we suggest that structural strategies, such as coaching, supervision and reflection, to support staff are important but can be further developed.

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CONFLICT OF INTEREST

None.

AUTHOR CONTRIBUTION

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IV

Participation in Everyday Life for People with Intellectual Disabilities in Sweden. The Experiences of Significant Others.

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Running title

Significant Others' Experiences of Participation

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Abstract

Background Many people with intellectual disabilities (ID) still lack opportunities to experience full participation, both in society and on an individual level. This means that they are dependent on other people's willingness to facilitate participation. Therefore, the aim was to explore significant others' experiences of participation in everyday life for people with ID in Sweden.

Method A qualitative study involving five focus group interviews with 34 significant others of people with ID was conducted from March 2017 to January 2018.

Findings Participation was experienced as double-edged. On the one hand, there are increasing opportunities in society for people with ID to achieve empowerment. On the other, there is still a risk of society marginalizing people with ID, something significant others must fight against.

Conclusions Significant others believe that they have an important role in facilitating and promoting participation for people with ID.

Keywords: disability policies, experiences, participation, people with intellectual disabilities, significant other, Sweden

Introduction

Many people with intellectual disabilities (ID) still lack opportunities to experience full participation, both in society in general and on an individual level (Dusseljee, Rijken, Cardol, Curfs & Groenewegen, 2011; Bigby, 2012; Bigby & Beadle-Brown, 2016). Their everyday life is characterized by loneliness as a consequence of the disability, described as the lack of ability to initiate and create social relationships (McVilly, Stancliffe, Parmenter & Burton-Smith, 2006; Petroutsou, Hassiotis & Afia, 2018). Moreover, people with ID have a limited social network that almost exclusively consists of other people with ID, staff and family members (Bigby & Knox 2009; McConkey, Kelly, Mannan & Craig, 2010). This means that for people with ID, participation depends on significant others' willingness to facilitate and promote it in everyday life (Johnson, Douglas, Bigby & Iacono, 2012). Therefore, exploring significant others' narratives may provide a complementary perspective on what participation in everyday life means for people with ID.

Previous research that includes significant others' perceptions of what participation means for people with ID is particularly scarce. However, there are a number of studies in this area that have illuminated experiences of parents of people with ID, but without a focus on participation. For instance, one study that investigated parents' experiences of having a child with ID revealed that they often had contradictory feelings; negative in terms of the diagnosis and positive in relation to the child (Boström, 2012). Moreover, the same study (aa) highlighted the fact that an open approach from professionals and the surrounding community was important both for children with ID and for their parents. One conclusion is that an open approach from professionals may increase the likelihood of participation in social life for children with ID.

Furthermore, a study by Sorbring, Molin & Löfgren-Mårtensson (2017) illuminated parents' experiences of how the internet can promote participation for young adults with ID. The study illustrated the parents' belief that the internet can facilitate participation and that they themselves were important for ensuring safe participation. A study by Larsson, Rämgård & Bolmsjö (2017) points out that significant others of people in need of elder care want to be involved, have their views taken into account and listened to but feel ignored by healthcare professionals (aa). It is therefore of interest to further investigate how significant others experience what participation means for people with ID. Thus, the aim of the study was to explore significant others' experiences of participation in everyday life for people with ID in Sweden.

Participation is the key goal of Swedish disability policy for people with ID (The Swedish Agency for Participation SFS 2014:134), which is based on the United Nations (UN) Convention on the Rights of Persons with Disabilities (UN, 2006). It is emphasized that the work to implement disability policy should focus on identifying and removing obstacles to full participation in everyday life for people with ID. The World Health Organization (WHO, 2001) has addressed participation by the development of the International Classification of Functioning, Disability and Health (ICF). According to the ICF, participation is categorized into domains such as: learning and applying knowledge; communications; domestic life; interpersonal interactions and relationships; work, school and community; social and civic life (WHO, 2001). The definition of participation in the present study is based on the ICF, in which it is described as a person's involvement in a life situation, which encompasses partaking and being accepted or engaged in an area of life. Accordingly, people with ID should have the opportunity to fully participate in society. The increasing demands for

participation of people with ID put forward by the UN, WHO and Swedish disability policies, highlight the need to further explore what participation means from the perspective of significant others.

Method

This is a qualitative study where the data were collected by means of focus groups interviews to gain an understanding of significant others' experiences of participation in everyday life for people with ID. Focus groups are suitable as they enable individuals to interact, discuss and share experiences about a common theme (Kitzinger, 1994).

Informants

The inclusion criterion in this study was members of interest groups in the disability area who had personal experience of being a significant other of a person with ID. In this study, significant other was defined as a friend, relative or legal representative who is important in some way and provides support for a person with ID (Mead, 1976).

Initially, convenience sampling was employed to select members of various interest groups in the disability area as potential informants. A letter containing information about the study was sent by e-mail to ten Swedish interest groups in the disability area. After these groups had received the study information, representative of five of them contacted the first author by e-mail, inviting her to a meeting with members of their group to pose questions and obtain information about the study. After the first meeting, the representatives of all five interest groups contacted the first author and suggested the location, time and date for the focus group interviews. In total, 34 members of interest groups (24 women and 10 men) agreed to participate, of whom 18 were parents, six were legal representatives, five were friends and five were other relatives (three siblings, one cousin and one grandmother).

Data collection

Five focus group interviews were conducted from March 2017 to January 2018 with 6-11 informants per group. Each focus group session took place in a secluded room and digitally recorded. Two researchers were involved in the first focus group interview; the first author as moderator and the last author as an observer who took notes and ensured that the technical equipment functioned correctly. The first author solely moderated the remaining four focus groups without an observer.

Each focus group session started by providing information about the purpose of the interview, the voluntary nature of participation and the informants' right to withdraw at any time. The moderator started the focus group interview with an opening question, designed to enable the informants to concentrate on the topic; "What are your experiences of participation in everyday life for people with ID?", followed by probing questions such as "What do you mean?" or "Can you tell me more about that?" in order to facilitate discussion and deepen reflection. Each interview ended with closing questions; "Did we leave out anything?", or "Is there anything you would like to add?". The focus group interviews lasted from 60 to 85 minutes.

Data analysis

The focus group interviews were transcribed verbatim, after which the transcripts were analysed using a thematic analysis procedure as described by Braun and Clarke (2006), as this method is suitable for identifying, analysing and reporting patterns in qualitative data.

Furthermore, this procedure is progressive and iterative rather than linear (Braun & Clarke, 2006), which is useful when collecting and describing subjective perceptions in a qualitative study. Inductive analysis was carried out to elucidate themes that arise naturally in the data comprising the informants’ experiences. First, the transcripts were read numerous times by all authors separately in order to become familiar with the data. Second, the transcripts were coded line-by-line and essential codes clustered into categories, including patterns highlighting meaningful sub-themes. Next, the identified sub-themes were compared with each other and labelled. The main theme, “Double-edged participation”, was found to represent all the data. Finally, illustrative quotations were selected to produce a report and to enhance credibility. Table 1 provides an example of the analysis process from data collection to the clustering of codes in order to identify the main theme “Double-edged participation” (Table 1).

TABLE 1: *Development of codes and sub-themes from data for the main theme “Double-edged participation”.*

Quotes from focus groups	Codes	Sub-themes	Main theme
“To have the opportunity to live like everyone else”...”to be able to take part in activities in the community”.	Changes in society	Opportunities to achieve empowerment	Double-edged participation
“To be given the opportunity To vote, even if they do not understand what it means to vote, but to have the opportunity to participate in that activity”.	Participate in politics	Opportunities to achieve empowerment	
“It’s ridiculous, it’s either staff or the social administrator’s who have the right to decide for them”.	Right to interpret	Fighting against marginalization	
“The municipality invite us when they have already made decisions”.	Neglect	Fighting against marginalization	

Ethical Considerations

The study was approved by The Swedish Regional Ethical Review Board (Reg.No. 2016-712). The data have been treated confidentially and no individual can be identified.

Findings

The main theme “Double-edged participation” emerged in the analysis and was interpreted from two sub-themes, which were based on the informants’ experiences: 1) Opportunities to achieve empowerment and 2) Fighting against marginalization. With regard to the presentation of the quotations, the fourth focus group, for example, is denoted FG4 and the informants are numbered consecutively, as FG4:1, FG4:2 etc.

Double-edged participation

The main theme illustrates the ambiguity of significant others' experiences of participation in the everyday life of people with ID. Participation is experienced as double-edged because on the one hand it is perceived as an ongoing and positive development in society where people with ID have obtained more opportunities to gain empowerment, and on the other, as a continuous fight against marginalization, which could jeopardize opportunities for participation.

Opportunities to achieve empowerment

Informants described opportunities to achieve empowerment as a result of important changes in society that enable participation in various life situations for people with ID. This meant that through changes in legislation, the government and the municipalities ensured increased inclusion, equality and empowerment.

To be able to take part in activities in the community (FG4:1). Participation means that the principle of normalization is followed by the municipality in terms of supporting people with intellectual disabilities so that they can be a part of society on equal terms (FG4:2). To have the opportunity to live like everyone else (FG4:3).

Informants described that such empowering processes of change also meant that people with ID were given new opportunities for participation in society. For example, when they turned 18, they were allowed to participate in politics and the democratic processes by being able to vote.

To be given the opportunity to vote, even if they do not understand what it means to vote, but having the opportunity to participate in that activity, participation is the most important thing, and having staff members available to inform them... "who do you want to lead Sweden?", "who or what party is working with disability policy issues?" To be a citizen with equal rights in the society, their voices must be considered (FG3:3).

Informants described how access to independent living, job opportunities and respectful treatment on the part of professionals led to increased self-esteem, autonomy and independence, thus providing a sense of empowerment. Another aspect of participation put forward by the informants was opportunities for community participation such as being a member of interest group for people with ID as well as those for people without ID.

In this interest group it is important that people with intellectual disabilities are represented on the board, that is participation, but unfortunately not all interest groups have it (representation), but they should be involved in all decisions taken, it is participatory, we are here for them and not vice versa (FG1:8).

Informants described that the opportunity for people with ID to live more independently in group homes or their own apartment also largely depended on their own attitude. For example, informants who were parents experienced an existential dilemma when an individual with ID was in a transition of moving out from the parents' home. Being able to let go of their adult child also meant an opportunity for the individual to become more empowered.

My daughter has developed and can do more by herself, even if it did hurt when she moved (FG1:2). Letting go as parents and allowing them to move to a group home, away from home, although it took a long time, he was 29 when he moved away from home (FG1:4).

Significant others described that being met by group home staff with a positive attitude gave them the impression that the person with ID received better treatment that promoted participation in everyday life. They also experienced that their own role was important for creating conditions for participation and wanted to share their knowledge about the individual's preferences to staff. They believed that such individual knowledge could contribute to a broader understanding of the individual's needs as well as better treatment when residing in a group home.

Supporting my adult child is important and I also want staff at the group home to feel that my knowledge and experience are of benefit to them (FG4:5). When staff members treat me with respect it makes me feel that they will also treat our daughter well (FG4:6).

Fighting against marginalization

The informants described fighting against marginalization and limited opportunities for a vulnerable group. Sometimes participation was perceived as an illusion, as the people with ID were not empowered to make their own decisions and be in control. The informants reported that it was the professionals, for example social administrators, staff and managers on all levels, who had the power and the legal right to interpret the preferences of people with ID.

It is a platitude to say that as a person with intellectual disabilities, you have the same right as everyone else, as long as the social administrators in the municipality are legally entitled to interpret their needs and wishes (FG2:4). There are limitations in the opportunity for participation and being able to live like everyone else, it's ridiculous, it's either staff or the social administrators who have the right to decide for them (FG2:3).

The informants described that as members of an interest group they wanted to be invited to forums where disability issues could be discussed with representatives from the municipality. However, they experienced though was a sense of marginalization affecting themselves and people with ID, as they felt excluded from information meetings regarding disability policy issues and decisions at municipal level.

According to the disability policies, the municipality must arrange collaboration forums with us, or with people with intellectual disabilities at least once a year, but they invite us when they have already made decisions (FG4:3). As an interest group we want to be involved before decisions are made (FG4:4).

The financial situation of the municipalities was another factor that created a risk of marginalization for people with ID, thus reducing their opportunities for participation.

Those who live in group homes in our municipality have not been given the opportunity to participate in leisure activities because of the municipality's limited budget. If they want to do something, it must be inside the group home. If any of them want to take part in any activity in the community, we have to arrange it (FG5:2). There is not enough staff in the evenings or on weekends in the group home (FG5:3).

Discussion

Our main finding, labelled double-edged participation, is based on two opposing themes, where on the one hand over time society has succeeded in promoting the participation of people with ID, while on the other, the informants have to compensate for some activities that the municipalities do not provide. This is based on the finding that significant others saw themselves as important facilitators of increased participation for a relative with ID on an individual level as well a part of an interest group that includes people with ID.

In the present study, an interesting aspect mentioned by the informants is that participation means that people with ID must be given the same opportunities for inclusion in society as everyone else. For example, they stated that participation means that the municipality adheres to the principle of normalization in terms of supporting people with ID to be a part of society on equal terms. This can be interpreted to mean that the principle of normalization is well known and recognized by the informants. Thus, opportunities for participation can be understood in the light of the paradigm shift in Swedish disability policy during the 1960s with the emergence of the principle of normalization (Nirje 1969/2003; Wolfensberger, 1972). The principle state that people with ID should be given the same opportunity to participate in society as everyone else (Wolfensberger, 1972). In Sweden, this led to a breakthrough for people with ID during the 1960s, not least due to deinstitutionalization, which contributed to more integrated accommodation in group homes. As several decades have passed since the principle of normalization was implemented in disability policies, it can be assumed to be well established today. This seems to be in line with how Nirje (1969, p.181) formulated the principle of normalization, namely “to make society accessible to people with intellectual disabilities for everyday conditions as other citizens”. Tideman (2000) emphasizes that the principle of normalization is not to change the individuals, but to normalize the conditions in the surrounding environment. Such an interpretation of the principle highlights the obstacles that exist in the environment for people with ID. This interpretation of disability policies has become increasingly important within Swedish disability policy, where both participation and accessibility are seen as areas that require further development (The Swedish Agency for Participation, 2015). The principle of normalization has contributed to an obvious improvement for the target group. However, at the same time the findings reveal in some cases, more needs to be done in order to enable people with ID to live like everyone else. For example, group home staff and social administrators are the ones who decide which support should be given, i.e., they have the right to interpret the wishes and needs of people with ID.

From a historical perspective, the principle may also be interpreted to mean that people with ID have acquired more opportunities to achieve empowerment. Empowerment can be defined as a process, which occurs on an individual, organizational and political level (Tengland, 2008). This can be interpreted as a democratic process that has given people with ID increased civil rights and opportunities to participate in society. The informants in this study stated that empowerment is demonstrated by the fact that people with ID are included to a greater extent in societal change processes by being allowed to exercise their political and democratic rights as well as having their own apartment and work. Ramcharan, Roberts, Grant & Borland (1997) argue that the aim of empowerment is participation, which includes being involved in empowering relationships. Thus, empowering relationships may be interpreted to mean that significant others have an important role in strengthening and promoting participation for people with ID. Furthermore, in this study the informants highlighted the importance of giving people with ID the opportunity participate in interest groups together with people without ID. Similar findings were reported by Bigby, Andersson

& Cameron (2017), who argued that increased participation of people with ID in social activities in which those who do not have ID also take part is crucial for improving their inclusion in the community. Based on our findings we argue that interest groups provide arenas for social inclusion, empowering relationships and may thereby contribute to increased participation for people with ID.

The present study also reveals the opposite of empowerment and participation, as significant others still have to fight against the risk of people with ID being marginalized. The findings in this study demonstrate that people with ID are not given enough opportunities to participate on similar terms as other citizens. For example, due to the financial circumstances in the municipality, there was a shortage of group home staff and consequently a lack of leisure activities. This finding corresponds with the study by Dusseljee *et al.* (2011), which highlights that participation of people with ID within the domains of work, social contact and leisure activities does not involve a high level of interaction with the community, because the majority of people in society rarely interact with individuals with ID. One can conclude, that there still exist challenges to increase participation for people with ID and that needs to be explored in the future.

Furthermore, our findings illustrate that significant others felt neglected, one clear example being an occasion when they and people with ID wanted to participate in information meetings at which the municipality was to discuss disability issues. This neglect of significant others was also found by Larsson *et al.* (2017) in elder care. Instead, professionals in the disability service should move towards a participatory approach, which means including the voices of significant others.

One can conclude that participation is a multifaceted, and double-edged concept. As it emerged that at the same time as there are opportunities for participation there is also a lack of participation, it is clear that challenges still remain that could threaten the participation of people with ID in Sweden. Such challenges are, for example, when people with ID or their significant others are not invited to participate in collaboration forums organized by the municipality as well as a lack of financial resources that creates a risk of marginalizing people with ID.

Methodological considerations

The beliefs and experiences expressed in the focus group interviews contributed to a broader understanding of participation in everyday life for people with ID. Sharing experiences in focus groups together with people the informants already knew seemed to create a relaxed and supportive atmosphere, which encourage them to discuss, interact and share their experiences of participation. A long period of contact may also increase the credibility (Lincoln & Guba, 1985), which was achieved in this study by the early contact established during the initial meeting aimed at providing information about the study and building trust. The recommendations for conducting focus group interviews state that two researchers should be present; one as the moderator who conducts the conversation and the other as an observer who makes notes (Kitzinger, 1994; Kamberelis, Dimitriadis, & Welker, 2018).

Therefore, a limitation may be that it was only possible to have a moderator and an observer during the first focus group interview. However, in this study, the moderator was well trained and the number of informants in each focus group was manageable. This resulted in

committed informants and rich discussions in all interviews. To ensure rigour, all authors read the transcribed interviews and took part in the analysis process.

Conclusions

Overall, the study highlights the importance of making use of significant others' experiences of participation in everyday life for people with ID in Sweden. Significant others' experiences contribute an important piece of the puzzle to our understanding of what participation looks like for a vulnerable group, and what still needs to be done by society in order to come closer to the goal of full participation in society. Significant others perceived that many obvious changes have taken place in society, leading to increased participation for people with ID. Nevertheless, much remains to be accomplished and to achieve this goal it is important to utilize the experiences of significant others. Such an improvement may be achieved by including significant others as important reference persons, together with individuals with ID, in decision-making regarding disability policy in Sweden. The involvement of significant others in central policy decisions as well as in local decisions should be a matter of course in the 21st century.

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