

# Ambivalence among staff regarding ageing with intellectual disabilities: Experiences and reflections

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**Abstract**

This study explores the experiences and reflections of staff in intellectual disability (ID) services concerning ageing with ID. Qualitative interviews were conducted with 24 staff members in group homes and daily activity centres. The findings showed that the staff were uncertain about the signs of ageing in people with intellectual disabilities; they compared the life conditions of these people with conditions in older people without intellectual disabilities. Their emphasis on an active lifestyle was very strong. The staff members also mentioned uncertainty about how to facilitate assistive devices and whether ‘ageing in place’ was the best solution. The overall theme was manifested as ambivalence where notions of older people with intellectual disabilities seemed incompatible with notions of old age in general and could be explained by the theoretical concept of age coding. The findings of this study indicate the need to provide education about ageing to staff working in ID services.

**Keywords**

age coding, intellectual disability service, learning disability, mental retardation, old age, person-centred care, professional perspective

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## Introduction

New challenges and demands on staff in intellectual disability (ID) services are emerging as ageing with ID is becoming more and more common. The life expectancy for people with ID has increased over the last decades (Blackman, 2007; Bowers et al., 2014; Patja et al., 2000; Swedish National Board of Health and Welfare, 2014; WHO, 2001). Ageing with ID is a growing phenomenon that requires specific knowledge about the conditions and needs of older people with ID. Therefore, this article focuses on ID service staff's experiences and reflections on ageing in older people with ID in Sweden.

Ageing with ID is often a more complex process than ageing in the wider population, involving so-called 'premature ageing' and secondary conditions. Premature ageing conditions in people with ID occur in relation to their primary health condition, that is, as comorbidities to ID; 'secondary conditions' are additional age-related health conditions or disabilities (Bigby, 2004; WHO, 2018). Several studies have reported a higher prevalence of diseases and health problems in people with ID than in the general population of the same age (Coppus, 2013; Haveman et al., 2010; Janicki et al., 2002; Kapell et al., 1998; Sandberg et al., 2017). More frequent somatic health problems among older people with ID than in the general population in Sweden include infections, respiratory diseases, diseases of the nervous and genitourinary systems as well as injuries (Axmon et al., 2019; Sandberg et al., 2017). Knowledge about the cause of death is a way to understand the main health problems in this group. A national cohort study on people older than 55 years with ID in Sweden demonstrated a four times higher mortality risk than the general population, mainly due to respiratory, nervous and circulatory system diseases (Ng et al., 2017). Compared with the general population, older people with ID show 10 times higher occurrence of psychotic disorders, followed by dementia, personality disorder, anxiety and mood disorder (Axmon et al., 2017; Cooper, 1997; Deb et al., 2001). To prevent unnecessary suffering in this vulnerable group, there is an urgent need for staff to have competence in ageing to provide care and support for older people.

The role of staff in ID services aims to support the balance between the individual competencies and environmental demands (Lawton and Nahemow, 1973). According to Lawton (1985), a reciprocal relationship exists between older people and their environment and older people should be understood in terms of changes that occur both in themselves and in the world around them. The more vulnerable the individual is, the more the environment will have an impact (Lawton and Simon, 1968). As older people with ID are considered a vulnerable group, the effects of environmental factors have great significance, and the staff plays an important function in creating a supportive and stimulating environment. For example, the ageing process might affect possibilities for participation if the staff cannot provide sufficient care and support. Largely, this should be regarded as a question of healthy ageing for all (WHO, 2000, 2015). Additionally, there are also indications that public attitudes and a lack of knowledge hinder participation and accessibility for people with ID, for instance affecting their access to health care (Starr et al., 2007; Wark et al., 2015; WHO, 2001). However, Burke et al. (2014) reported that older people with ID describe their health as good and that the expectations of later life in older people with ID mainly concern the opportunity to stay actively engaged in life, both physically and socially. Another study on the narratives of older people with ID showed that ageing and later life are processes of change, predominantly in relation to the activities of everyday life (Judge et al., 2010; Kåhlin et al., 2015b).

In Sweden, most older people with ID usually age 'in place', indicating that they are supported to remain in their group home, where the majority of these people lives, or in an ordinary home for as long as possible (Swedish National Board of Health and Welfare, 2014). Older people are

expected to maintain an independent life and keep their connections to their social network of friends and family through ageing in place (Wiles et al., 2012; WHO, 2007). However, as in many residential settings, ageing in group homes means increased vulnerability in terms of participation, due to fewer choices and control by older people with ID, and an increased influence of the staff (Kåhlin et al., 2016a). In addition, older people with ID living together with people without ID in residential aged care could be at greater risk of disadvantages such as inability to fit into the resident community, lack of participation in activities and lack of meaningful relationships (Bigby et al., 2008).

Furthermore, the well-being of older people with ID is highly dependent on the nature and availability of formal and informal support (Bigby, 2004; Kåhlin et al., 2015a, 2016a). Proper support from care staff in group homes or daily activity centres, for example, provide stimulating daily activities and ensure participation, has vital significance in the everyday life of people with ID (Bigby et al., 2011; Schuengel et al., 2010; Webber et al., 2014). In addition to the voices of the older people with ID, it is important to explore staff views on ageing and ID, because the staff's experiences and reflections will most likely influence the quality of care and service for persons with ID.

As Kåhlin et al. (2016b) have pointed out, there is limited understanding of how staff address matters of ageing and older age in the care and service of people with ID. Their study of group home staff showed how the main response concerning these issues was silence; ageing with ID was rarely articulated or discussed according to the staff (Kåhlin et al., 2016b). Another study, a systematic review of care for older people with ID, reported that the staff lacked knowledge and methods and needed training and support related to questions of ageing (Innes et al., 2012). A previous study with leaders (Johansson et al., 2017) showed that ageing is a neglected question in their management role. Consequently, further investigation is required to more clearly understand how staff members provide care and services for older people with ID and how they experience and reflect on ageing with ID.

## **Aim**

The aim of this study was to explore how staff in ID services experience and reflect on ageing in people with ID.

## **Methods**

The design of the study was qualitative and explorative. The current study is part of a project about ageing in people with ID. Another element of the study (an interview study with managers) has been previously published (Johansson et al., 2017).

### ***Intellectual disability service setting***

In Sweden, the municipality is responsible for organizing the ID services for all people of all ages with all types of permanent and considerable functional disabilities, such as people with ID. The Act Concerning Support and Service for Persons with Certain Functional Impairments (Swedish abbreviation: LSS) regulates the service and support for individuals with permanent and considerable functional impairment who can apply for services in accordance with the LSS Act (SFS, 1993:387). The Act covers individuals who can be categorized as belonging to one of three groups, group 1 comprising people who have been diagnosed with ID and/or autism, group 2 comprising

people with cognitive disability after sustaining brain injury or damage in adulthood and group 3 comprising people with other permanent and considerable disabilities. This study concerns staff working with people in group 1 who need support and services to manage everyday life (SFS, 1993:387). Older people with ID have the rights granted by the LSS Act but also the same rights to elderly care as other older people in the Swedish general population, according to the Social Service Act (SFS, 2018:347), and in need of health care, according to the Health Care Act (SFS, 2017:30).

Both accommodations in group homes and occupations in daily activity centres are two of eight measures of support and service for adults that are regulated by the LSS Act. The typical group home is shared by six to eight adults with ID. The daily activity centres provide daytime occupations for persons with ID of working age (18–67 years).

An epidemiological study mapping the geographical distribution of older individuals with ID in Sweden showed that the prevalence was consistently higher among men, and the gender gap was decreased in the older age groups (Ng et al., 2015). In the younger age group of those 55–59 years, the prevalence was 444 per 100,000 population, and it decreased steadily to 65 per 100,000 population among those aged 80+ years (Ng et al., 2015). The city of focus for this study is located in southern Sweden. In 2015, there were 200 people with ID aged 55 years or older in the city, among whom 107 were men (mean age: 63.9 years; range: 55–79) and 93 were women (mean age: 65.0 years; range: 55–88). They all had some measure of support and service regulated by the LSS Act and most of them likely lived in a group home, according to their age (Ng et al., 2015, unpublished data).

### *Sampling and participants*

The inclusion criteria for the staff were that they had to have at least 1 year of experience of working in group homes or at daily activity centres and experience working with people with ID who were aged 55 years or older. After approval by the manager responsible for all ID services in the included city, an information letter was sent to the managers of group homes and daily activity centres asking whether they would be interested in participating. The managers who had agreed to participate in a previous study (Johansson et al., 2017) asked their staff who met the inclusion criteria whether they might be interested in participating, and names of the staff who were interested were handed over to the researcher (MJ). If the number of staff members who fulfilled the inclusion criteria but declined to participate was unknown, it was estimated to be only a few based on the limited group of older people in the current city.

Of the 27 staff members who initially accepted participation, two dropped out because of the lack of time and one for unknown reasons. Therefore, 24 staff members participated in the study, with a mean age of 48 years (range: 24–65 years) and an average of 16.6 years (range: 2–41 years; SD:  $\pm 11.09$ ) of working experience in ID services. Additional background data of the study group are shown in Table 1.

### *The interviews*

The data collection for the project occurred during 2013–2014. The staff at each participating unit received an e-mail with information about the study and an invitation to participate. Time for an individual interview was arranged with staff who agreed to participate in the study. The participants had the opportunity to choose the place of the interview and all staff chose their workplace for the interview. The interviews were performed in a separate room to not disturb the service

**Table 1.** Characteristics of the participating staff ( $n = 24$ ).

Background data	<i>n</i> (%)
Women/men	20/4 (83/17)
Current workplace	
Group home	17 (70.8)
Daily activity centre	7 (29.2)
Years working in ID disability services	
<5 years	4 (16.7)
≥5–9 years	2 (8.3)
≥10–19 years	10 (41.7)
≥20– years	8 (33.3)
Highest education level	
Elementary school	1 (4.1)
Secondary/high school	13 (54.2)
Post-secondary/trade school	6 (25.0)
University/college	4 (16.7)
Experience of close relative ageing	24 (100)
Experience of close relative with ID	6 (25)

users. Interviews were based on an interview guide designed by the second and third author (MJ and GA) and comprised of two main open questions: 1. What does ‘ageing well’ mean for a person with ID? and 2. How do you perceive the service, support and care needs of ageing older persons with ID? The intention during the interviews was to encourage the participants to speak freely without interruption. The answers were clarified by follow-up questions that further deepened the answers. Frequently used follow-up questions in the study were: Can you tell me more? Can you explain? What did you think then? The interviews lasted between 35 min and 107 min, with an average duration of 65 min. The interviews were recorded after permission from the interviewee and were transcribed verbatim.

## Analysis

The interview transcripts were analysed using qualitative content analysis. According to Elo and Kyngäs (2008), this method focuses on important areas to increase understanding by systematically classifying parts of the text to fewer and overall terms. The content analysis process should be divided into three major phases, preparation, organizing and reporting. In the preparation phase of this study, the transcribed interview texts were read thoroughly several times. The organizing phase consisted of making notes and headings in the text while reading it, ‘open coding’ (Elo and Kyngäs, 2008). Thus, patterns emerged and text segments that referred to ageing from different perspectives were identified. The text segments were sorted and reread while searching for similarities and differences, and then they were organized into sub-themes. The sub-themes were re-read and quotes that captured the essence of each sub-theme were highlighted. The latent content of the sub-themes was interpreted and discussed by the three authors. From the discussions, an overall theme emerged. Quotations that illustrated the core content in the sub-themes were selected in the reporting phase. No comparison was made between the staff from group homes and the staff from daily activity centres, because they work with the same study group of people with

ID. Another reason for not comparing the two staff groups was their different numbers; the participants from group homes included 17 staff members compared with 7 staff members from daily activity centres.

### ***Ethical considerations***

The project received approval in 2013 from the Regional Ethical Review Board in Lund (Dnr 2013/83). The study followed the ethical principles for medical research (World Medical Association, 2013) and was conducted in accordance with the Swedish Ethical Review of Research Involving Humans Act (SFS, 2003:460) and Public Access and Secrecy Law (SFS, 2009:400).

The staff who participated in the interviews received oral and written information about voluntary participation and were informed that they could withdraw their participation at any time without providing explanation. All participants gave verbal and written informed consent before participating in the interviews. The collected data were anonymised to ensure confidentiality, and strict secrecy was maintained throughout the analysis and presentation of the data.

### **Findings**

The overall theme ‘ambivalence regarding ageing with ID’ emerged as the principal expression of the latent content of the five sub-themes that emanated from the interviews: (1) being uncertain about signs of ageing; (2) comparing life conditions in people ageing with ID with conditions in older people without ID; (3) supporting an active life; (4) facilitating assistive devices and (5) reflecting on ageing ‘in place’. The overall theme contained a condensed underlying meaning of uncertainties and reflections on ageing with ID, often compared with ageing without ID. The staff had no clear understanding of what ageing with ID meant or what it should be like. On the one hand, they perceived ageing with and without ID as the same; on the other hand, they regarded the ageing process in people with ID as different. Older people with ID were perceived by the staff as ageless as long as newly added disabilities and diseases could not be regarded as clear signs of ageing.

#### ***Being uncertain about signs of ageing***

The staff perceived ageing as essentially the same process for people with ID and people without ID, although they generally did not reflect upon the persons’ age or that people with ID grow old. They emphasized physical decline and fatigue, although they expressed uncertainty and ambivalence about whether these changes were due to ageing or the person’s disabilities. Reduced mobility, for example, not being able to walk or move as in the past, was often mentioned. This, in turn, could lead to increased need for support and care in the daily life of persons with ID. The staff brought up examples such as hygiene, clothing and meals as situations where persons with ID required more support than they had previously needed in their everyday life. They saw these as possible signs of ageing. Sleeping or resting during the daytime or feeling tired was also considered an indication of ageing.

Our patients here include someone who will be turning 70 this summer. He says, “I’m so tired, so tired,” and we say, “Yes, it’s okay to say you’re tired when you’re 70 years old – you can’t keep going at the same pace as you did before.” You notice tiredness more. (female, aged 56, group home)

Moreover, the staff associated ageing with the emergence of diseases such as cardiovascular diseases and diabetes. They described diseases as a natural part of the ageing process and viewed ageing as synonymous with illness. They often mentioned dementia and associated it with changed behaviour in older persons with ID. Changed behaviour was, in general, an important indication for the staff that the person with ID should be observed more carefully. One example of changed behaviour was when an older person with ID suddenly forgot that they had retired from their daily occupation and got ready in the morning and waited for the community transport vehicle to arrive to go to work. Another example was that of an older person with ID wanting to eat again immediately after a meal and not remembering that he/she just had eaten. According to the staff, a different behaviour could mean an emerging disease or symptoms of a natural ageing process.

Well, you need to pay attention when their behaviour changes – I mean, you find out if anything special is going on, because they can't express themselves like we can. It's a lot about body language and about things they do that are different from how they have always behaved before. It might be that they don't want to eat anymore. And if so, you might have to make sure they can swallow, because that's something that changes when they get older. It might be the case that they can't eat their food – you might have to mash it first. Or maybe they can't find the food on their plate, for some reason or another. Or maybe they get lost in the building, for instance – and can't find their way to their apartment. You have to be alert and notice things like that, that will show you that ageing is coming. (Female, aged 37, group home)

Nevertheless, the staff expressed ambivalence towards checking whether behavioural changes were part of the existing disability or whether they were caused by diseases and/or ageing. They found it difficult to decide how they should interpret changes in behaviour and capabilities.

Just the fact that someone's walking has deteriorated – if it's ageing or simply deteriorated mobility – or sometimes someone might be deteriorating in something they're already weak in. It's really difficult, it really is. (Male, aged 58, daily activity centre)

### *Comparing life conditions in people ageing with ID with conditions in older people without ID*

In comparing ageing in people with ID with ageing in people without ID, some of the staff said that ageing with ID meant ageing prematurely. Additionally, the participants thought that people with ID have difficulties understanding what age and ageing is. Age, they said, is an abstract concept, and they believed that people with ID perceived themselves as young and not changing in age.

I've been working in elder care for 12 years so I try to make comparisons a bit. An old man or woman is aware that they're getting older. The people here are not, not in the same way, because they might think they're 14, between 14 and 20 or so, and they might have an intellectual age between 7 and 10. No . . . I think they don't understand or they prefer not to understand that they've gotten older. There are many normal older people who might not want to know either, but I believe it's more usual for them to know. (Female, aged 47, daily activity centre)

In other words, the participants perceived that, in contrast to other older people, persons with ID are unaware of the ageing process. This lack of awareness seemed to be of some relevance for the staff as well; they explained that they usually did not think of the older persons with ID as old nor did they notice any differences according to gender. The ID was what defined them, and they

seemed ageless or without age, in contrast to older people without ID who, the staff perceived, were clearly 'old'. This generated ambivalence when staff reflected on ageing.

You think in terms of the persons with ID and their care or their living situation, but you don't think as much about the fact that they're growing older. It becomes yet another question to consider – that they're not just intellectual disabled but that people with ID get older too. It's as if it's two separate things – two boxes to take into consideration. (Female, aged 47, group home)

One of the interviewees described the importance of talking about ageing with the person with ID. She had noticed that an older person with ID can experience uncertainty when the body does not work as before; however, at the same time, this person may not have words for the process or understand what is happening. It can be very difficult for an older person with ID to manage decreased ability to move as well as other new problems in everyday life. This interviewee stressed that care staff need to explain to the older person with ID what ageing means, and not only provide support.

The staff discussed the support and care they could give to ageing people with ID in compared with elderly care for older people without ID. Older people with ID were considered to have better social protection than other groups of older people, because older people with ID have already established access to formal support. According to the staff, several of whom had personal experiences with elderly care; nursing homes are more stressful to work in, with shortages of staff and lack of time to care for the residents. By comparison, in group homes for people with ID, more staff members are available and there is more time for social activities, for example excursions. Another difference pointed out was that staff members in group homes can focus on individual residents and spend time with them in a way that is not possible in nursing homes.

Here, we do meal preparation ourselves and we plan excursions for them. We do a lot of our work on an individual basis and there is a huge difference between this and working in a home for the aged. I believe living in a group home is definitely much better for them. (Female, aged 36, group home)

I really think our service recipients are much better off [laughs]. You read about horrible situations – older people left pathetically sitting all by themselves, some family member turning up maybe once a month. But ours always have company and they can choose whether to stay inside in their apartment or sit in the common space – from the moment they wake up in the morning to the time they go to bed. They use their apartments for sleeping in – not much more [laughs]. (Female, aged 46, group home)

### *Supporting an active life*

A dominant view that emerged was the staff's emphasis on activity. Interviewees strongly expressed the notion that it is important to support an active life in older people with ID. Examples of activities, besides daily occupational activities, were baking, shopping, dancing, going for a walk or to the café and going on excursions. Taking part in activities was regarded as crucial to create feelings of participation and wellbeing in people with ID, although some of the staff also reflected on the need for less extensive activities. The interviewees associated being able to be active with a good ageing process. This meant that staff sometimes took on a persuasive role and pushed for activities.



There's a lot of coaxing involved, because there's not much they want to do. They enjoy being in their apartments and are content to stay home, so you really have to push to get them to go out. (Female, aged 57, group home)

The pursuit of an active life was sometimes complicated, for instance, when a person with ID retired from working at the daily activity centre. Many staff members stressed the importance of helping the older person with ID find new activities to replace the activity at the daily activity centre.

You could say retirement often occurs in stages . . . It certainly doesn't happen in the usual way – that you work until you retire and then go on a pension; rather, it's more of a phasing out. You might start with 1 day off per week, and then 2 days off, etc so you get used to it gradually. There's a significant focus on finding other things to keep busy with during the period of phasing out from the daily activity centre. Particularly if someone is lively and alert – so they'll have something to fill up their leisure time. (male, aged 24, group home)

According to the staff, retirement from the daily activity centre could be very distressful to the older person with ID. Therefore, sometimes the occupational activity could be extended for a while.

It's quite hard for them to understand, so we have actually applied to allow them to work a bit longer, for their own sake. So it tends to be up to age 67, but they are not allowed to continue after that, because at that point they must retire just like everyone else . . . It's a kind of a pity. It's okay to reduce their work time, but . . . I think many of them miss it and they don't understand why it has to be this way. "Why can't I go back to my job?" (female, aged 36, group home)

Another example of when an active life can become more difficult was when older persons with ID need more support and care in the activities of everyday life. The interviewees acknowledged that the persons with ID needed more support; however, at the same time, they said they wanted them to maintain an active lifestyle as much as possible. The staff emphasized the importance of continuity; for instance, they said that the older persons with ID should not stop going outdoors, even if they needed more support and going outdoors became quite difficult.

Some of the staff problematized the emphasis on activity. They were aware that older persons can have less energy and willingness to participate in activities. They knew older persons with ID who no longer wanted to join excursions or events but, rather, wanted to stay at home. Many activities, involving many people and a noisy environment, only made the older persons tired. For the staff, it was sometimes difficult to recognize that changed interests could be connected to ageing. Their focus on activity sometimes overshadowed any signs and needs connected to ageing, and they actually forgot that people with ID age.

I myself forget that they do age. When you first notice there's been a change . . . I might think to myself "How strange – why, why doesn't this person want to . . . ?" So I forget, because that's exactly the way I want it to be [laughs]. It's like, you don't want to see the shortcomings, or, I really just don't know. That you would have to remind yourself, but my God! They, too, get . . . [older]. (Female, aged 48, group home)

One of the staff members also mentioned that filling the older persons' lives with activities could sometimes appear to be meaningful for the staff, but not for the older persons themselves.

Contributing to an active life for persons with ID was satisfying for the staff, but could lead to too many activities and too little recuperation for the persons with ID.

I also think we've talked about this sometimes, that just like for other people perhaps, you always have to fill time. And maybe it becomes just too much, and maybe because of age, you simply can't do as much as you used to be able to do. We here on the staff may also have had to slow down a bit, accept that this or that person just wants to be at home. Just like anyone else. The idea that there always has to be something going on – that we forget maybe even more here that people's brains get tired even more easily. Maybe they just want to stay home and sit on the sofa, that is also . . . a way to relax and feel content. But as staff we might think that doesn't feel right – I mean, it's more about my own satisfaction then [laughs]. (Female, aged 49, group home)

### *Facilitating assistive devices*

In supporting an active life for people with ID, the staff sometimes needed to help with assistive devices. According to the staff, it was only natural that ageing should include the use of assistive technology that would facilitate everyday life. Assistive devices included a shower chair, a walker or a wheelchair, or a hearing aid or pair of glasses. The request for assistive devices often came from the staff, not from the persons with ID. The interviewees explained that it was difficult for people with ID to express their needs. On the other hand, it was also difficult for staff to always determine what needs people had due to ageing.

Yes, but of course they can't – they can't communicate that in the same way. We know that many people here have poor eyesight and wear glasses, but we actually can't say if the glasses are right or not, because they can't actually participate in an eye examination. Of course we have certain types of walking aids, and introducing walking aids works sometimes and other times not at all. (Female, aged 34, daily activity centre)

The staff expressed that assistive devices could be difficult to manage for people with ID even if the devices were necessary for their daily wellbeing.

You can see that they don't hear well and it's the same here – that some of them can cope with a hearing aid, whereas others can't cope at all. Many of them just pick them apart – they destroy them, and that has to do with their disability. (Female, aged 48, group home)

Moreover, the staff said that starting to use an assistive device was a change and changes could be experienced as troublesome by persons with ID. The difficulty of handling new objects, as well as the risks connected to change, had led to uncertainty and ambivalence about whether the staff should or should not introduce assistive items. The time aspect was also mentioned by giving the person with ID more time to try out and test an assistive device that was needed, they could be supported to adjust and familiarize themselves with the new situation and feel secure. Some of the staff also discussed how to introduce new assistive devices. The idea was not to be too abstract but, rather, to show how to use the item in practice.

I mean you can try, I mean sometimes with a gripper or some such aid, you might demonstrate . . . : "Look, this is great – now I don't have to bend down!" For example, actually show someone how to do it, instead of just putting it in their hand and say, "If it's hard to bend down . . ." – we show them how it's done . . . (Female, aged 51, group home)

### *Reflecting on 'ageing in place'*

Supporting people to remain in their homes for as long as possible, that is, ageing in place, is a current social policy of which the staff were well informed. The consequences of the ageing process for people with ID were reflected upon by the staff in relation to ageing in place. They felt that ageing in place is beneficial because it enables older people to maintain independence and autonomy. The question of dementia raised the discussion about whether an older person with ID should move to a nursing home for older people without ID. Some of the staff said that it was difficult to give proper care to a person with dementia in a group home because they did not always feel that they had the right knowledge. It might also be difficult for the other residents to understand and interact with the person with dementia. Other staff members expressed a wish that the older person with ID should age in place, regardless of dementia. One of the staff members had negative experiences of having placed an older person with ID into a nursing home for older people without ID because the person in question had been mistreated by the other residents. For all of the staff, the question of ageing in place or not was ambivalent and triggered reflection.

Sometimes I've just cried out in exasperation, "We don't actually understand dementia – [...] shouldn't be living here." But what is supposed to be the deciding factor? Is the dementia patient supposed to decide? And are they supposed to have quality of life? It's perhaps more important that these people are here and recognize staff and their neighbours in the home and on the grounds and in the surrounding area. That's maybe more important than us putting all our energy into the fact that they have dementia. I don't know. (Female, aged 45, group home)

Another issue brought up by the staff was that the group homes had residents of different ages. Older people with ID could be sharing common areas with younger people with ID. Some of the staff regarded this as irrelevant since they did not believe that people with ID had notions about age differences. Other staff commented that living with younger people could be positive for the older persons, making the home livelier and making the older residents more active. On the other hand, living with younger people could be tiring for the older persons who also needed calm and quiet surroundings. Again, ambivalence was reflected in the staff's thoughts and concerns.

I mean, the older you get, in general in any case, the more often you will want to take things more slowly. If you have a 20-year-old always running around the residence it can be very challenging and if you can't communicate that to anyone, it makes it even more burdensome. But at the same time, you shouldn't – it shouldn't be something you avoid, either... If someone enjoys their living situation, where they have lived for, say, 10 years, you should definitely not relocate them, but the option has to be available. (Male, aged 24, group home)

## **Discussion**

The main finding that emerged was 'ambivalence regarding ageing with ID', which expressed the staff's experiences of uncertainty, contradictions and inconsistency regarding ageing. The staff seemed to recognize the ageing process in persons with ID as being the same as for people without ID, although still different. Part of these contradictions and inconsistencies was also the lack of distinction between changes due to ageing and changes due to disabilities. From the staff's perspective, it seemed to be the ID that primarily defined the persons with ID, a finding that also reflected the staff's perception that there were no differences in gender regarding ageing with ID.

The staff described being uncertain about signs of ageing and whether the changes they noticed were due to the ageing process or to the disability itself. They also described that people with ID themselves were unaware of the ageing process. However, signs of ageing were predominantly associated with medical aspects and physical abilities, and ageing often meant an increased need for support. This is in line with Kåhlin et al. (2016b)'s study reporting that staff members rarely discussed ageing. However, when they did, it was related to a change in a resident's physical or mental abilities which affected that person's everyday life and, consequently, the daily work of the staff.

The staff made comparisons between the life conditions of older people with ID and those of older people without ID, suggesting that disability services such as group homes were better than general care services for older people, a view in line with opinions found in the interview study by Kåhlin et al. (2016b). There, the staff pointed out that the staff–resident ratio was better in group homes for people with ID than in nursing homes in general elderly care, enabling the staff to spend more time with the older persons with ID.

Our study revealed that the staff considered supporting an active life as important. Being able to be active is part of a good ageing process. This perspective agrees with the widely used terms 'successful ageing' and 'healthy ageing' and WHO has stressed the importance that this is not only for the general population (Reppermund and Trollor, 2016; WHO, 2001). Older people with ID are highly heterogeneous in their ability often with with chronic diseases since an early age and increasing multimorbidity at a higher age. In their ageing, their skills decrease due to this multimorbidity, inactive unhealthy lifestyle, limited awareness of risk factors by staff and missed diagnosis of health problems because of a lack of understanding from the person with ID (Reppermund and Trollor, 2016; WHO, 2001). Lawton's press-competence model can support staff in applying the health policy of successful ageing and healthy ageing in people with ID at risk of unhealthy ageing processes. This theory is providing staff with deeper understanding of competencies and needs in the persons with ID themselves and importance of a supportive environment that they as staff are part of (Bigby, 2004; Lawton, 1985; Lawton and Nahemow, 1973). Retirement from working at the daily activity centre could cause problems, and the staff tried to find new activities to replace the occupational activity. According to Bigby et al. (2011), staff in ID services sometimes express concern about the risks of retirement for people with ID and emphasize the importance of continued activity.

Nevertheless, in our study there were also instances where interviewees reflected on the need to reduce activities, a finding that is inconsistent with the strong emphasis on activity. They recognized that older persons may have less energy and may be less willing to participate in activities. Furthermore, they recognized the risk that activities could be for the satisfaction of the staff rather than that of the older persons with ID. The need for balance between activity and rest emphasizes the importance of person-centredness as the professional approach in the ID service. Edvardsson et al. (2010) have stressed that the core aspect is 'promoting a continuation of self and normality'. A necessary condition of person-centredness is the person's narrative about his/her experiences, feelings, beliefs and preferences. These narratives give the staff the best basis to understand and plan care and services for a person with decreased ability to express themselves. Documenting the preferences, beliefs and values highlight the importance of knowing the person behind the service and care. Person-centredness involves interaction between the staff and persons with ID based on the individual's needs, personality and abilities (Bigby, 2004; Edvardsson et al., 2010; McCormack, 2004). Several countries have included a person-centredness approach as the goal for ID

service. However, what is noteworthy is that there is no published research study where an intervention in the practice is evaluated in the ID service.

Being, or staying, active in old age often means having to use assistive devices. The staff considered it part of their work to facilitate residents' acquisition and use of assistive devices. However, it was difficult for the staff to make accurate decisions based on the needs that emerged from the ageing process. According to the interviewees, older people with ID do not have the ability to express their needs, and they cannot easily manage assistive devices, which can in turn lead to uncertainty about whether to introduce assistive devices. Ageing, with or without ID, often involves an increasing number of assistive devices, which can either be accepted or resisted by the individual who is expected to use them (Alftberg, 2017). In this case, the presence of intellectual disability, rather than older age, seemed to be a barrier to the use of assistive technology, according to the staff.

The question of ageing in place created ambivalence and led to reflection. The staff discussed whether they could give proper care to an ageing person with ID, perhaps suffering from dementia, and how this might affect the interaction with other residents. However, they also emphasized that ageing in place meant continuity and a better wellbeing, a notion that agrees with the literature (Wiles, 2012). Another aspect discussed was that group homes house residents of different ages, a situation that was perceived as both positive and negative. It was positive in the sense that younger residents could encourage the older residents to be more active; it was negative if living with younger people was experienced as tiring by the older persons. Kåhlin et al. (2016b) reported that staff members favour ageing in place for people with ID in group homes. Older persons with ID should remain in the group home even when they have increased care and support needs, an argument grounded in the belief that this is a human right (Kåhlin et al., 2016b). Contradictory results show that at some point ageing residents with ID will need more intensive or skilled care than can be provided in a group home and the solution is then relocation to aged care (Webber et al., 2010). Declining health appears to be a major reason for relocation (Webber et al., 2016). As mentioned previously, when the staff in our study discussed an eventual relocation, they raised the concern of the risk of mistreatment and neglect from other residents without ID. This is also highlighted by Webber et al. (2014) who reported that the primary concern in connection with relocation is social isolation.

Different ages and age-based groups are assumed to possess certain inherent qualities, distinct from each other. According to Krekula (2009), one and the same action will have different consequences depending on the perceived age of the person. One example of an ageing stereotype is that of decline, disease and dementia, which tend to be attributed to all older people (Katz, 2009). For instance, actions that demonstrate any signs of memory loss will be understood in one way if performed by an older person but regarded differently if performed by a younger person. In Krekula (2009)'s words, reference to age (in this case, old age) is assumed to represent something taken for granted in every situation. Thus, each age is attributed different norms, ideas and expectations. However, older people with ID do not seem to fit into these normative figures of thought (Närvänen, 2004). People with ID are often considered to be like children or are looked upon as eternal youths (Lövgren, 2013). They can even seem ageless (Kåhlin et al., 2016b). Therefore, they are not assumed to possess the inherent qualities of older people. By contrast, there appears to be an absence of norms, ideas and expectations regarding older people with ID – perhaps because growing old with ID still is a reasonably new phenomenon – that, in turn, may lead to uncertainty and ambivalence among the staff members that interact with this group. Age has little significance in the staff's understandings of older people with ID, a phenomenon that was at

display when the staff interviewed for this study described that they generally did not think of the residents as old. They said that the intellectual disabilities overshadowed age – which can be related to diagnostic overshadowing (Mason and Scior, 2004; Standen et al., 2017) – and the older persons with ID were first and foremost defined by their disabilities, from the staff's point of view. The concept of age coding highlights how age intersects with other social categories such as gender, class and ethnicity – which all constitute principles to generate social order and relations of power (Krekula, 2009). A study with the managers in ID services within the same project (Johansson et al., 2017) identified that ID overshadows the characteristics of gender. In their narratives, gender was overshadowed and the authors highlighted the importance of the concept of intersectionality in understanding how a person's several social identities interact (Johansson et al., 2017). However, it seems clear that (dis)ability is a significant aspect in this intersection with, or even overshadows, other categories (Barron, 2002; Lövgren, 2013; Priestley, 2003; Thomas, 2006). In our study, the staff seemed to alternate between notions of old age and notions of ID and they had difficulties to bring them together producing ambivalence.

There are some methodological issues on which we would like to focus. The sample consisted of staff with a relatively long working experience (mean 16.6 years). The purposeful sample, which is usual for qualitative studies, included staff with experiences in supporting older people with ID. The data on working experience typical for staff in group homes and at daily activity centres are unknown and need to be considered when interpreting the findings in this study. Data collection was performed by one of the authors (MJ), while the analysis was conducted by another (ÅA). This could have affected the interpretation, because the impressions during the interviews in qualitative research may also be of importance. Credibility was secured by several meetings with thorough discussions of the analysis by all three authors; also, MJ re-read the transcribed interviews and reiterated the sub-themes. The interviews occurred at the staff's workplaces during their working hours, meaning that the interviewees could interrupt the interview if they were suddenly needed at work. The overall impression was that this did not produce any stress or unwillingness to participate in the study.

## **Conclusion**

Age had minor significance in the staff's understandings of older people with ID, and their experiences and reflections suggest ambivalence regarding ageing with ID. Older persons with ID are defined by their disabilities from the staff's point of view, producing uncertainty and inconsistency regarding their ageing process and ultimately the care provided to them. The findings indicate the need for increased awareness and knowledge, among staff in ID services, about how age and other social categories, including disability, are interrelated. Therefore, developing and dissemination knowledge about ageing with ID to all who work in ID service is an urgent issue in the increased ageing population.

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## Author contributions

ÅA conducted the analysis and wrote the first draft of the manuscript. MJ contributed to the design of the study, collected the data and performed a critical revision of the results by re-reading the data and validating the analysis. GA developed the design of the project, applied for the research grant and wrote part of the manuscript draft. Comments on the findings and improvement of the draft were made by MJ and GA. All authors have approved the final version of the manuscript.

## Data availability

Even if the data generated and analysed have been anonymised in the current study they are not publicly available as they contain sensitive information on a vulnerable group, namely, older persons with ID. Therefore, the Regional Ethics Review Board in Lund set restrictions regarding accessibility of the data. However, the data may be available upon reasonable request, pending consultation between the principal researcher (GA) of the project and the review board.


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## References

- Alftberg Å (2017) New objects, old age. The material culture of growing old. *Ethnologia Fennica* 44: 23–34.
- Axmon A, Ahlström G and Sandberg M (2019) Falls resulting in health care among older people with intellectual disability in comparison with the general population. *Journal of Intellectual Disability Research* 63(3): 193–204.
- Axmon A, Björne P, Nylander L, et al. (2017) Psychiatric diagnoses in older people with intellectual disability in comparison with the general population: a register study. *Epidemiology and Psychiatric Sciences* 27(5): 479–491.
- Barron K (2002) Who am I? Women with learning difficulties (re)constructing their self-identity. *Scandinavian Journal of Disability Research* 4(1): 58–79.
- Bigby C (2004) *Ageing with a Lifelong Disability: A guide to Practice, Program, and Policy Issues for Human Services Professionals*. London; New York: Jessica Kingsley, 2004.
- Bigby C, Webber R, Bowers B, et al. (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.
- Bigby C, Wilson NJ, Balandin S, et al. (2011) Disconnected expectations: staff, family, and supported employee perspectives about retirement. *Journal of Intellectual and Developmental Disability* 36(3): 167–174.
- Blackman N (2007) People with learning disabilities – an ageing population. *Journal of Adult Protection* 9(3): 3–8.

- Bowers B, Webber R and Bigby C (2014) Health issues of older people with intellectual disability in group homes. *Journal of Intellectual & Developmental Disability* 39: 261–269.
- Burke E, McCarron M, Carroll R, et al. (2014) What it's like to grow older: the aging perceptions of people with an intellectual disability in Ireland. *Intellectual & Developmental Disabilities* 52(3): 205–219.
- Cooper SA (1997) Epidemiology of psychiatric disorders in elderly compared with younger adults with learning disabilities. *British Journal of Psychiatry* 170: 375–380.
- Coppus AM (2013) People with intellectual disability: what do we know about adulthood and life expectancy? *Developmental Disabilities Research Reviews* 18(1): 6–16.
- Deb S, Thomas M and Bright C (2001) Mental disorder in adults with intellectual disability. I: prevalence of functional psychiatric illness among a community-based population aged between 16 and 64 years. *Journal of Intellectual Disability Research* 45: 495–505.
- Edvardsson D, Fetherstonhaugh D and Nay R (2010) Promoting a continuation of self and normality: person-centred care as described by people with dementia, their family members and aged care staff. *Journal of Clinical Nursing* 19(17-18): 2611–2618.
- Elo S and Kyngäs H (2008) The qualitative content analysis process. *Journal of Advanced Nursing* 62(1): 107–115.
- Haveman M, Heller T, Lee L, et al. (2010) Major health risks in aging persons with intellectual disabilities: an overview of recent studies. *Journal of Policy and Practice in Intellectual Disabilities* 7(1): 59–69.
- Innes A, McCabe L and Watchman K (2012) Caring for older people with an intellectual disability: a systematic review. *Maturitas* 72: 286–295.
- Janicki MP, Davidson PW, Henderson CM, et al. (2002) Health characteristics and health services utilization in older adults with intellectual disability living in community residences. *Journal of Intellectual Disability Research* 46(4): 287–298.
- Johansson M, Björne P, Runesson I, et al. (2017) Healthy ageing in people with intellectual disabilities from managers' perspective: a qualitative study. *Healthcare* 5(3): 1–14.
- Judge J, Walley R, Anderson B, et al. (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.
- Kapell D, Nightingale B, Rodriguez A, et al. (1998) Prevalence of chronic medical conditions in adults with mental retardation: comparison with the general population. *Mental Retardation* 36(4): 269–279.
- Katz S (2009) Introduction. In: Katz S (ed) *Cultural Aging: Life course, Lifestyle, and Senior Worlds*. North York: University of Toronto Press, pp.11–20.
- Krekula C (2009) Age coding – on age-based practices of distinction. *International Journal of Ageing and Later Life* 4(2): 7–31.
- Kåhlin I, Kjellberg A and Hagberg JE (2015a) Staff experiences of participation in everyday life of older people with intellectual disability who live in group homes. *Scandinavian Journal of Disability Research* 17(4): 335–352.
- Kåhlin I, Kjellberg A, Nord C, et al. (2015b) Lived experiences of ageing and later life in older people with intellectual disabilities. *Ageing & Society* 35(3): 602–628.
- Kåhlin I, Kjellberg A and Hagberg JE (2016a) Choice and control for people ageing with intellectual disability in group homes. *Scandinavian Journal of Occupational Therapy* 23(2): 127–137.
- Kåhlin I, Kjellberg A and Hagberg JE (2016b) Ageing in people with intellectual disability as it is understood by group home staff. *Journal of Intellectual & Developmental Disability* 41(1): 1–10.
- Lawton MP (1985) The elderly in context. Perspectives from environmental psychology and gerontology. *Environment and Behaviour* 17(4): 501–519.
- Lawton MP and Nahemow L (1973) Ecology and the aging process. In: Eisdorfer C and Lawton MP (eds) *Psychology of Adult Development and Aging*. Washington: American Psychological Association, pp. 619–674.
- Lawton MP and Simon B (1968) The ecology of social relationships in housing for the elderly. *Gerontologist* 8(2): 108–115.



- Lövgrén V (2013) *Villkorat vuxenskap. Levd erfarenhet av intellektuellt funktionshinder, kön och ålder*. In Swedish. [Conditional Adulthood: Lived Experience of Intellectual Disability, Age and Gender]. PhD Thesis, Umeå University, Sweden.
- Mason J and Scior K (2004) 'Diagnostic overshadowing' amongst clinicians working with people with intellectual disabilities in the UK. *Journal of Applied Research in Intellectual Disabilities* 17(2): 85–90.
- McCormack B (2004) Person-centredness in gerontological nursing: an overview of the literature. *Journal of Clinical Nursing* 13(3a): 31–38.
- Ng N, Sandberg M and Ahlström G (2015) Prevalence of older people with intellectual disability in Sweden: a spatial epidemiological analysis. *Journal of Intellectual Disability Research* 59(12): 1155–1167.
- Ng N, Flygare Wallén E and Ahlström G (2017) Mortality patterns and risk among older men and women with intellectual disability: a Swedish national retrospective cohort study. *BMC Geriatrics* 17(1): 269.
- Närvänen AL (2004) Age, ageing and the life course. In: Öberg BM, Närvänen AL, Näsman E and Olsson E (eds) *Changing Worlds and the Ageing Subject. Dimensions in the Study of Ageing and Later Life*. Burlington: Ashgate, pp.65–80.
- Patja K, Iivanainen M, Vesala H, et al. (2000) Life expectancy of people with intellectual disability: a 35-year follow-up study. *Journal of Intellectual Disability Research* 44(5): 591–599.
- Priestley M (2003) *Disability: A Life Course Approach*. Cambridge: Polity.
- Reppermund S and Troller JN (2016) Successful ageing for people with an intellectual disability. *Neurodevelopmental Disorders* 29(2): 149–154.
- Sandberg M, Ahlström G and Kristensson J (2017) Patterns of somatic diagnoses in older people with intellectual disability: a Swedish eleven year case-control study of inpatient data. *Journal of Applied Research in Intellectual Disabilities* 30(1): 157–171.
- Schuengel C, Kef S, Damen S, et al. (2010) 'People who need people': attachment and professional caregiving. *Journal of Intellectual Disability Research* 54(suppl 1): 38–47.
- SFS 1993:387 (1993) *Act Concerning Support and Service for Persons with Certain Functional Impairments*. [In Swedish: Lag om stöd och service till vissa funktionshindrade]. Stockholm: Swedish Code of Statutes, Swedish Parliament, Sweden.
- SFS 2003:460 (2003) *Act Concerning the Ethical Review of Research Involving Humans*. [In Swedish: Lag om etikprövning av forskning som avser människor]. Stockholm: Swedish Code of Statutes, Ministry of education and research.
- SFS 2009:400 (2009) *Public Access and Secrecy Act*. [In Swedish: Offentlighets-och Sekretessförordning]. Stockholm: Swedish Code of Statutes, Government Offices of Sweden.
- SFS 2017:30 (2017) *Health and Medical Services Act*. [In Swedish: Hälso-och sjukvårdslag]. Stockholm: Swedish Code of Statutes, Ministry of Health and Social Affairs.
- SFS 2018:347 (2018) *The Swedish Social and Services Act*. [In Swedish: Socialtjänstlag]. Stockholm: Swedish Code of Statutes, Ministry of Health and Social Affairs.
- Standen PJ, Clifford A and Jeenkeri K (2017) People with intellectual disabilities accessing mainstream mental health services: some facts, features and professional considerations. *Journal of Mental Health Training, Education & Practice* 12(4): 215–223.
- Starr J, Fender A and Marsden L (2007) Assessing the health of older adults with intellectual disabilities: a user-led approach. *Journal of Intellectual Disabilities* 11(3): 223–239.
- Swedish National Board of Health and Welfare (2014) *Persons with Certain Functional Impairments – Measures Specified by LSS 2013. Official Statistics of Sweden. Statistics – Social welfare*. [In Swedish with a summary in English]. Stockholm: Socialstyrelsen.
- Thomas C (2006) Disabilities and gender: reflections in theory and practice. *Scandinavian Journal of Disability Research* 8(2–3): 177–185.
- Wark S, Canon-Vanry M, Ryan P, et al. (2015) Ageing-related experiences of adults with learning disability resident in rural areas: one Australian perspective. *British Journal of Learning Disabilities* 43(4): 293–301.

- Webber R, Bowers B and Bigby C (2014) Residential aged care for people with intellectual disability: a matter of perspective. *Australasian Journal on Ageing* 33(4): E36–E40.
- Webber R, Bowers B and Bigby C (2016) Confidence of group home staff in supporting the health needs of older residents with intellectual disability. *Journal of Intellectual & Developmental Disability* 41(2): 107–114.
- Webber R, Bowers B and McKenzie-Green B (2010) Staff responses to age-related health changes in people with an intellectual disability in group homes. *Disability & Society* 25(6): 657–671.
- Wiles JL, Leibing A, Guberman N, et al. (2012) The meaning of “aging in place” to older people. *Gerontologist* 52(3): 357–366.
- WHO (2000) *Ageing and Intellectual Disabilities - Improving Longevity and Promoting Healthy Ageing: Summative Report*. Geneva, Switzerland: World Health Organization. Available at: [https://www.who.int/mental\\_health/media/en/20.pdf](https://www.who.int/mental_health/media/en/20.pdf) (accessed 1 September 2019).
- WHO (2001) Healthy ageing – adults with intellectual disabilities: summative report. *Journal of Applied Research in Intellectual Disabilities* 14(3): 256–275.
- WHO (2015) *World Report on Ageing and Health*. Geneva: WHO Press. Available at: <https://www.who.int/ageing/events/world-report-2015-launch/en/> (accessed 1 September 2019).
- World Health Organization (2007) Global age-friendly cities project. Available at: [www.who.int/ageing/age\\_friendly\\_cities\\_network](http://www.who.int/ageing/age_friendly_cities_network) (accessed 10 May 2019).
- WHO (2018) Disability and Health. Fact Sheet No. 352. Available at: <http://www.who.int/en/news-room/fact-sheets/detail/disability-and-health> (accessed 23 May 2018).
- World Medical Association (2013) *WMA Declaration of Helsinki – Ethical Principles for Medical Research Involving Human Subjects*. Fortaleza: WMA General Assembly.