

Staff experiences of participation in everyday life of older people with intellectual disability who live in group homes

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This article aims to explore ways in which members of staff in group homes for people with intellectual disability experience participation, and what participation means for older people with intellectual disability. Qualitative interviews were performed with 15 members of staff at group homes in Sweden. The findings of this study are illustrated by considering two interacting themes and six subthemes. These involve staff experiences of the meaning of participation and factors which facilitate or inhibit it. The meaning of participation was expressed as doing and feeling. Staff described that participation for older people with intellectual disability was influenced by the individual characteristics of the residents, such as the relationship between age and disability. They also expressed the view that participation was influenced by organizational and physical contextual factors such as economics, time and space as well as the social environment. The latter included staff knowledge and skills, family and peers.

Keywords: intellectual disability; participation; ageing; staff; group home

Introduction

Becoming old with intellectual disability is a new phenomenon in Sweden, as in the rest of the Western world (World Health Organization 2001a). This article focuses on the staff experience of participation in the everyday life of older people with intellectual disability living in group homes in Sweden. Participation is a central concept in Swedish disability policy and research related to people with intellectual disability (Government Office of Sweden 2013; Ericsson 2002; Kjellberg 2002). Additionally, participation is often used as an indicator of high-quality outcomes in group homes for people with intellectual disability (Clement and Bigby 2010; Kozma, Mansell, and Beadle-Brown 2009).

In the International Classification of Functioning, Disability and Health (ICF) participation is defined as a person's 'involvement in a life situation', and specific definitions of involvement include 'taking part', 'being engaged' or 'being included' (World Health Organization 2001b). ICF is regarded as providing a multidimensional view of health-related factors such as participation, but this view is not sufficient to understand all dimensions of human participation (Kramer, Bowyer, and Kielhofner 2008; Hemmingson and Jonsson 2005). The act of participation in everyday life does not automatically

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mean that people think they are participating or vice versa. Participation has both subjective and objective dimensions, as well as internal and external preconditions which affect a person's volition, ability, access to and opportunity for participation (Molin 2004). In order to understand the concept, there must also be a multidimensional view of environmental factors, which can be seen as both facilitators and barriers to a person's participation (Hemmingsson and Jonsson 2005). This understanding of participation was the starting point for this study.

To live in small-scale community settings has been shown to be superior to living in larger institutions when it comes to outcomes such as residents' participation (Kozma, Mansell, and Beadle-Brown 2009). However, for the present generation of older people with intellectual disability small-scale residential settings have not always been an available option. De-institutionalization began in Sweden during the 1970s, as it did in many other Western countries (Kjellberg 2002). As a result, many people with intellectual disability moved from large-scale institutions to smaller accommodation units, which were integrated into the surrounding community (Race 2007; Ericsson 2002). Small-scale group homes are today the most common residential option for adults with intellectual disability in Sweden (Socialstyrelsen 2012). The first generation of people with intellectual disability that have now become old evidently have experiences of both institutional and community living.

Today, there are approximately 2500 people with intellectual disability over the age of 65 who live in group homes in Sweden. This number will increase sharply in the coming years (Socialstyrelsen 2012). Consequently, staff in group homes for people with intellectual disability will increasingly be confronted with age-related challenges, such as changes in residents' health, activity and participation (Kåhlin et al. 2013). A recent systematic review of caring for older people with intellectual disability (Innes, McCabe, and Watchman 2012) showed that there is a lack of knowledge among staff regarding issues related to ageing and later life. Working methods, training and mentoring of staff have together with staff ambitions and values been shown to have a decisive influence on what staff actually do in their workplace (Bigby et al. 2012; Felce, Lowe, and Jones 2002) and thereby on the quality and types of participation that residents engage in (Clement and Bigby 2010; Kozma, Mansell, and Beadle-Brown 2009). In order to enable high-quality support for older residents, Innes, McCabe, and Watchman (2012) recommend frameworks for care and services. This recommendation involves issues relating to disability services, housing and retirement, as well as a demand that staff should have specific knowledge of the needs of this specific population group.

In earlier studies, age has been shown to be a determining factor when it comes to participation for people with intellectual disability. Older people in this situation seem to be more at risk of reduced participation than younger age groups, and this risk seems to increase even more for people with moderate or severe levels of intellectual disability (Dusseljee et al. 2011). This involves changes related specifically to physical ageing such as reduced mobility, reduced cognitive ability and changed health status, which are the same kind of factors likely to impact people ageing without intellectual disability (Ellison, White, and Chapman 2011; Webber, Bowers, and McKenzie-Green 2010). These types of age-related changes in people with intellectual disability can lead to reduced engagement in both work-related as well as social and leisure activities (Dusseljee et al. 2011). Additionally, some people with intellectual disability seem to undergo premature ageing and acquire secondary disabilities, which may lead to a risk of reduced participation earlier in life compared to the general population (World Health

Organization 2013; Bigby et al. 2008; Kemp 2005; Bigby 2004). Others, however, seem to age under the same realities as people without intellectual disability (Hurst 2009; Bigby et al. 2008; Bigby 2004; Holland 2000).

Participation in everyday life for older people with intellectual disability is closely related to contextual factors such as the social and physical environment surrounding the individual. Supportive social environments, including staff, contribute to participation by fostering continuity, communion and a sense of coherence (Ellison, White, and Chapman 2011; Judge et al. 2010; Bigby et al. 2008; Bigby 2005). Modifications in the physical environment, such as technical devices and home modifications, have also been shown to be important factors in accessing participation for older people with intellectual disability (Webber, Bowers, and McKenzie-Green 2010; Mirza and Hammel 2009; Hutchings, Olsen, and Moulton 2008).

Several studies have also highlighted organizational factors as crucial components when it comes to participation for this group of people. National and international disability policy, community policy, funding, level of education of staff members and attitudes of staff and society in general are examples of factors which have an impact on access to and opportunity for participation (Ellison, White, and Chapman 2011; Ingvaldsen and Balandin 2011; Bigby et al. 2011; Webber, Bowers, and Bigby 2010; Bigby 2005; Lifshitz 2002).

Despite this background, little is known about how staff in group homes experiences the age-related challenges of the residents. This is specifically the case in regard to participation, a concept which is a cornerstone of Swedish disability policy and practice. By taking the voices of staff as its starting point; this study therefore aims to explore ways in which members of staff in group homes for people with intellectual disability experience participation, and what participation means for older people with intellectual disability.

Method

The context of the study

The study is based on qualitative data collected at residences arranged for people with intellectual disability, which operate in accordance with the Swedish Disability Act (SFS 1993:387). All of them can be described as group homes. They are referred to in this article as Park Lane, Church Road, Kingsway and West Street.

A group home should ensure each individual with disabilities to have good living conditions since everyone has the right to self-determination, empowerment and integrity. This is in compliance with the general Swedish disability policy aiming for a society that allows people with disabilities of all ages full participation in the life of the community (Government Office of Sweden 2013).

All group homes in this study consisted of a house with a small number of separate but linked flats located in an ordinary housing area. Residents had access to communal activities and 24-hour staff support. Each group home had seven to nine residents. They were between 39 and 90 years old ($m = 62$) and had mild to profound level of intellectual disability (Schalock et al. 2010). Several also had additional disabilities such as reduced mobility, dementia or psychiatric conditions. Most residents had lived in the group homes for a long time, though a few had moved in more recently. The direct care staff provided support with all kinds of personal care, housing and leisure activities that took place on a

daily basis. All group homes in this study were funded, organized and managed by the municipality.

Informants

The selected informants in this study were members of staff in group homes with experience of giving support to older people with intellectual disability. A purposive sampling method was used in the recruitment process (Patton 2002). After discussions with the managers at the office of social affairs in two municipalities, four group homes were selected based on the inclusion criterion of having older residents with intellectual disabilities. After agreement with each of the managers, contact was made with staff members at each group home. The first author together with the staff identified individuals to ensure variations in the data. A spread of gender, age, years of working experience and working position was requested.

In total, 15 members of staff from these group homes were sampled and all of them agreed to take part in the study. Thirteen of them were women and two were men. Three informants were executive managers, one was a team leader and the others worked as assistant nurses at the group home (for more information, see Table 1). All informants in this article will be termed staff, regardless of their position.

Data collection

Data were collected from September 2011 to March 2012. Fifteen individual, qualitative interviews (Kvale 1996) were conducted by the first author. A semi-structured interview guide served as a checklist during the conversational interviews (Patton 2002; Kvale 1996). The interview guide consisted of broad topics involving questions on the informants' accounts of older residents participation and how, in their daily work, they could support older residents' participation (for example, see Table 2). Probing was used during the interview in order to clarify the informants' experience of the topic they were describing (Taylor and Bogdan 1998).

Each interview lasted between one and two hours, and was conducted in a private location at the informants' place of work. With permission from the informants, all interviews were recorded.

Ethics

The project was approved by the Regional Research Ethics Board in Linköping (No. 2011/116-31). Oral and written information on the study was given to the informants in line with the principle of informed consent (Swedish Research Council 2011). The informants' oral consent was recorded before the interview.

Data analysis

The recorded interviews were transcribed verbatim by the first author. The analysis was inspired by Giorgi's (2009) descriptive phenomenological method, which consists of three steps. In the first step, the transcriptions were read through several times by the first and second authors to gain an overall picture of the material in relation to the aim of the study (Giorgi 2009). In the second step, the authors employed the computer software package MAXQDA (version 10, 2011, Marburg, VERBI Software). In this step, the

Table 1. Information about the informants.

Group home	Staff, <i>n</i>	Age, <i>M</i> (range)	Educational level (related to disability, care, ageing or equal), <i>n</i>		Total working years providing services for people with intellectual disability <i>M</i> (range)	Total working years in the group home <i>M</i> (range)
			Upper secondary school	University/college		
Park Lane	4	48.5 (38–60)	3	1	22 (8–35)	11.5 (2.5–18)
Church Road	4	39 (29–52)	3	1	15 (2–33)	13 (0.5–25)
Kingsway	4	47 (26–59)	3	1	14 (5–35)	9 (5–14)
West Street	3	44 (33–51)	2	1	9.5 (2–20)	5.5 (2–7)
In total	15	44.5 (26–60)	11	4	15 (2–35)	10 (0.5–25)

Table 2. Interview topics and examples of questions.

Participation in everyday life of older people with intellectual disability	Giving support in participation in everyday life of older people with intellectual disability
How would you describe participation for older people with intellectual disability living in this group home?	How do you do to support participation for the residents? Tell me about situations which have supported/inhibited participation in everyday life of the residents.
Tell me about situations where ageing has influenced participation.	How does the group home environment influence participation in everyday life of the residents? What do older people with intellectual disability need to be able to participate in everyday life?

authors identified shifts in meaning in the descriptions (Giorgi 2009). We captured units of meaning and established them as codes. Similarities between the coded meanings were merged together in categories. In the third step, the merged units of meaning were transformed from the informants' own vocabulary into what Giorgi (2009) calls 'a phenomenologically sensitive language'. In this step, the authors constantly referred back to the coded meaning units to make sure the transformation could be justified. Once this had been done, the categories of coded meanings were used to create a structure of the phenomenon which was to be studied. The structure was expressed as themes and subthemes, which placed the descriptions of the informants' experience in an overall context. Themes and subthemes were discussed between the three authors until a consensus was reached. Lastly, the themes and subthemes were validated in citations from the transcriptions.

Results

Two interacting themes and six subthemes (see Figure 1) illustrate ways in which staff experience participation and what it means for older people with intellectual disability.

The first theme, 'staff experiences of the meaning participation for older residents', shows how informants talked about and expressed participation as a phenomenon. This theme consists of two subthemes, which reveal that participation involves both doing and feeling. The second theme, 'staff's experiences of preconditions for the participation of older residents', describes factors which affect participation negatively or positively. This theme consists of four subthemes, which include environmental and resident-related factors.

Staff experiences of the meaning of participation for older residents

Participation as doing

The informants described older residents' participation in terms of their everyday activities. It was often expressed as 'doing what you can for as long as you can' in relation to everyday tasks such as personal care, housework or activities outside the group home. However, to a minor extent, descriptions of participation involved older residents

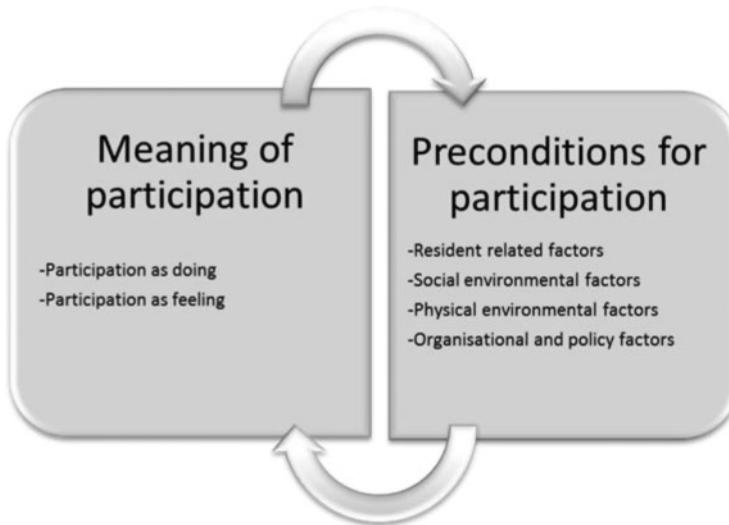


Figure 1. Themes and subthemes characterizing ways in which group home staff experience participation and what it means for older people with intellectual disability living in a group home.

undertaking activities on their own. This type of socially contextualized doing perceived older residents as co-actors rather than actors, in three dimensions.

One dimension was *doing things with others*. In this context, the informants spoke about communal activities in or outside the group home. Examples mentioned were meals, watching TV, playing games, going to church or doing sensory stimulation activities. A significant factor in the descriptions in this dimension was that staff and older residents tended to participate largely on the same terms, under equal conditions, ignoring limitations of age or disability.

Another dimension was *doing for others*. Several informants noted that older residents participated by helping staff with different kinds of domestic activity such as cleaning, laying the table or cooking. One member of staff at West Street said: 'She [the resident] likes to join us [the staff] and help to set the table and things like that'.

A third dimension of socially contextualized doing was *being in someone else's doing*. This dimension covered the participation of older residents who were considered less able to undertake activities by themselves, due to disability or age. The informants said that these residents participated just by being in the apartment while it was being cleaned by staff, by sitting in the kitchen while someone else was peeling potatoes, or by being taken on a spring stroll in a wheelchair.

Participation as feeling

The informants' descriptions also projected participation as feeling, a sense of coherence or experiencing meaning in everyday life. In this way, the informants also described it as a subjective experience for the older resident. Feeling participation involved what the informants described as minor nuances of everyday life which, taken as a whole, were described as important for the residents' experience of participation.

Some informants described the importance of closeness in establishing a feeling of participation. 'Everybody needs to feel that someone likes them. Everybody needs some kind of closeness, and I think that is what they get here, either from each other or from us

[the staff]', one staff member at Church Road said. Something that was often mentioned was the informants' desire to help older residents feel safe. One informant at Church Road said:

We strive to make residents feel safe – to ensure they [the residents] are among people who know them and like them, and so on, and that they are where they belong, so to speak. This is something we [the staff] all work towards, and we do a good job in this respect, I think. Everyone has the right to feel safe.

Communication and interaction were also mentioned as important for the experience of a feeling of participation. Several informants mentioned the importance of properly sitting down and watching TV together, playing a game or singing a song. Actually having coffee with the residents, as opposed to just serving them coffee, was considered important.

Some mentioned the importance of speaking to the residents, especially to those who had reduced communication and interaction skills. One of the staff at Park Lane said: 'I think that they [the residents] experience participation when you talk to them about things, and explain that today it is like this and today it is like that'.

Others described the importance of a home-like environment, not only that it should look like an ordinary home, but also that it should smell and feel like one. One staff member at West Street said: 'It has a lot to do with framing the day, I think, and it also creates a sort of feeling of being in a home, when there is a smell of cooking, and so on'.

Staff's experiences of preconditions for the participation of older residents

Resident-related factors

When the informants described internal preconditions for participation they consistently referred to individual characteristics of older residents as factors inhibiting participation. The most prominent individual factor was ageing. The informants noted physical, psychological and cognitive age-related changes which negatively affected the residents' chances of participating in daily life. Tiredness, risk of falling, inattention and lack of engagement were given as examples of inhibitors which affected activity and participation. They also mentioned health-related changes, such as dementia, diabetes or hearing and visual impairments, which they considered more prominent in older residents. 'They do not have the strength. They do not want to ... that is how it is ... it's the age, I guess', an informant at Park Lane said.

Intellectual disability was mentioned as another prominent factor inhibiting participation. The informants gave examples of reduced ability to understand concepts such as time, quantity and causality, and noted that these inhibited participation in activities such as shopping, going to concerts or choosing healthy food. The informants also related inhibited participation to older residents' communication skills and to their level of intellectual disability, describing severe intellectual disability as a more significant inhibitor of participation than mild disability.

Some informants also noted that the combination of age and disability was an inhibiting factor, such as the fact that older residents had to cope with a lifetime experience of intellectual disability. Informants compared the situation of younger people with intellectual disability, growing up today, with the negative experiences many older people with this type of disability had suffered, and how reduced participation had been a reality in parts of their life course. One informant at Park Lane said: 'They [the residents]

went to those boarding schools for retarded people and I think they had a tough time there. They had no opportunity to participate or to speak up for themselves.' These experiences could, according to some informants, result in residents having reduced interest or engagement in making their own decisions and speaking up for themselves, particularly as they did not have the skills required for empowerment or self-advocacy.

Social environmental factors

The social environment, including peers, family and friends and staff, was described, by all informants, as an important precondition for participation of older people with intellectual disability.

Peers were generally described as important for facilitating participation. Older and younger residents were considered to be engaged in each other's everyday lives, and worried about each other if they were ill or when age-related health changes took place, such as dementia, reduced mobility or difficulty in communicating. 'I think they lift each other up ... they help each other in some way, and push each other and hang on to each other', one informant at Church Road said. Older residents were also described as being more like a family than neighbours, since many of them had lived together for a long time, and shared other disability services, such as daily work-related activities or special leisure activities. Their shared experiences were also mentioned in terms of their experiences of deinstitutionalization, increased opportunities for participation and the development of contemporary disability policy and practice; experiences younger residents were unfamiliar with.

Also significant others were described as prominent in the lives of older residents. Informants mentioned brothers, sisters or others who had known the resident for his or her whole life. This was helpful when creating individual life history documents, which became increasingly important for residents who were developing dementia or had reduced communication skills due to age-related changes.

The informants also identified inhibiting factors in the social environment. To have few social contacts outside the group home was seen as an obstacle to the older residents' participation. Some informants related this to the fact that the residents, due to old age, were less engaged in daily work-related or leisure activities and spent more time in the group home and therefore had fewer opportunities for social interaction. A few informants mentioned that older residents might be better off in a regular nursing home for older people, as this would give them more opportunities to interact with other old people.

The assembly of residents living together in the group home was also considered inhibiting. A number of informants said that some residents had few interactions with peers, and that there was a risk of conflicts between them. These risks could be caused by bad chemistry between residents, but different ages, life experiences, interests, levels of intellectual disability and secondary disabilities were also frequently mentioned as inhibiting factors. One of the informants at West Street explained:

Well, these are ten people [residents] who need to work together in this small area, so of course there will be conflicts; conflicts that could have flared up anywhere. You just watch any soap opera ... but then, we have people who are acting out psychiatric problems, and also, to a certain extent conflicts grow out of intellectual disability.

The informants described themselves as being important for improving participation and they described strategies used in their daily work with older residents. When they

described general strategies, a central concept was to maintain a person-centred approach. This was seen as a fundamental method of facilitating participation and was characterized by a continuous focus on the residents' wishes and everyday needs. Most of these person-centred strategies were described on an individual level, as approaches used in 'one-to-one' situations. Informants saw strategies in terms of interpreting non-verbal signs, which they related to a need to know the older resident properly, as a person.

A person-centred strategy that was used to facilitate the older residents' participation was to ask questions about a person's preference. The informants felt that these questions needed to be asked all the time, in all kinds of situations and activities, regardless of the age of the resident. They needed to ask about personal preferences in the shower as well as in the supermarket, and regardless of whether staff expected and received the same answer every time. All informants considered this never-ending questioning important in terms of encouraging participation. One informant at West Street said: 'that you always think about, I mean, think about individual [residents'] needs. And that you ask them, I mean, in every single moment, about everything, from weekly planning about which food to eat ... to planning holiday trips.' Informants also spoke about giving residents alternatives and asking them to choose between them. This was mentioned in terms of residents who were less able to make independent, everyday decisions depending on the intellectual disability or the resident's life-course experiences.

However, general staff strategies were also mentioned on a group level. The informants described strategies which involved formal and informal meetings with the residents as a group. A formal one could involve, for example, monthly group meetings with residents to discuss matters such as holidays or excursions. Informal meetings took place in everyday situations. For example, during a coffee break with the residents, the menu was discussed and planned for the following week.

An important general strategy involved a continuous discussion between staff about the importance of the residents' participation. The informants felt that these ongoing discussions should take place at formal staff meetings, and during courses and lectures, but also in everyday one-to-one communications between staff.

Several of the informants described strategies that were intended to help residents to be and remain active in their later life. This was considered to be important for individual residents as well as for the older residents as a group. Filling the daily schedule with activities, inside and outside the group home, was advocated. These strategies included creating routines to follow, and trying to maintain habits and skills in everyday life. Being able to continue with daily work-related activities for as long as possible was described as an important factor in participation, and several informants emphasized this.

When the informants described how they encouraged participation, they also mentioned themselves as inhibiting factors. One informant at Kingsway said:

Well, sometimes, when it comes to following up, you might just lose track of it ... maybe we sometimes have double standards ... We [the staff] have the same goal of course [referring to the general disability policy goals], I mean, every one of us should be goal-oriented in our work, but sometimes you lose track of things.

Most informants said they were aware that participation was a cornerstone of disability policy, and that they worried when they as individuals, failed to put it into practice in their daily work with the residents. Some of them related this concern to their own abilities, knowledge and interests. An example mentioned was weekend staff choosing food they themselves liked, without interacting with the residents. Several informants had

taken over activities such as cleaning the apartments or washing laundry, simply because they would be done faster by staff than residents, even if there was enough time for the residents to do it themselves. An informant at Kingsway explained:

I don't feel stressed [at work], I seldom do. I have the time I need with the residents ... and when I think about it ... why do I rush? Why don't I wait and let them do it themselves? You are, maybe too quick to step in and help.

Several informants mentioned that staff habits could inhibit residents' participation. They meant that they generally did things in the same way without really questioning why, and related this to the number of years they had been working in the group home. One Church Road informant said: 'When you have worked in one place for a long time, you develop habits. You stop questioning your own behaviour. I think this makes it difficult to retain a professional approach.'

Physical environmental factors

Access to adapted equipment and mobility devices was mentioned as conducive to participation for older people with intellectual disability. The informants reported that age-related changes led to an increase in the use of technical devices in everyday life, such as walkers, wheelchairs and hand rails. Other physical environmental factors mentioned were whether the group home was situated close to a bus stop, near the supermarket or in the countryside. In the few cases where cognitive devices were used, to compensate for intellectual disability, informants considered these to have had a positive effect on participation, helping older residents to control time by, for example, using daily time schedules with pictures.

When informants mentioned the physical environment as a barrier to participation, it was generally in terms of the common areas, and not the residents' own apartments. Many informants described these as small and narrow, with limited opportunities for activity. Several had also experienced how the inhibiting effects of the physical environment had increased as the residents reached old age. Narrow passages and hallways made it hard to manoeuvre the wheelchairs, walkers and other mobility devices that the older residents needed with the decline in their health and abilities.

Three of the group homes were situated on the second floor, which gave rise to age-related issues. The stairs had started to become a problem for a number of residents and lifts were described as too small to carry more than one wheelchair at a time, which meant older residents could not always go outside when they wanted to. 'Church Road is supposed to be a group home for older people, and in that sense the spaces are not optimal, especially not the access between the outdoor and indoor environments', one of the informants explained.

Several informants regretted that there was no garden where the residents could spend time, but on the other hand, in cases where there was a garden, this had become a negative factor in winter, as residents risked slipping and falling. There could also be accessibility problems for mobility aids, which meant older residents spent more time inside than before.

Another inhibiting factor in the physical environment was the shortage of cognitive devices to compensate for intellectual disability. Some informants mentioned this lack of support in terms of factors linked to ageing. 'Time is spent on the younger ones when it comes to adapted remote controls and time aids and such ... you [we] do not realize that these older people also have a need', one informant at Kingsway said.

Organizational and policy factors

The overall disability policy was considered supportive. Several informants underlined that the Disability Act gave older people with intellectual disability the right to take part in activities which were not available to older people in general. The informants mentioned that some older residents felt less lonely, and had participated more in everyday life since they had moved to the group home. One informant at West Street said:

I think it [the Disability Act] makes the group home more beneficial than a nursing home [for older people without intellectual disability]. I think we [the staff] have more chance of giving ... a better end of life, compared to those working in a nursing home or in the home-help service, or any other services [for older people without intellectual disability].

The informants also described inhibiting factors in the organizational environment. These included issues involving staffing and lack of funding or other organizational resources. One of the informants at West Street said:

I think there are a lot of small issues, that are hard to come to terms with, as you also have a business to run, and often some sort of daily schedule to keep, and you must ... you have others to take care of, and so on... but I think, this is the biggest job and the hardest thing to come to terms with.

Several informants had experienced a reduction in funding, which had resulted in staff cuts. This meant that they had less time, and could not do things spontaneously, such as going on excursions or having picnics. These factors were mentioned as a threat to participation, and were linked to a feeling of lower quality of life for the residents. Another restricting factor connected with organization was that staff might also be responsible for clients living outside the group home, which inhibited their flexibility and ability to be spontaneous in terms of the older residents' wishes and requirements when it came to activities. An inhibiting factor was that the group home had to share facilities or services with others, such as staff at ordinary nursing homes for older people with no intellectual disabilities. One informant at Church Road explained: 'Well, we [the staff] do the washing on Tuesdays and Thursdays when they [the residents] are not at home ... This is because we share washing facilities with the nursing home. We do not have our own washing machines.'

General discussion

The starting point of our study is the voices of group home staff, who are significant persons for people who live in these kinds of residential settings (Bigby et al. 2012; Clement and Bigby 2010; Schuengel et al. 2010). According to our study, group home staff constantly face factors which jeopardize the participation of residents. Coping with such factors is an ongoing part of their daily work, regardless of the age of residents. The study, however, shows that staff experience ageing as having a significant impact on participation in older people with intellectual disability, which is consistent with earlier findings (see, for example Doody, Markey, and Doody 2013; Dusseljee et al. 2011; Webber, Bowers, and McKenzie-Green 2010; Fahey-McCarthy et al. 2009). Life-course experiences such as institutionalization and stigmatization, specifically related to this generational group of people with intellectual disability (Ericsson 2002; Kjellberg 2002), were described as inhibitors by the staff. Physical, psychological and social changes

related to old age, combined with intellectual disability, were considered to affect participation in a negative way. It would be inaccurate to say that the combination of age and disability results in a multiple jeopardy, but it certainly adds challenges to the everyday work of staff.

According to our findings, one dimension of this everyday challenge involved how staff talked about participation as both doing and feeling. This emphasizes the importance of including more than doing in the way we understand the concept of participation (Molin 2004). Expressing participation as both doing and feeling also reveals the multi-dimensional nature of participation. Our study, however, found on the whole that *participation as doing* was negatively affected by age-related changes. This could make *participation as feeling* an even more important dimension of participation in later life for people with intellectual disability. Staff strategies and environmental factors related to participation as feeling could then become increasingly important in supporting participation, as more and more people with intellectual disability who are living in group homes reach old age. The findings of this study mainly identify participation in terms of carrying out activities. A transition from *doing* to *feeling* will have consequences when supporting participation in people with intellectual disability as they get older. This is an important implication for practice. Group home staff, including executive managers, need to be aware of this multidimensional nature of participation and should strive to implement it in their daily work with older residents.

Another dimension of the everyday challenges faced by staff involves activity. The meanings given to participation in the subtheme *participation as doing* and the strategies mentioned for improving ways of encouraging participation, focused prominently on remaining active. Staff advocated continuous work-related activities, such as preserving habits and routines in everyday life. An earlier study (Higgins and Mansell 2009) found that older people who live in accommodation for people with intellectual disability were more engaged in activities, and spent more time participating in the community, than people with or without this disability living in nursing homes for older people. Our findings, in line with Higgins and Mansell (2009), can be related to disability policy and practices, such as person-centred active support (Mansell and Beadle-Brown 2012; Ashman et al. 2010), but the approach found in our study can also be related to an ideology of active ageing (World Health Organization 2002). This ideology is derived from activity theory (Lawton and Nahemow 1973) and is nowadays generally and normatively prevalent in society (Council of the European Union 2012; World Health Organization 2002), as well as among older people with intellectual disability (Kählin et al. 2013; Buys et al. 2008). Studies on active ageing in people with this type of disability (Buys, Aird, and Miller 2012; Buys et al. 2008), show that different individual needs within each group of people must be taken into account when this ideology is implemented. On the one hand the ideology of active ageing (Council of the European Union 2012; World Health Organization 2002) seems to share fundamental characteristics with the contemporary disability policy. On the other hand the ideology of active ageing sees activity in old age in a normative way, in that it presupposes that an active life style is preferable and desirable for all older people. This is different to Swedish disability policy, which advocates that individuals should make independent decisions about their everyday life, with no normative preconceptions. However, participation can be considered a fundamental requirement for an experience of active ageing in people with an intellectual disability.

Our study shows that staff find environmental factors important in encouraging participation, which is in accordance with earlier findings (see, for example Ellison, White, and Chapman 2011; Ingvaldsen and Balandin 2011; Bigby et al. 2011; Webber, Bowers, and McKenzie-Green 2010). At the same time, social, physical and organizational environmental factors seem both to inhibit and improve participation, as has been discussed by Hemmingsson and Jonsson (2005). Mobility devices were described by the staff as improving participation for older people with intellectual disability, but the confined space in the group home made them hard to manoeuvre, which inhibited participation. Peers were considered both important for, and a threat to, participation for older people with intellectual disability. Similarly, disability policies, such as the Disability Act, were described as a facilitating factor, whereas community organization and funding were described as inhibiting participation. However, factors related to the social environment were more frequently mentioned than others in the informants' descriptions of the participation of older people with intellectual disability. Similar to earlier findings (see for example Buys, Aird, and Miller 2012; Bigby et al. 2012; Clement and Bigby 2010; Felce, Lowe, and Jones 2002), this study shows that group home staff consider themselves as essential for older people with intellectual disability when it comes to participation; they describe themselves, in a reflective way, sometimes as improvers, and sometimes as inhibitors of the residents' participation.

Another finding worth further attention is that staff described resident related-factors, such as intellectual disability and ageing, as inhibiting participation. In our study, staff described ageing as an inhibiting factor, but several strategies to improve participation in old age were also mentioned. Many of these can be related to strategies used as part of person-centred support (see for example Mansell and Beadle-Brown 2012; Ashman et al. 2010; Clement and Bigby 2010); however, staff described, a shortage of assistive technology to compensate for intellectual disability. Earlier studies have shown for instance that cognitive assistive devices, such as time aids or communication tools, can support participation in people with intellectual disability, even in old age, but staff knowledge and attitudes seem to be determining factors of whether assistive devices or adaptations should be used or not (Wennberg and Kjellberg 2010; Mirza and Hammel 2009; Arvidsson and Jonsson 2006; Hammel, Lai, and Heller 2002; Hammel 2000). In our study, some informants explained the lack of cognitive assistive devices as a consequence of the residents' old age. This could be evidence of ageism (Andersson 2008) in disability policy and among service providers, based on stereotypical preconceptions about the relationship between old age and intellectual disability. It would therefore be of interest in future research to study whether increased use of these kinds of supportive devices in the group homes may change staff perceptions about the inhibiting effect of the combination of age and intellectual disability on residents' participation.

In terms of *participation as doing*, informants described how residents did things for them, such as helping staff with household activities like setting the table. This is an interesting finding in terms of how staff members saw their role in supporting participation, and it raises questions about staff power and control, and the actual impact of deinstitutionalization and normalization in the everyday lives of these older residents. It can be argued that the group homes in this study, in line with Mallander's (1999) discussion, retain norms and values from the 'total institutions', described by Goffman (1961). One reason for this finding could be that these residents are older and have life course experiences, which make them unprepared to speak up for themselves. However, another reason could be that the group home staff are limited in their professional

knowledge and the working methods they use related to old age and to the contemporary disability policy, which is in line with the findings of Innes, McCabe, and Watchman (2012). Our findings support both these possible reasons.

Staff experienced participation to be a multidimensional concept when it was applied to older people with intellectual disability. They experienced a discrepancy between disability policy, and the internal and external preconditions for implementing it in practice. This discrepancy can be understood in several ways. It seems to depend on organizational and physical contextual factors such as funding, time and space, but also the social context, which involves staff knowledge and skills. Additionally, staff also experience participation as being influenced by the individual characteristics of older residents. In this reasoning, physical ageing seems to be a significant internal precondition for participation among older people with intellectual disability.

This qualitative study involved a small number of respondents, in three different but rather similar group homes, which must be taken into consideration when discussing and implementing its findings. It is also crucial to remember that the starting point for the present study was the experiences of staff and not of the residents. Therefore, our study as best can shed some indirect light on how older people with intellectual disability, themselves, experience participation. In an earlier study (Kåhlin et al. 2013) we made some contributions to the understanding of how ageing is understood by residents with intellectual disability but their perspective needs to be further addressed from a variety of angles. Gaining knowledge about the subjective experiences of older people with intellectual disability is important for improving the quality of life of these people (McDonald, Kidney, and Patka 2013). The perspective of group home staff is, however, important when exploring participation in older people with intellectual disabilities. Staff perspectives, e.g. working methods, ambitions and values, have been shown to be crucial for what staff actually do in their daily work (Bigby et al. 2012; Felce, Lowe, and Jones 2002) and for residents quality of life (Kozma, Mansell, and Beadle-Brown 2009). Additionally, in our earlier study (Kåhlin et al. 2013), we found that older residents with intellectual disability give staff increased importance as they and other residents become older. The current study has its importance as it contributes to the understanding of how staff experience the older resident's participation, and how they talk about how they work with residents' participation. The informants' tellings have their starting point in their everyday work. The tellings are rich of examples from the everyday life in the group homes. However, this, on its own, is of course just a second hand perspective on the residents' situation and what occurs between staff and residents in their daily encounters. In order to know if the results of this study mirror what staff actually do in their everyday work, further studies have to be done, e.g. studies including observations of interaction between staff and residents.

Noteworthy, most studies on participation have been carried out with people who are less than 65 years old (Vessby and Kjellberg 2010). In conclusion, more studies from a variety of perspectives need to be carried out on participation in later life, specifically in relation to different life-courses and the combination of age and disability, which this study found to be critical. In future research related to participation in older people with intellectual disability it is also crucial not only to view ageing as a biological phenomenon, but to acknowledge it as being a continuous interaction of physical, psychological and social processes. Despite being on the agenda for several years (see for example Priestley 2003; Putnam 2002), the combination of age and disability has been more or less invisible both in gerontological research and disability studies (Jeppsson Grassman

and Whitaker 2013). Our study is a step towards bringing ageing and later life into critical disability studies.

References

- Andersson, L. 2008. *Ålderism* [Ageism]. Lund: Studentlitteratur.
- Arvidsson, G., and H. Jonsson. 2006. "The Impact of Time Aids on Independence and Autonomy in Adults with Developmental Disabilities." *Occupational Therapy International* 13 (3): 160–175. doi:10.1002/oti.215.
- Ashman, B., J. Ockenden, J. Beadle-Brown, and J. Mansell. 2010. *Person-centred Active Support. A Handbook*. Brighton: Pavilion.
- Bigby, C. 2004. *Ageing with a Lifelong Disability. A Guide to Practice, Program and Policy Issues for Human Services Professionals*. London: Jessica Kingsley.
- Bigby, C. 2005. "Comparative Program Options for Aging People with Intellectual Disabilities." *Journal of Policy and Practice in Intellectual Disabilities* 2 (2): 75–85. doi:10.1111/j.1741-1130.2005.00019.x.
- Bigby, C., M. Knox, J. Beadle-Brown, T. Clement, and J. Mansell. 2012. "Uncovering Dimensions of Culture in Underperforming Group Homes for People with Severe Intellectual Disability." *Intellectual and Developmental Disabilities* 50 (6): 452–467. doi:10.1352/1934-9556-50.06.452.
- Bigby, C., R. Webber, B. Bowers, and B. McKenzie-Green. 2008. "A Survey of People with Intellectual Disabilities Living in Residential Aged Care Facilities in Victoria." *Journal of Intellectual Disability Research* 52 (5): 404–414. doi:10.1111/j.1365-2788.2007.01040.x.
- Bigby, C., N. J. Wilson, S. Balandin, and R. J. Stancliffe. 2011. "Disconnected Expectations: Staff, Family, and Supported Employee Perspectives about Retirement." *Journal of Intellectual and Developmental Disability* 36 (3): 167–174. doi:10.3109/13668250.2011.598852.
- Buys, L., R. Aird, and E. Miller. 2012. "Active Ageing among Older Adults with Lifelong Intellectual Disabilities: The Role of Familial and Nonfamilial Social Networks." *Families in Society: The Journal of Contemporary Social Services* 93 (1): 55–64. doi:10.1606/1044-3894.4179.
- Buys, L., G. Boulton-Lewis, J. Tedman-Jones, H. Edwards, M. Knox, and C. Bigby. 2008. "Research: Issues of Active Ageing: Perceptions of Older People with Lifelong Intellectual Disability." *Australasian Journal of Ageing* 27 (2): 67–71. doi:10.1111/j.1741-6612.2008.00287.x.
- Clement, T., and Bigby, C. 2010. *Group Homes for People with Intellectual Disabilities: Encouraging Inclusion and Participation*. London: Jessica Kingsley.
- Council of the European Union. 2012. *Council Declaration on the European Year for Active Ageing and Solidarity between Generations (2012): The Way Forward*. EPSCO, 17468/12. Brussels: Council of the European Union.
- Doody, C. M., K. Markey, and O. Doody. 2013. "The Experiences of Registered Intellectual Disability Nurses Caring for the Older Person with Intellectual Disability." *Journal of Clinical Nursing* 22 (7–8): 1112–1123. doi:10.1111/jocn.12020.
- Dusseljee, J. C. E., P. M. Rijken, M. Cardol, L. M. G. Curfs, and P. P. Groenewegen. 2011. "Participation in Daytime Activities among People with Mild or Moderate Intellectual Disability." *Journal of Intellectual Disability Research* 55 (1): 4–18. doi:10.1111/j.1365-2788.2010.01342.x.
- Ellison, C., A. White, and L. Chapman. 2011. "Avoiding Institutional Outcomes for Older Adults Living with Disability: The Use of Community-based Aged Care Supports." *Journal of Intellectual and Developmental Disability* 36 (3): 175–183. doi:10.3109/13668250.2011.597377.
- Ericsson, K. 2002. "From Institutional Life to Community Participation. Ideas and Realities Concerning Support to Persons with Intellectual Disability." PhD diss., Uppsala University.
- Fahey-McCarthy, E., M. McCarron, K. Connaire, and P. McCallion. 2009. "Developing an Education Intervention for Staff Supporting Persons with an Intellectual Disability and Advanced Dementia." *Journal of Policy and Practice in Intellectual Disabilities* 6 (4): 267–275. doi:10.1111/j.1741-1130.2009.00231.x.
- Felce, D., K. Lowe, and E. Jones. 2002. "Staff Activity in Supported Housing Services." *Journal of Applied Research in Intellectual Disabilities* 15 (4): 388–403. doi:10.1046/j.1468-3148.2002.00130.x.
- Giorgi, A. 2009. *The Descriptive Phenomenological Methods in Psychology. A Modified Husserlian Approach*. Pittsburgh, PA: Duquesne University Press.

- Goffman, E. 1961. *Asylums. Essays on the Social Situation of Mental Patients and Other Inmates*. New York: Anchor Books.
- Government Office of Sweden. 2013. "Objectives and Priorities for the Disability Area." Accessed November 1. <http://www.government.se/sb/d/15472/a/184236>.
- Hammel, J. 2000. "Assistive Technology and Environmental Intervention (AT-EI) Impact on the Activity and Life Roles of Aging Adults with Developmental Disabilities: Findings and Applications for Practice." *Physical & Occupational Therapy in Geriatrics* 18: 37–58.
- Hammel, J., J.-S. Lai, and T. Heller. 2002. "The Impact of Assistive Technology and Environmental Interventions on Function and Living Situation Status with People Who Are Ageing with Developmental Disabilities." *Disability and Rehabilitation* 24 (1–3): 93–105. doi:10.1080/09638280110063850.
- Hemmingsson, H., and H. Jonsson. 2005. "An Occupational Perspective on the Concept of Participation in the International Classification of Functioning, Disability and Health – Some Critical Remarks." *American Journal of Occupational Therapy* 59 (5): 569–576. doi:10.5014/ajot.59.5.569.
- Higgins, L., and J. Mansell. 2009. "Quality of Life in Group Homes and Older Persons' Homes." *British Journal of Learning Disabilities* 37 (3): 207–212. doi:10.1111/j.1468-3156.2009.00550.x.
- Holland, A. J. 2000. "Ageing and Learning Disability." *British Journal of Psychiatry* 176 (1): 26–31. doi:10.1192/bjp.176.1.26.
- Hurst, J. 2009. "The Older Adult and Life Changes." In *Occupational Therapy for People with Learning Disabilities. A Practical Guide*, edited by J. Goodman, J. Hurst, and C. Locke, 183–193. Edinburgh: Churchill Livingstone/Elsevier.
- Hutchings, B. L., R. V. Olsen, and H. J. Moulton. 2008. "Environmental Evaluations and Modifications to Support Aging at Home with a Developmental Disability." *Journal of Housing for the Elderly* 22 (4): 286–310. doi:10.1080/02763890802458445.
- Ingvaldsen, A. K., and S. Balandin. 2011. "'If We Are Going to Include Them We Have to Do It before We Die': Norwegian Seniors' Views of including Seniors with Intellectual Disability in Senior Centers." *Journal of Applied Research in Intellectual Disabilities* 24 (6): 583–593. doi:10.1111/j.1468-3148.2011.00636.x.
- Innes, A., L. McCabe, and K. Watchman. 2012. "Caring for Older People with an Intellectual Disability: A Systematic Review." *Maturitas* 72 (4): 286–295. doi:10.1016/j.maturitas.2012.05.008.
- Jeppsson Grassman, E., and A. Whitaker. 2013. "Ageing with Disability: An Introduction." In *Ageing with Disability. A Lifecourse Perspective*, edited by E. Jeppsson Grassman and A. Whitaker, 1–15. Bristol: Policy Press.
- Judge, J., R. Walley, B. Anderson, and R. Young. 2010. "Activity, Aging, and Retirement: The Views of a Group of Scottish People with Intellectual Disabilities." *Journal of Policy and Practice in Intellectual Disabilities* 7 (4): 295–301. doi:10.1111/j.1741-1130.2010.00279.x.
- Kåhlin, I., A. Kjellberg, C. Nord, and J.-E. Hagberg. 2013. "Lived Experiences of Ageing and Later Life in Older People with Intellectual Disabilities." *Ageing and Society* FirstView Articles: 1–27. doi:10.1017/S0144X13000949.
- Kemp, B. J. 2005. "What the Rehabilitation Professional and the Consumer Need to Know." *Physical Medicine and Rehabilitation Clinics of North America* 16 (1): 1–18. doi:10.1016/j.pmr.2004.06.009.
- Kjellberg, A. 2002. "Participation – Ideology and Everyday Life. How to Understand the Experiences of Persons with Learning Disabilities." PhD diss., Linköping University.
- Kozma, A., J. Mansell, and J. Beadle-Brown. 2009. "Outcomes in Different Residential Settings for People with Intellectual Disability: A Systematic Review." *American Journal on Intellectual and Developmental Disabilities* 114 (3): 193–222. doi:10.1352/1944-7558-114.3.193.
- Kramer, J., P. Bowyer, and G. Kielhofner. 2008. "The Model of Human Occupation, the ICF, and the Occupational Therapy Practice Framework: Connections to Support Best Practice around the World." In *Model of Human Occupation. Theory and Application*, 4th ed., edited by G. Kielhofner, 519–531. Philadelphia, PA: Lippincott Williams & Wilkins.
- Kvale, S. 1996. *Interviews. An Introduction to Qualitative Research Interviewing*. London: Sage.
- Lawton, M., and L. Nahemow. 1973. "Ecology and the Aging Process." In *Psychology of Adult Development and Aging*, edited by C. Eidsdorfer and M. Lawton, 619–674. Washington, DC: American Psychological Association.
- Lifshitz, H. 2002. "Later Life Planning Training Program: A Pre-test Assessment in Israel." *Journal of Gerontological Social Work* 37 (3–4): 87–103. doi:10.1300/J083v37n03_07.

- Mallander, O. 1999. "De hjälper oss till rätta. Normaliseringsarbete, självbestämmande och människor med psykisk utvecklingsstörning [They Help Us Out – Normalization Work, Self-determination and People with Learning Disabilities]." PhD diss., Lund University.
- Mansell, J., and J. Beadle-Brown. 2012. *Active Support. Enabling and Empowering People with Intellectual Disabilities*. London: Jessica Kingsley.
- McDonald, K. E., C. A. Kidney, and M. Patka. 2013. "'You Need to Let Your Voice Be Heard': Research Participants' Views On Research." *Journal of Intellectual Disability Research* 57 (3): 216–225. doi:10.1111/j.1365-2788.2011.01527.x.
- Mirza, M., and J. Hammel. 2009. "Consumer-directed Goal Planning in the Delivery of Assistive Technology Services for People Who Are Ageing with Intellectual Disabilities." *Journal of Applied Research in Intellectual Disabilities* 22 (5): 445–457. doi:10.1111/j.1468-3148.2009.00495.x.
- Molin, M. 2004. "Delaktighet inom handikappområdet – en begreppsanalys [Participation in Disability Domains – A Conceptual Analysis]." In *Delaktighetens språk [The Language of Participation]*, edited by A. Gustavsson, 61–81. Lund: Studentlitteratur.
- Patton, M. Q. 2002. *Qualitative Research & Evaluation Methods*, 3rd ed. London: Sage.
- Priestley, M. 2003. *Disability. A Life Course Approach*. Cambridge, MA: Polity Press.
- Putnam, M. 2002. "Linking Aging Theory and Disability Models: Increasing the Potential to Explore Aging with Physical Impairment." *The Gerontologist* 42 (6): 799–806. doi:10.1093/geront/42.6.799.
- Race, D. 2007. *Intellectual Disability. Social Approaches*. New York: Open University Press.
- Schalock, R. L., S. A. Borthwick-Duffy, V. J. Bradley, W. H. E. Buntinx, D. L. Coulter, E. M. Craig, S. C. Gomez, et al. 2010. *Intellectual Disability: Definition, Classification, and Systems of Supports*, 11th ed. Washington, DC: American Association of Intellectual and Developmental Disabilities.
- Schuengel, C., S. Kef, S. Damen, and M. Worm. 2010. "People Who Need People: Attachment and Professional Caregiving." *Journal of Intellectual Disability Research* 54 (Suppl. 1): 38–47. doi:10.1111/j.1365-2788.2009.01236.x.
- SFS (Svensk författningssamling) [Swedish Code of Statutes] 1993:387. *Lagen om stöd och service till vissa funktionshindrade [The Act Concerning Support and Service for Persons with Certain Functional Impairments]*. Stockholm: Swedish Government.
- Socialstyrelsen. 2012. *Official Statistics of Sweden. Statistics – Social Welfare. Persons with Certain Functional Impairments – Measures Specified by LSS 2011*. Stockholm: Socialstyrelsen.
- Swedish Research Council. 2011. *Good Research Practice*. Stockholm: Swedish Research Council.
- Taylor, S. J., and S. Bogdan. 1998. *Introduction to Qualitative Research Methods. A Guidebook and Resource*. 3rd ed. New York: John Wiley and Sons.
- Vessby, K., and A. Kjellberg. 2010. "Participation in Occupational Therapy Research: A Literature Review." *British Journal of Occupational Therapy* 73 (7): 319–326. doi:10.4276/030802210X12759925544380.
- Webber, R., B. Bowers, and C. Bigby. 2010. "Hospital Experiences of Older People with Intellectual Disability: Responses of Group Home Staff and Family Members." *Journal of Intellectual and Developmental Disability* 35 (3): 155–164. doi:10.3109/13668250.2010.491071.
- Webber, R., B. Bowers, and B. McKenzie-Green. 2010. "Staff Responses to Age-related Health Changes in People with an Intellectual Disability in Group Homes." *Disability & Society* 25 (6): 657–671. doi:10.1080/09687599.2010.505736.
- Wennberg, B., and A. Kjellberg. 2010. "Participation when Using Cognitive Assistive Devices - from the Perspective of People with Intellectual Disabilities." *Occupational Therapy International* 17 (4): 168–176. doi:10.1002/oti.296.
- World Health Organization. 2001a. "Healthy Ageing - Adults with Intellectual Disabilities: Summative Report." *Journal of Applied Research in Intellectual Disabilities* 14 (3): 256–275. doi:10.1046/j.1468-3148.2001.00071.x.
- World Health Organization. 2001b. *International Classification of Functioning, Disability and Health (ICF)*. Geneva: World Health Organization.
- World Health Organization. 2002. *Active Ageing. A Policy Framework*. Geneva: World Health Organization.
- World Health Organization. 2013. "Disability and Health." Fact Sheet No. 352. Accessed November 1. <http://www.who.int/mediacentre/factsheets/fs352/en/>.