

RESEARCH

How do People with Intellectual Disabilities in Norway Experience the Transition to Retirement and Life as Retirees?

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People with intellectual disabilities have increased life expectancy compared to just a few decades ago, and there is a lack of knowledge about the experiences of transition into retirement for this group. In this study, semi-structured in-depth interviews with seven retirees with intellectual disabilities were conducted in order to investigate their reasons for retirement, experiences of the transition, their activities and satisfaction with their lives as retirees. Data was analysed with systematic text condensation.

Most participants described that, although they experienced the retirement process and transition as abrupt, retirement had a positive impact on health, satisfaction and self-determination. Findings in this novel study in a Nordic context are need of increased knowledge on ageing and retirement among people with intellectual disabilities, and that individual guidance might improve their transition into retirement.

Keywords: intellectual disability; ageing; retirement; leisure activities; life change events; patient care planning

Introduction

Many countries worldwide, including Norway, are experiencing an increase in the number of senior citizens in general as well as among people with intellectual disabilities (Janicki et al. 1999, Patja et al. 2000, WHO 2015). Improved health and welfare services have led to an increase in child survival rates and, at the other end of the life span, extended life expectancy for older people (WHO 2014, 2015). As a result, the number of older people with intellectual disabilities has also risen, and will continue to rise even more the coming decades (Janicki et al. 1999, Patja et al. 2000). Although this is a positive development, people with intellectual disabilities will, to a larger extent than before, experience the same age-related challenges as the general ageing population, including declines in health, level of function, and daily activities (Crimmins and Beltrán-Sánchez 2010). Moreover, the onset of ageing processes for people with intellectual disabilities varies according to their level of disability and associated comorbidities (Bittles et al. 2002, Lawton and Nahemov 1973, Zigman 2013). For people with mild intellectual disability the onset of the ageing processes may have the same individual variation as seen in the general population. However, many people with intellectual disability experience earlier onsets due to factors associated with their diagnosis or comorbidities (e.g. Downs Syndrome) (Janicki et al. 1999).

Transition to retirement

Meleis (2010) describes transition as a passage from one life phase, condition and status to another. The experience of a transition is individual and may lead to personal growth, but may also be stressful and lead to decreased well-being, loss of networks and support (Schumacker, Jones, and Meleis 1999). Retirement is a heterogenous experienced transition but requires knowledge and often behavioural change, for both the general population and people with intellectual disabilities.

Retirement is complex and have been defined in various ways (Denton and Spencer 2009). Most commonly it marks a shift from paid employment to senior life. People with intellectual disabilities may not engage in ordinary paid work,

nevertheless they may consider themselves to be retirees upon leaving comparable positions in later life. In this article, retirement refers to withdrawal from employment or work-related activity that he or she considered to constitute work and defining him- or herself as a retiree.

Thus far, disability research has tended to focus on coping, learning, living conditions, and work participation, although recently an increasing number of studies have focused on retirement for people with intellectual disabilities. Few studies have considered the experience of retirement from the perspectives of people with intellectual disabilities themselves. One Scottish study has shown that considering retirement induces worries about major life changes prior to actual retirement for many people with intellectual disabilities (Judge et al. 2010). The researchers conclude that we need to increase self-determination in the retirement process for people with intellectual disabilities. Many of the Scottish retirees felt that the services cut them off when they retired and indicated that they did not make decisions about their retirement themselves. Judge et al. (2010) emphasised the need for retirees to remain active and to have a social network after retirement.

The experience of transitioning to retirement is highly individual in all populations and can depend on whether retirement is voluntary or involuntary and how well prepared individuals are for the transition (Mutran, Reitzes, and Fernandez 1997, Weiss 2005). Some interviews with retirees with intellectual disabilities reports fear of inactivity and lack of support as retirees (Bigby et al. 2011). For example, one of Bigby et al.'s participants returned to work after retirement out of boredom.

Studies have demonstrated that maintaining a social network and a social support system are necessary goals for life satisfaction as retirees (Bates and Davis 2004, Wadsworth, Harper, and McLeran 1995). The work setting is a social community and a place to develop and maintain friendships. A small US study reported a strong correlation between commitment to work and life satisfaction among people with intellectual disabilities (Laughlin and Gotten 1994). The researchers also tested the efficacy of a pre-retirement program, and the results showed that such a program can be effective in teaching older individuals with intellectual disabilities about options during retirement. However, the program did not result in a significant change in attitude towards retirement.

Statistics show that 43 percent of people in sheltered employment in Norway are 45 years or older (Spjelkavik et al. 2012). Employees at sheltered workplaces have diagnoses of various disabilities, including intellectual disabilities. Living with lifelong impairments and experiencing disabilities throughout life can substantially influence the ageing process. Individual differences often make it difficult to determine the appropriate age for reducing work or entering retirement (Hahn et al. 2016, Zigman 2013). For some, it might be appropriate to retire earlier than the average retirement age.

There are no official guidelines for retirement or retirement planning for people with intellectual disabilities in sheltered employment in Norway except that employees automatically become retirees at the age of 67, in line with governmental legislation (National Insurance Act 1997, § 19). In practice, this means that when an employee reaches 67 years of age, the sheltered company for which he or she works stops receiving financial support for the employee from the Norwegian Labour and Welfare Service, and the employee receives an age pension instead of a disability pension. This results in differences among workplaces. Some allow employees to stay at the workplace, often because other activities are unavailable, whereas others have internal guidelines requiring retirement when employees turn 67 years old.

Research on the transition to retirement has rarely included the voices of people with intellectual disabilities (Savage et al. 2015). There is a need for increased knowledge about the challenges they face and how caregivers can help make the transition as smooth as possible. Often, many people are involved in the process including workplace supervisors, relatives, and municipal employees. Knowing more about the experiences of retirement for people with intellectual disabilities might enable us to facilitate a more successful transition for this population.

People with intellectual disabilities are considered a vulnerable population, and many researchers claim that it is difficult to obtain valid data directly reported by them (Mallander 1999, Thorsen 2005). However, excluding people with intellectual disabilities from studies concerning their lives is problematic (Ellingsen 2010), and therefore, interviewing this population in order to obtain important information about their experiences with transitioning to retirement is necessary. To the present authors' knowledge, no studies about the experiences of retirement for people with intellectual disabilities in the Nordic countries have been conducted. Such research is thus vital to increase knowledge about retirement, expressed by Norwegian retirees with intellectual disabilities themselves.

Aims

The overarching aim of this study was to learn more about seniors with intellectual disabilities in Norway concerning their reasons for retirement, experiences with transition to retirement, their activities as retirees, and how they experience their new situations as retirees. An additional aim was to compare the perceptions of the transition to retirement for people with intellectual disabilities with those among retirees in the general population.

Method

Semi-structured interviews

In-depth interviews with seven people with intellectual disabilities who had retired from sheltered employment one to two years earlier were conducted. The interviews were semi-structured, which is a suitable method for gathering information about subjective experiences and feelings (Kvale 2002, Malterud 2008). Semi-structured interviews

allow researchers to ask control questions, and solicit clarify statements about unclear responses in order to prevent misunderstandings (Whiting, 2008).

An interview guide addressing demographic information, work experience, and retirement situation was prepared. A reference group and research collaborators approved the interview guide, and a group of five employees with intellectual disabilities at a sheltered company tested it.

The interviews were conducted by the corresponding author, who is a nurse experienced with working with people with intellectual disabilities. All participants were informed that they could withdraw from the study at any time during the project, and could contact the project manager to receive more information or needed to talk. The interviews were conducted during a period of three months.

Ethics

This project was approved by Norwegian Social Science Data Services. All participants were capable of giving consent. Written informed consent, with short sentences and simple language, were obtained from the participants through guardians or caregivers and additionally a person of trust, as requested by Norwegian Social Data Services. The information was also provided orally by the corresponding author prior to the interviews to secure the participants' understanding of participation. Prior to the interviews, the participants were informed by their caregivers about the themes of the interviews.

Anonymity and confidentiality for the participants was essential goals of the project. This was explained and guaranteed to the participants by explaining the secure storing of audio files, and that no data identifying data would be published.

During the interviews, the participants were asked to reminisce on their lives, which was expected to possibly evoke positive and negative feelings. The interviewer was prepared to support the participants emotionally, and to discontinue any interview if necessary.

Recruitment

Given the lack of official or national registrations in Norway available to identify retirees from sheltered workshops with intellectual disabilities as well as the presumably low number within this group in Norway, a convenience sampling procedure was used. To decrease bias, the recruitment of participants was ended when the sample represented a sufficient variation in term of age, gender, living conditions, and residence. Potential participants were recruited via supervisors at sheltered workshops. Information about the project was sent to interested retirees and their guardians or caregivers, and they were encouraged to contact the corresponding author if they were interested in participating in the project. Inclusion criteria sought individuals with intellectual disabilities, able to communicate verbally in Norwegian. In addition, the informant previously must have worked in a sheltered company, retired one to two years ago, be over 40 years old, and could recall events for a minimum of three years prior. Finally, informants could not have any serious illnesses. After four months, eight participants were recruited. One was later excluded due to lack of confirmation on a diagnosis of intellectual disability.

Interview settings

To ensure that participation in this study should feel safe for the participants, the interviews took place in environments familiar to them. Six interviews took place in the homes of the respective participants, and one in her current activity centre. Interviews at home enabled observing the individual's surroundings in order to establish contact and build trust in the interview situation (Ellingsen and Kittelsaa 2010). Establishing a comfortable environment for the interviewee can help the interviewer obtain useful and reliable information. In two of the interviews, the interviewees were alone with the researcher, whereas another interview was conducted with a guardian present and four others with caregivers. Guardians or caregivers were encouraged to allow the participant to speak freely, with interruptions only when the participants desired help to express themselves. That measure was taken to make the interviews similar to normal conversations and ensure that the participants' experiences stayed in focus.

A possible bias common in interviews with people with intellectual disabilities is 'yes-saying' or acquiescence (Barron 2002, Heal and Sigelman 1995, Tøssebro 1989). This means that people with intellectual disabilities often tend to respond to questions in a way they think is expected or desired. One strategy used to reduce the chance of this bias was avoiding questions that sought 'yes' and 'no' answers during interviews.

Data management

The corresponding author encrypted the recorded files of the interviews and stored them on a secure server. Interviews were transcribed by the interviewer, and comments from the written notes were added to the transcription to support the audio content and capture nonverbal communication. One interview was not recorded, but fully written out of notes immediately after the interview and proofread by the informant and a guardian to clarify misunderstandings and add missing information. The text files were stored on the same secure server as the audio files. The list with participant's names and contact information was securely locked in a filing cabinet and shredded after analysis ended.

Analysis

The transcribed interviews were analysed using Malterud’s (2012) method of systematic text condensation (STC), a modification of psychological phenomenological analysis developed by Giorgi, but that is not as strictly phenomenological (Giorgi 1985, 2009). STC focuses on the exact descriptions of the experiences of the interviewees and aims to reduce the personal interference and preconceptions of the researchers (Malterud 2012). STC is a four-step process. In this study, the first step was reading through the transcribed material several times to attain a total impression of the text. Step two was identifying collection of meanings, numerous preliminary themes were drawn from the text, and the text was reread and color-coded based on themes and meanings relevant to the research questions. Health issues, deciding for themselves, activities and positivity came out as some of the preliminary themes. In the next step, substantial content was drawn from the themes, and significant meanings and experiences were condensed into substantial content. In the final step these meanings and substantial content was grouped and organised into main categories.

The categories were amended and adjusted to fit the meanings, and the final categorisation led to four main categories that focused on the experiences on transition to retirement and ageing:

- Health status: before and after retirement
- Self-determination and satisfaction: before and after retirement
- Knowledge on ageing and retirement
- Needs of activities and social interaction

Findings

Presentation of the participants

The participants in the study are four men and three women aged 42–68 years of age. **Table 1** presents the participants.

Four of the participants had mild intellectual disabilities with unknown causes; one had a moderate disability, also without a known cause; and two had Down syndrome with moderate intellectual disabilities. Four of the participants had worked in packaging and assembling and three in production and stock. Two were part-time retirees, whereas the rest were fully retired. The two participants with Down syndrome left work when they were 42 and 53 years old respectively. Another of the participants retired at age 65 years, and five retired at retirement age (i.e., 67 years). On average, participants retired one and a half year prior to the interviews. Six participants retired due to a decrease in their level of functioning, musculoskeletal degeneration, and tiredness. One, without any specific ailments, retired upon reaching retirement age.

Some participants spoke very freely, whereas others gave short, concrete answers to direct questions. No strong negative emotional reactions were occurred during or after any interviews. Some participants had never been interviewed before and thus especially valued the experience.

The objective of the analysis was to highlight variances between participants within the main categories. There was a marked distinction in experience of health, satisfaction, and self-determination before and after retirement. The greatest variation between the participants was found in the need for regular activities and social interactions.

Health status and coping

Health was a theme mentioned by all the participants, and most talked about their health with a clear distinction between before and after retirement. Prior to retirement nearly all participants described that their level of functioning did not correspond to their ability to perform work tasks. These participants experienced their decreased level of health in various ways, such as pain and tiredness. Although they felt that their workplaces had provided tasks and work schedules fitting their level of functioning and limitations, there were still variances in the way they experienced health issues and tiredness.

Table 1: presents the participants.

Interview	Gender	Age	Years since retirement	Retired	Activities as retiree	Living arrangement
1	Man	42	2	Fulltime	No fixed activities	With parents
2	Woman	68	1.5	Fulltime	Fixed activities every day	Shared accommodations
3	Man	55	2	Fulltime	No fixed activities	Shared accommodations
4	Woman	68	1.5	Fulltime	Previously: Day care Currently: No fixed activities	Shared accommodations
5	Man	68	1.5	Part-time	Work for 3 days, other fixed activities 2 days a week	Shared accommodations
6	Man	66	1	Part-time	Work for 3 days, other fixed activity 1 day a week	Shared accommodations
7	Woman	68	1.5	Full-time	Senior centre	With brother

Some explained having musculoskeletal issues that prompted pain and thus made work difficult. As one recounted: 'My fingers were stiff, and at work I could not use my fingers anymore'. Another could no longer lift because his 'back hurt and would not do the work'. Three participants with pain needed to take painkillers prior to retirement, but only one continued to need them after retirement.

Tiredness emerged as an important category for the participants. For some, increased tiredness also prompted difficulties in coping with other activities. As one participant explained: 'I was so tired, I could not do my tasks anymore. At home, I only wanted to sleep'. One experienced tiredness as physical signs of the body: 'I was very tired, so it became hard to work. I thought I was so tired, because my heart and pulse beat so fast when I'm tired. Then I fell asleep'.

After retirement, several participants experienced a decrease in tiredness. To describe the sensation, they said: 'I have more energy to do other activities', 'I can do much more now' and 'I don't need to sleep during the day anymore'. When asked about what would happen if they had to return to work, all but one said that they did not want to return to the workplace. With considerable sigh, one participant explained: 'I don't want to go there anymore. My body doesn't want to go there. You see, I can't bear it no more'. Another participant stated that retirement made life more relaxing and that going back to work was not an option: 'I wanted to be more by myself. I don't like working anymore. I have worked enough. I relax more here at home'. Only one said that she would feel the same if she were at work or the senior centre.

Most participants experienced decreased coping skills at the end of their working lives, even if the workplace had assisted in making their tasks easier. Some of the participants underwent a downward spiral of coping: 'They [the workplace] did not find anything I could do. I felt bored. At the end, I fell asleep in a corner'. Prior to retirement the person with stiff fingers also explained his decreased sense of coping when he could not manage work tasks anymore. This upset him. Another expressed relaxed feelings when experiencing lowered demands after retirement: 'I'm not that tired and angry anymore. I don't stomp the floor like before'.

Activities and social interaction

The activity level varied for the participants, as did their desire for activities. Some had daily activities, and others had no regular activities at all. The ones without regular activities decided what to do on a day-to-day basis. Another mentioned no need for any specific activities but appreciated the possibility of taking it easy at home. The participants who experienced the greatest health issues or tiredness prior to retirement did not want to have fixed activities. Some retirees also pointed out that their workplace supervisors expressed concern about their possible inactivity and lack of activities during retirement.

All participants talked about the importance of friends and stated having as many or more friends after retirement. Some remained in contact with friends at the old workplace, and others had met new friends at new activities. Interestingly those who expressed having as many friends as before, said that most of their social interactions were with the people in their homes, either family or friends in shared accommodations. That seeming contradiction might stem from their conception of former colleagues as friends, even though they no longer stay in contact. Another reason might be bias in the interviews that promoted them to answer according to what they felt was expected. A few participants also stated that it was nice to relax by themselves, and that they felt a decreased need for social interaction as retirees because of increased tiredness.

Six of the participants said that they did not visit their former workplaces, and one had visited only once during the past year. The participants stated that they did not want to visit their former workplaces anymore either, though it was difficult for them to explain why. They did not seem to have the need for it, and that the need for social interaction was fulfilled at other places.

The part-time retirees talked about days at work, compared to their days off, with a clear distinction. They defined themselves as workers on their days at work, and as retirees on their days at home. As one put it: 'I'm retired on Wednesdays and Fridays'.

Self-determination and satisfaction

Several recent studies have identified an increase in self-determination among people with intellectual disabilities (Nota et al. 2007, Söderström and Tøssebro 2011). However, our participants seemed to experience low self-determination during their transitions to retirement. Four participants felt that others had made the decision for them, and they talked about their lack of choice in the retirement process: 'Others decided that I should retire, and me a bit. Mostly the others.' Lack of choice in the retirement process is supported by findings reported of an Australian study by McDermott and Edwards (2012). The lack of choice in the retirement process is a recurring finding in research on activities and life in general for people with intellectual disabilities (Abells, Burbidge, and Minnes 2008, Hall 2010, Stalker and Harris 1998), even though it is well known that choice is an important factor for coping and well-being.

There were clear differences in satisfaction before retirement, in working life. Only one participant expressed dissatisfaction at work, because of too physical demanding tasks in relation to his employability. Two experienced tiredness, overly high demands, and feeling useless. They both described an increase in satisfaction after retirement. The rest were satisfied at work.

Participant satisfaction either stayed the same or increased after retirement. An interesting finding is that participants who continued working part time had the greatest increase in satisfaction after beginning part-time retirement: this

included the informant with physically demanding tasks at work and another who felt extremely tired. Indeed, there was no difference in satisfaction before and after retirement between participants who decided to retire themselves and those who indicated that others had made the decision for them. Some mentioned high satisfaction at work as well as after retirement. Based on the statements of the participants, differences in satisfaction between those who decided for themselves to retire and those who did were very small.

Even if they did initially want to retire, all participants expressed positive feelings about their lives as retirees. Contemplating life as a retiree, participants described their experiences in different ways: 'I'm enjoying life. It was lovely to stop working. I could not bear it. I enjoy other activities more now. It would have been exhausting to be at work now'. Another said: 'I wanted to stay at work. But I had to get used to it. It has been nice becoming a retiree. I'm more relaxed'.

These statements express the importance of being able to slow down the pace in later life. In addition, most participants directly described being able to decide more themselves after retirement as a positive factor. As one put it: 'I couldn't decide much at work. I can decide a lot more now, after retirement'. Another explained that others had mostly used to decide for him before, but as a retiree he was 'his own master'. A third expressed with a grand smile: 'Now I can do whatever I want, whenever I want'. Those statements, suggest that self-determination was clearly a positive element in life after retirement. Based on these findings, we hypothesise that self-determination could facilitate and improve the experience throughout the transition to retirement.

Knowledge on ageing and retirement

Knowledge on ageing and retirement was consistently poor among participants. Several said that they had not been educated about ageing at all prior to retirement, whereas some reported having learned only a little. Mostly, they wished that they had learned more about ageing prior to retirement. There were no big variations in the way they described this. One said, 'I wish I knew more about ageing, nobody talked to me about it'.

All participants who wanted to learn more, also said that they had thought a great deal about getting old or about death. Furthermore, most participants expressed problems relating to their own ageing. Some spoke about the ageing and deaths of other, including family members, guardians, and friends, but only one described thinking about ageing and death related to both his own life and the lives of people around him, and he still expressed a great need to talk and learn more about those concepts. Such findings are supported by other research that found that people with intellectual disabilities often have limited understanding of the concepts of ageing and death (McEvoy, MacHale, and Tierney 2012, Stancliffe et al. 2016).

All participants but one experienced the transition as abrupt, even those who were involved in the planning or decided for themselves to retire. The one with activities at a senior centre for people with intellectual disabilities did not experience the transition as abrupt. An interesting finding was that all participants who had learned little about ageing or retirement found the transition into retirement to be abrupt.

Discussion

The present study investigates the experiences of the retirement process among people with intellectual disabilities in Norway. In general, transitions in life can be challenging for everyone, and most likely even more challenging for people with cognitive disabilities. Ageing is a complex process that may be difficult to comprehend, as we also found in our study. A person has to know his or her own age and have the ability to understand the psychological and social perspectives of age, which may be difficult for people with intellectual disabilities (McEvoy, MacHale, and Tierney 2012, Stancliffe et al. 2016, Thorsen 2000). Moreover, many people with intellectual disabilities live their entire lives with physical disabilities, which may lead to problems relating to health issues and ageing (Thorsen 2000). In addition, the lack of knowledge about the possible early ageing in some people with intellectual disabilities may cause delays in connecting impaired health to biological age.

Our study confirms both similarities and differences between the general population and people with intellectual disabilities, as with other studies on retirement for people with intellectual disabilities. Similarities can especially be seen in reduced health as a main reason for retirement, increases in experienced health as retirees, and the varying needs for activities (Geyer, Spreckelsen, and von dem Knesebeck 2014, Vickerstaff and Cox 2005). It is important to map a decrease in the level of functioning to facilitate better ageing and life as a retiree.

The participants in this study experienced the transition into retirement as abrupt, and they expressed a need for time to adapt to the new situation. These findings are supported by studies on the general population as well as among people with intellectual disabilities in other countries (Bigby et al. 2011, Judge et al. 2010, Vickerstaff and Cox 2005). Our participants experienced a gap between knowledge and the wish for knowledge about ageing and retirement. Bridging this gap might decrease the fear of the transition and strengthen the possibility of self-determination in the process. The value of a more relaxed life with increased self-determination is another similarity and supported by both research concerning the general population and on people with intellectual disabilities (Judge et al. 2010, Vickerstaff and Cox 2005).

Economic and family factors, including wanting to spend more time with grandchildren, may be decisive in determining retirement in the general population and differs from people with intellectual disabilities (Geyer, Spreckelsen, and von

dem Knesebeck 2014, Vickerstaff and Cox 2005). In our study and previous research about retirement for employees with intellectual disabilities, these factors have not been an issue.

People with intellectual disabilities often need more predictability than people in general (Stewart et al. 2010). Therefore, it is important to facilitate their process of transitioning into retirement as much as possible. In a literature review, Stewart et al. (2010) reported the importance of individuals being prepared and having knowledge about ageing and retirement. A study from the US showed that satisfaction in life in general and the feeling of being prepared for retirement are strongly correlated with a positive attitude towards retirement (Laughlin and Gotten 1994).

Australian research has shown that the more control that people have over their retirement decisions, whether they have disabilities or not, the more that they one experience well-being in retirement (Quine et al. 2007). Even if our study does not have such findings, it nevertheless reflects the importance of maintaining self-determination in the process, a notion supported by several studies (McDermott and Edwards 2012, Nota et al. 2007, Rogers, Hawkins, and Eklund 1998). However, people with intellectual disabilities are often given few choices; furthermore, choices are often made by others on their behalf (Thorsen 2005, Wehmeyer and Metzler 1995).

Our study detected an unresolved contradiction regarding self-determination and retirement for people with intellectual disabilities. Many participants did not choose for themselves to retire, and several stated they did not want to retire. Presumably, some would have liked to continue working if given the choice. Nevertheless, they experienced retirement as a positive state. A reason for that might be that most people with intellectual disabilities have been forced to change and adapt to new situations throughout their lives. In any case, promoting self-determination might increase the chance of having an even more positive experience with retirement.

However, the knowledge and understanding that people with intellectual disabilities possess highly depends on the people in their lives. They often need assistance to acquire knowledge necessary to cope with a transition such as retirement. That means that caregivers also need to have knowledge about ageing and retirement to be able to support the people for whom they care.

The right time for adaptation at work and for planning the transition to retirement should be determined on an individual basis. Reduced physical functioning and tiredness can indicate when it is appropriate to initiate retirement planning for people with intellectual disabilities.

Worries about not having other senior activities have emerged in the literature as well as in our study (McDermott and Edwards 2012, Wadsworth, Harper, and McLeran 1995). In that case, poor planning seems to be the reason for the lack of senior activities. This situation also results in keeping employees at work for a longer time than their health may dictate, and thus diminishing their quality of life. Our interviews have shown that, even if people with intellectual disabilities do not want to stop working, they can still have a positive retirement experience, and may even prefer it to continuing to work. Interviews with retired people with intellectual disabilities in Australia confirm these findings (McDermott and Edwards 2012).

Many of our findings of the present study are supported in previous research. However, our sample was small and is not generalisable. To acquire more in-depth knowledge in the field, it would be necessary to conduct studies with larger random samples. To increase the quality of future studies, interviews could be repeated. Having more researchers to transcribe and analyse the interviews would also be preferable to secure an understanding of interviews and increase the reliability of the studies. Another limitation is that our study was retrospective. By contrast, future research should include prospective, longitudinal studies to obtain an increased understanding of retirement for people with intellectual disabilities.

Conclusion

This study has investigated the experience of the transition to retirement for people with intellectual disabilities and its findings can be used to better support future retirees. A consistent finding is a lack of knowledge and self-determination in the retirement process. Self-determination is important for all people, and it is especially important that caregivers of people with intellectual disabilities provide essential support help them make self-determined decisions. Our participants especially valued the increase in self-determination after retirement, a finding supported by several previous studies (McDermott and Edwards 2012, Nota et al. 2007).

Our interviews revealed that the process of and experience with retirement in Norway for this population depends heavily on the people surrounding the retiree. More structured follow-up systems for individuals with intellectual disabilities with a declining level of functioning are thus necessary. If caregivers are aware of the possible early onset of the ageing processes, they can be more responsive to changes and facilitate proper activities. The participants also consistently stated that it is fully possible to have a positive experience as retirees, even if the transition was experienced as abrupt.

Another important finding is the need to increase knowledge about variations in the ageing process for people with intellectual disabilities, not only for themselves but also for service workers, families, and municipal employee planning services, largely in order to identify the best practices for people with intellectual disabilities. Such efforts may decrease worries among seniors with intellectual disabilities and their caregivers during the transition from work to retirement. Hopefully, this research will promote an increased focus on the retirement process for people with intellectual disabilities.

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Competing interests

The authors have no competing interests to declare.

References

- Abells, Dara, Julia Burbridge, and Patricia Minnes. 2008. "Involvement of Adolescents with Intellectual Disabilities in Social and Recreational Activities." *Journal on Developmental Disabilities* 14(2): 88–94.
- Barron, Karin. 2002. "Who am I? Women with Learning Difficulties (Re)Constructing Their Self-Identity." *Scandinavian Journal of Disability Research* 4(1): 58–79. DOI: <https://doi.org/10.1080/15017410209510783>
- Bates, Peter, and Fabian A. Davis. 2004. "Social Capital, Social Inclusion and Services for People with Learning Disabilities." *Disability & Society* 19(3): 195–207. DOI: <https://doi.org/10.1080/0968759042000204202>
- Bigby, Christine, Nathan J. Wilson, Susan Balandin, and Roger J. Stancliffe. 2011. "Disconnected Expectations: Staff, Family, and Supported Employee Perspectives about Retirement." *Journal of Intellectual and Developmental Disability* 36(3): 164–174. DOI: <https://doi.org/10.3109/13668250.2011.598852>
- Bittles, Alan H., Beverly A. Petterson, Sheena G. Sullivan, Rafat Hussain, Emma J. Glasson, and Philip D. Montgomery. 2002. "The Influence of Intellectual Disability on Life Expectancy." *Journals of Gerontology Series A: Biological Sciences and Medical Sciences* 57(7): 470–472. DOI: <https://doi.org/10.1093/gerona/57.7.M470>
- Crimmins, Eileen M., and Hiram Beltrán-Sánchez. 2010. "Mortality and Morbidity Trends: Is There Compression of Morbidity?" *Journal of Gerontology: Social Sciences* 66B(1): 75–86. DOI: <https://doi.org/10.1093/geronb/gbq088>
- Denton, Frank T., and Byron G. Spencer. 2009. "What Is Retirement?: A Review and Assessment of Alternative Concepts and Measures." *Canadian Journal on Aging/La Revue canadienne du vieillissement* 28(1): 63–76. DOI: <https://doi.org/10.1017/S0714980809090047>
- Ellingsen, Karl E. 2010. "Begrensninger og Forskningsmetodiske Kneiker." In *Usedvanlig Kvalitativ Forskning. Metodologiske Udfordringer Når Informanter Har Utviklingshemming*, edited by Rikke G. Gjørum. Oslo: Universitetsforlaget.
- Ellingsen, Karl E., and Anna Kittelsaa. 2010. "Å Velge det Trygge. Utviklingshemmede og Selvbestemmelse." *FONTENE Forskning* 2(10): 4–16.
- Geyer, Siegfried, Ove Spreckelsen, and Olaf von dem Knesebeck. 2014. "Wealth, Income, and Health Before and After Retirement." *Journal of Epidemiology & Community Health* 68(11): 1080–1087. DOI: <https://doi.org/10.1136/jech-2014-203952>
- Giorgi, Amedeo. 1985. *Sketch of a Psychological Phenomenological Method, Phenomenology and Psychological Research: Essays*. Pittsburgh, PA: Duquesne University Press.
- Giorgi, Amedeo. 2009. *The Descriptive Phenomenological Method in Psychology: A Modified Husserlian Approach*. Pittsburgh, PA: Duquesne University Press.
- Hahn, Joan E., Jennifer A. Grey, Philip McCallion, Corina B. Ronneberg, Roger J. Stancliffe, Tamar Heller, Carrie H. Guiden, Susan Fox, and Matthew P. Janicki. 2016. "Transitions in Aging: Health, Retirement and Later Life: Review of Research, Practice and Policy." In *Critical Areas in Intellectual and Developmental Disabilities: Contemporary, Research, Practice and Policy*, edited by AAIDD, 149–174. Washington: American Association on Intellectual and Developmental Disabilities.
- Hall, Edward. 2010. "Spaces of Social Inclusion and Belonging for People with Intellectual Disabilities." *Journal of Intellectual Disability Research* 54: 48–57. DOI: <https://doi.org/10.1111/j.1365-2788.2009.01237.x>
- Heal, Laird W., and Carol K. Sigelman. 1995. "Response Biases in Interviews of Individuals with Limited Mental Ability." *Journal of Intellectual Disability Research* 39(4): 331–340. DOI: <https://doi.org/10.1111/j.1365-2788.1995.tb00525.x>
- Janicki, Matthew P., Arthur J. Dalton, Michael Henderson, and Philip W. Davidson. 1999. "Mortality and Morbidity among Older Adults with Intellectual Disability: Health Services Considerations." *Disability and Rehabilitation* 21(5–6): 284–294. DOI: <https://doi.org/10.1080/096382899297710>
- Judge, Joe, Robert Walley, Bethany Anderson, and Ruth 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: <https://doi.org/10.1111/j.1741-1130.2010.00279.x>
- Kvale, Steinar. 2002. *Det Kvalitative Forskningsintervjuet*. Oslo: Gyldendal Akademiske.
- Laughlin, Carl, and Paul D. Cotten. 1994. "Efficacy of a Pre-Retirement Planning Intervention for Ageing Individuals with Mental Retardation." *Journal of Intellectual Disability Research* 38(3): 317–328. DOI: <https://doi.org/10.1111/j.1365-2788.1994.tb00398.x>
- Lawton, M. Powell, and Lucille Nahemov. 1973. "Ecology and the Aging Process." In *The Psychology of Adult Development and Aging*, edited by Carl Eisdorfer, and M. Powell Lawton, 619–674. Washington, DC: American Psychological Association. DOI: <https://doi.org/10.1037/10044-020>

- Mallander, Ove. 1999. *De Hjälper Oss Till Rätta: Normaliseringsarbete, Självbestämmande och Människor med Psykisk Utvecklingsstörning*. Lund: Socialhögskolan.
- Malterud, Kirsti. 2008. *Kvalitative Metoder i Medisinsk Forskning – En Innføring*. Oslo: Universitetsforlaget.
- Malterud, Kirsti. 2012. "Systematic Text Condensation: A Strategy for Qualitative Analysis." *Scandinavian Journal of Public Health* 40(8): 795–805. DOI: <https://doi.org/10.1177/1403494812465030>
- McDermott, Shannon, and Robyn Edwards. 2012. "Enabling Self-determination for Older Workers with Intellectual Disabilities in Supported Employment in Australia." *Journal of Applied Research in Intellectual Disabilities* 25(5): 423–432. DOI: <https://doi.org/10.1111/j.1468-3148.2012.00683.x>
- McEvoy, John, Rosemary MacHale, and Edel Tierney. 2012. "Concept of Death and Perceptions of Bereavement in Adults with Intellectual Disabilities." *Journal of Intellectual Disability Research* 56(2): 191–203. DOI: <https://doi.org/10.1111/j.1365-2788.2011.01456.x>
- Meleis, Afaf I. 2010. *Transitions Theory*. New York: Springer.
- Mutran, Elisabeth J., Donald C. Reitzes, and Maria E. Fernandez. 1997. "Factors that Influence Attitudes Toward Retirement." *Research on Aging* 19(3): 251–273. DOI: <https://doi.org/10.1177/0164027597193001>
- National Insurance Act, § 19. 1997. No. 19 of 1997. (*Lov om folketrygd (folketrygdloven)*). LOV-2015-12-18-114 last edited 01.01.2016: Ministry of Health and Social Affairs.
- Nota, Laura, Lea Ferrari, Salvatore Soresi, and Michael L. Wehmeyer. 2007. "Self-Determination, Social Abilities and the Quality of Life of People with Intellectual Disability." *Journal of Intellectual Disability Research* 51(11): 850–865. DOI: <https://doi.org/10.1111/j.1365-2788.2006.00939.x>
- Patja, Kristiina, Matti Iivanainen, Hannu Vesala, Hanna Oksanen, and Isto Ruoppila. 2000. "Life Expectancy of People with Intellectual Disability: A 35-Year Follow-Up Study." *Journal of Intellectual Disability Research* 44(5): 591–599. DOI: <https://doi.org/10.1046/j.1365-2788.2000.00280.x>
- Quine, Susan, Yvonne Wells, David De Vaus, and Hal Kendig. 2007. "When Choice in Retirement Decisions is Missing: Qualitative and Quantitative Findings of Impact on Well-Being." *Australasian Journal on Ageing* 26(4): 173–179. DOI: <https://doi.org/10.1111/j.1741-6612.2007.00251.x>
- Rogers, Nancy B., Barbara A. Hawkins, and Susan J. Eklund. 1998. "The Nature of Leisure in the Lives of Older Adults with Intellectual Disability." *Journal of Intellectual Disability Research* 42(2): 122–130. DOI: <https://doi.org/10.1046/j.1365-2788.1998.00103.x>
- Savage, Teresa A., Teresa T. Moro, Jackelyn Y. Boyden, Allison A. Brown, and Karen L. Kavanaugh. 2015. "Implementation Challenges in End-of-Life Research with Adults With Intellectual and Developmental Disabilities." *Applied Nursing Research* 28(2): 202–205. DOI: <https://doi.org/10.1016/j.apnr.2014.10.002>
- Schumacker, Karen L., Patricia S. Jones, and Afaf I. Meleis. 1999. "Helping Elderly Persons in Transition: A Framework for Research and Practice." In *Life Transitions in the Older Adult: Issues for Nurses and Other Health Professionals*, edited by Elisabeth A. Swanson, and Toni Tripp-Reimer, 1–26. New York: Springer.
- Söderstrom, Sylvia, and Jan Tøssebro. 2011. "Innfridde Mål eller Brutte Visjoner." *NTNU Samfunnsforskning AS, Mangfold og Inkludering*.
- Sjølkvik, Øystein, Pål Boring, Kjetil Frøyland, and Ingeborg Skarpaas. 2012. *Behovet for Varig Tilrettelagt Arbeid, AFI-rapport*. Rapport 14/2012. Oslo: Arbeidsforskningsinstituttet (AFI).
- Stalker, Kirsten, and Philip Harris. 1998. "The Exercise of Choice by Adults with Intellectual Disabilities: A Literature Review." *Journal of Applied Research in Intellectual Disabilities* 11(1): 60–76. DOI: <https://doi.org/10.1111/j.1468-3148.1998.tb00034.x>
- Stancliffe, Roger J., Michele Y. Wiese, Sue Read, Gail Jeltis, and Josephine M. Clayton. 2016. "Knowing, Planning for and Fearing Death: Do Adults with Intellectual Disability and Disability Staff Differ?" *Research in Developmental Disabilities* 49(5): 47–59. DOI: <https://doi.org/10.1016/j.ridd.2015.11.016>
- Stewart, Debra, Matthew Freeman, Mary Law, Helen Healy, Jan Burke-Gaffney, Mary Forhan, Nancy Young, and Susan Guenther. 2010. "Transition to Adulthood for Youth with Disabilities: Evidence from the Literature." In *International Encyclopedia of Rehabilitation*, edited by John H. Stone, and Marie Blouin.
- Thorsen, Kirsten. 2000. *Et Langt Liv med en Alvorlig Funksjonshemming. Utfordringer i et Livsløpsperspektiv*. Tonsberg: Forlaget Aldring og Helse.
- Thorsen, Kirsten. 2005. *Livshistorier, Livsløp og Aldring. Samtaler med Mennesker med Utviklingshemming*. Tonsberg: Forlaget Aldring og Helse.
- Tøssebro, Jan. 1989. *Metodespørsmål ved Undersøkelse av Velferdsordninger for Psykisk Utviklingshemmede*. Trondheim: Vernepleierhøgskolen i Sør-Trøndelag. Notat nr. 3.
- Vickerstaff, Sarah, and Jennie Cox. 2005. "Retirement and Risk: The Individualisation of Retirement Experiences?" *The Sociological Review* 53(1): 77–95. DOI: <https://doi.org/10.1111/j.1467-954X.2005.00504.x>
- Wadsworth, John S., Dennis C. Harper, and Hermine E. McLeran. 1995. "The Transition from Work to Retirement among Adults with Mental Retardation." *Journal of Applied Rehabilitation Counseling* 26(3): 42–48.
- Wehmeyer, Michael L., and Christina A. Metzler. 1995. "How Self-Determined Are People With Mental Retardation? The National Consumer Survey." *Mental Retardation* 33(2): 111–119.
- Weiss, Robert S. 2005. *The Experience of Retirement*. New York: Cornell University Press.

WHO. 2014. *World Health Statistics 2014*. Geneva: World Health Organization.

WHO. 2015. *World Report on Ageing and Health*. Geneva: World Health Organization.

Zigman, Warren B. 2013. "Atypical Aging in Down Syndrome." *Developmental Disability Research Reviews* 18(1): 51–67.
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