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Doctoral thesis

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Thesis for the Degree of
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Department of Psychology

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Summary

Background: Meaningful activites are important for all, and affects our quality of life. But the employment rate for people with intellectual disabilities is low. There is also an increase in life expectancy, and as for the general population, people with intellectual disabilities have a need for meaningful activities for also in later life. There is a lack of knowledge about facilitators and barriers for employment for people with intellectual disabilities in Norway. Additionally, there is a need for increased knowledge on experiences of retirement for this group.

Aims: The overall aim of this thesis is to increase knowledge about the status of the employment and day care situation for people with intellectual disabilities. Knowledge about facilitators and barriers for participation in daily activites might increase the employment rate for this group. The thesis also aims to add knowledge regarding reasons for retirement for people with intellectual disabilities, their experience with the transition to retirement and activities as retirees.

Methods: The study has a multi-method design, including both a quantitative and a qualitative approach. Linked registry-based data were used in two quantitative studies, to investigate facilitators and barriers for participation in daily activities for people with intellectual disabilities, through binomial and multinomial logistic regression analyses. Data on the experience of retirement was collected through semi-structured interviews of retirees with intellectual disabilities, and analysed through systematic text condensation.

Results: The studies revealed a low participation in daily activities. The likelihood of employment and participation in day care was associated with younger age but differed between genders and diagnoses of intellectual disabilities. High functional level and not having a functional level registered decreased the likelihood of employment. For people with mild intellectual disabilities, results in paper II revealed decreased likelihood of daily activities if having hospital admissions, especially for those having both somatic and psychiatric hospital admissions the previous years. Results in paper III also indicate a gap in the transition from school to employment, revealing higher odd being neither employed nor in day care for people with higher level of education. Findings in the interviews of the retirees, paper I, revealed improved health, satisfaction and self-determination after retirement.

Conclusion: Insight into differences between people with intellectual disabilities in participation in daily activities, might inform policy makers on action needed to prevent inequalities. A more standardised assessment of ability to work, with a more user-oriented focus, might promote participation in daily activities for people with intellectual disabilities. Additionally, there is a need for knowledge on ageing and retirement among people with intellectual disabilities, and individual focus on meaningful activities in throughout life, might improve their experience of retirement.

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Finally, I give big thanks to my family, who motivated and contributed to the completion of the thesis. Thanks for giving me the opportunity to work long days in the final phase of the project. I am looking forward to spending time with my family, and to new and exciting projects and work tasks in Ageing and Health.

LIST OF STUDIES/PAPERS

Paper I

Engeland, J., Kittelsaa, A. & Langballe, E. M. (2018). How do people with intellectual disabilities in Norway experience the transition to retirement and life as retirees? *Scandinavian Journal of Disability Research, 20*(1), 72-81. doi: https://doi.org/10.16993/sjdr.41

Paper II

Engeland, J., Strand, B. H., Innstrand, S. T. & Langballe, E. M. (2020). Employment and attendance in day care centres for people with mild intellectual disabilities – do age, gender, functional level or hospital admissions matter? *Journal of Intellectual Disability Research, 64,* 197– 208. doi: 10.1111/jir.12709

Paper III Employment and

Engeland, J., Strand, B.H., Innstrand, S.T., Langballe, E.M. (2020). Participation in employment and day care for adults with intellectual disabilities: Equal access for all? A Norwegian registry-based study. Revised and resubmitted to Journal of Applied Research in Intellectual Disability after minor revision, 1st of July 2020.

Abbreviations

DPIA	Data Protection Impact Assessment
EEA	European Economic Area
EU	European Union
GDPR	General Data Protection Regulation
ICD	The international Classification of Diseases
ICF	The International Classification of Functioning, Disability, and Health
ICIDH	The International Classification of Impairment, Disabilities, and Handicaps
IPLOS	Individbasert pleie- og omsorgsstatistikk [The Norwegian Information System for the Nursing and Care Sector]
NAV	Norges Arbeids- og Velferdsforvaltning [The Norwegian Labour and Welfare Administration]
NRPC	The Norwegian Registry for Primary Health Care
NTNU	Norges Teknisk-Naturvitenskapelige Universitet [the Norwegian University of Science and Technology]
NSD	Norsk Senter for Forskningsdata (previous Norsk samfunnsvitenskapelig datatjeneste) [Norwegian Social Science Data Services
SOC	Sense of Coherence
SSB	Statistisk Sentralbyrå [Statistics Norway]
WHO	World Health Organization

1 Introduction

Daily activities and work are important for peoples experience of meaning and quality of life (Eakman, Carlson, & Clark, 2010; Fleming, Fairweather, & Leahy, 2013; Darren McCausland, McCallion, Brennan, & McCarron, 2020; Saunders & Nedelec, 2014). Employment participation may be important for the maintenance of physical and mental health (Eggleton, Robertson, Ryan, & Kober, 1999; Kilsby & Beyer, 1996; Wehman, 2011), and work inclusion may discourage some people from falling outside the mainstream (Fleming et al., 2013; Nota, Santilli, Ginevra, & Soresi, 2014).

In Norway, a high degree of work participation and low unemployment are important political objectives, and there is an aim of employment for people with intellectual disabilities who can work (Ministry of Children, 2012-2013; Ministry of Labour and Social Affairs, 2002-2003). Equal rights to employment for people with intellectual disabilities are also included in the UN's Convention on the Rights of Persons with Disabilities (United Nations, 2006, Article 27). Additionally, the right to a meaningful life is asserted in the Norwegian Health and Care Service Act (2011, §1-1), saying that the municipalities are responsible for inhabitants having the possibility to live an active life, participate in society, and allow people to exploit their potential to the fullest. In these laws and political guidelines, a resource-oriented view of humanity is pervasive.

Nevertheless, there has been a decline in the last decades in employment and day care participation among people with intellectual disabilities in Norway (Engeland & Langballe, 2018; Søderstrøm & Tøssebro, 2011). In 2015, more than half of the people in this group were neither registered as employed nor involved in municipal day care (Engeland & Langballe, 2018). A similar downward trend has been observed internationally (Lysaght, Šiška, & Koenig, 2015; Taanila, Rantakallio, Koiranen, Von Wendt, & Järvelin, 2005).

In Norway, diagnoses of intellectual disability are defined by the International Classification of Diseases version 10 (ICD-10) (World Health Organization, 2016) and determined by a health care specialist. People with intellectual disabilities are a heterogeneous group, both between and within groups of diagnoses. Mental, functional, and social abilities, as well as education might vary (Eagar et al., 2006; Harris, 2006; Ireys, Salkever, Kolodner, & Bijur, 1996; Katz & Lazcano-Ponce, 2008; Lysaght, Ouellette-Kuntz, & Lin, 2012; Smith & Matson, 2010; Verdonschot, de Witte, Reichrath, Buntinx, & Curfs, 2009). This indicates that the assessment of individual functional levels and interest is essential to finding the right activities. We may accept that not all people with intellectual disabilities are able to work, but many people with intellectual disabilities are both able and want to be included in the labour market (Katz & Lazcano-Ponce, 2008; Li, 2004). However, they might need more support and facilitation compared to the general population (Khayatzadeh-Mahani, Wittevrongel, Nicholas, & Zwicker, 2019; Rose, Saunders, Hensel, & Kroese, 2005; Siperstein, Heyman, & Stokes, 2014).

In Norway, 71% of the people in the general population, between 18 and 67 years of age, was employed in 2015, and only 0.2% under the age of 67 was registered in day care (Statistics Norway, 2015). Employment for people with intellectual disabilities is defined in a broader way than with the general population. An official Norwegian report on how to improve rights for people with intellectual disabilities defines work as activities that add value related to the production of goods and services (NOU, 2016: 17, p. 72). Even with this broader definition, including supported employment, only 25% of people with intellectual disabilities in Norway, in the same age group, were registered as employed and 21% as participants in day care (Engeland & Langballe, 2018). A disability pension is almost automatically granted at the age of 18 by the Norwegian Labour and Welfare Administration (NAV) to people with a diagnose of intellectual disability, most often without an assessment of functional level, and without questioning their desire for work (Mandal, 2008; Wendelborg & Tøssebro, 2018). 97% of adults with intellectual disabilities receives disability pensions (Wendelborg & Tøssebro, 2018), and the numbers from Norwegian registers show that about 14,800 adults with intellectual disabilities received disability pensions in Norway in 2013 (Engeland & Langballe, 2018). Only 9% of the general population received disability pensions, and requires assessment of ability to workability (Statistics Norway, 2019).

Employment services in Norway are organised by local Norwegian Labour and Welfare Administration offices (Labour and Welfare Administration Act, 2006, §14a; Ministry of Labour and Welfare, 2010). The services aim to increase the employment rate and counteract exclusion by helping people with problems entering or maintaining mainstream employment. These services are especially directed to people with reduced ability to work, long-term unemployed, youth, long-term recipients of social benefits, and immigrants. The employment services are responsible for identifying work capacity and finding suitable workplaces for people with reduced working capacity, including people with intellectual disabilities. Most people with intellectual disabilities are assisted with daily activities in day care centres or in supported employment in sheltered workshops, hereafter called 'sheltered employment'.

International studies show that people with intellectual disabilities who quickly enter the mainstream labour market extend their social networks are more included in society, and have better quality of life (Borg & Kristiansen, 2008; Borg & Topor, 2007; Catty et al., 2008). The rate of people with intellectual disabilities in mainstream employment in Norway is very low, and statistics show that only 2-3% are employed in supported employment in the open labour market (Engeland & Langballe, 2018; Reinertsen, 2012).

Most day care centres in Norway are community-based, and day care activities are part of the municipal services in Norway aimed towards active care with meaningful activities directed to participants' interests and abilities (The Norwegian Directorate of Health, 2020a). For people with intellectual disabilities, day care activities are meant to maintain active everyday life experiences as meaningful and pleasant, building up individual levels of function and contributing to increased quality of life (The Norwegian Directorate of Health, 2017, 2020a).

Day care centres may be especially valuable for ageing people with intellectual disabilities when health problems increase and the ability to work decreases. The time for the appearance of age-related disabilities varies, but in the Norwegian general population, there is a particular increase in the rate of disability pensions at 55-60 years of age (Statistics Norway, 2020). For people with intellectual disabilities, these changes often start earlier than in the general population (Bittles et al., 2002; Janicki & Deb, 1994; Putnam, Molton, Truitt, Smith, & Jensen, 2016; Zigman, 2013). When functional level changes activities need to be evaluated (Bickenbach, Chatterji, Kostanjsek, & Üstün, 2003). It is important to find the right activities, balanced to their subjective experiences of functional level, health, and age. Finding the appropriate activities for people with intellectual disabilities may be a challenge. Employees at NAV offices report that they are experiencing the distinction between sheltered employment and municipal day care activities as unclear (Mandal, 2008).

Success in work inclusion for people with intellectual disabilities depends on many factors: example individual abilities, possibilities in the communities, and interactions between and within different instances. Ability to work may depend on a person's health, functional level, motivation, skills, knowledge, and education (Cheng et al., 2018; Harvey, 2001; Jahoda, 1982; Khayatzadeh-Mahani et al., 2019). The municipalities should facilitate suitable opportunities for work or other activities, and the workplaces must facilitate appropriate work tasks.

In activity theory, the meanings of activities are central. For work and activities to be meaningful, it is important to focus on individual resources, which is essential in Aron Antonovsky's salutogenic model of sense of coherence, that searches for factors which enhance human health (Jenny, Bauer, Vinje, Vogt, & Torp, 2017). The positive focus on peoples' abilities and resources is also the basis for the International Classification of Functioning (ICF) (World Health Organization, 2001) and can be useful to clarify possibilities and needs for daily activities.

Activity theory, Antonovsky's sense of coherence, and ICF will be used as a framework to highlight the importance of research on work inclusion and daily activities for adults with intellectual disabilities. Additionally, the activity theory is useful to elucidate the complexity of a system of daily activities for people with intellectual disabilities within the communities. The theories will also be used to emphasise the need for continuous assessment of the level of function and the need for evaluation of the activities when a decrease in function is present. In the discussion, the theories will contribute to identifying important factors to promote inclusion in different activities for this group. On the contrary, the theories may contribute to identify contradictions that preventing work inclusion and participation in day care.

The knowledge regarding factors associated with work inclusion for people with intellectual disabilities is scarce. Increased knowledge on facilitators and barriers for employment and participation in day care may increase the employment rate and participation in other meaningful activities for persons with intellectual disabilities. Adding knowledge about the retirement process and the experience of retirement may make it easier to prepare for a smooth transition and a meaningful life after retirement for people with intellectual disabilities.

1.1 Background

As presented in the introduction, daily activities may be complex for individuals with intellectual disabilities, and often many people, laws and systems must be involved to succeed in work inclusion. To people with intellectual disabilities, barriers to employment often are a combination of personal and environmental challenges, and cross-sectional collaboration is needed to succeed in work inclusion (Khayatzadeh-Mahani et al., 2019; Waisman-Nitzan, Gal, & Schreuer, 2019)

The importance of being active and having meaningful daily activities is well documented in many studies, both for the general population and for people with intellectual disabilities. In addition to improved physical and mental health (Eggleton et al., 1999; Kilsby & Beyer, 1996; Wehman, 2011), increased quality of life and experience of meaningfulness in everyday life are especially pointed out as positive outcomes for daily activities and work (Eakman et al., 2010; Fleming et al., 2013; Darren McCausland et al., 2020; Saunders & Nedelec, 2014). Activity theory, Antonovsky's theory on sense of coherence, and the ICF model will in the following chapter be presented.

1.1.1 Activity theory

Activity theory (cultural-historical activity theory) originated in Marxist philosophy, and the foundation of the theory lies in the work of Soviet-Russian developmental psychologists Lev Vygotsky, Alexander Luria, and Aleksei Leontiev in the 1920s and 1930s (Engeström, 1987). Activity theory describes the relationship among individuals, tools, artefacts, as well as whether the outcome of a purposeful activity is intended and desired (Engestrom, Miettinen, & Punamäki, 1999).

The theory is based on the idea that people learn and develop through activities, while society affects their thoughts and actions (Säljö, 2001). We live in a physical, social, and cultural world with mental and physical abilities and disabilities, and we live in relation to others and the world around us (Vygotsky, 1978). Vygotsky stated that human activities were mediated by cultural tools, including language and signs or by using construction of artefacts to perform activities. This leads to human development and the experience of meaningfulness (Vygotsky, 1978).

Vygotsky's basic model of activity theory had three nodes: the human *subject* uses *tools* to achieve an *object*. The object is the motivation for the activity, and the activity is mediated by an artefact or artefacts, sometimes called tools, instruments, or technologies. The process is that a subject works towards an object by using an artefact, which brings about an outcome. It is possible for the outcome to be unintended and even undesired, and it may be qualitatively different than the object. The Russian word 'object' has several meanings and has also been referred to as a goal of or a motivation for activities in the literature (Yamagata-Lynch, 2010).

Vygotsky's model was subsequently extended by Leontiev to take into account the socially mediated nature of activity and the roles of other individuals in the activity (Engestrom et al., 1999). In the 1980s, Engeström represented Leontiev's work diagrammatically, sometimes referred to as Extended Activity System. The system builds on Vygotsky's earlier mediational model and visually incorporates the extensions to the theory developed by Leontiev. Additionally, Engeström added connections between all the nodes in an activity system: individual, mediating artefact, object, community, rules, and division of labour. The relationship between the nodes is flexible and may change over time (Engeström, 2000; Yamagata-Lynch, 2010).

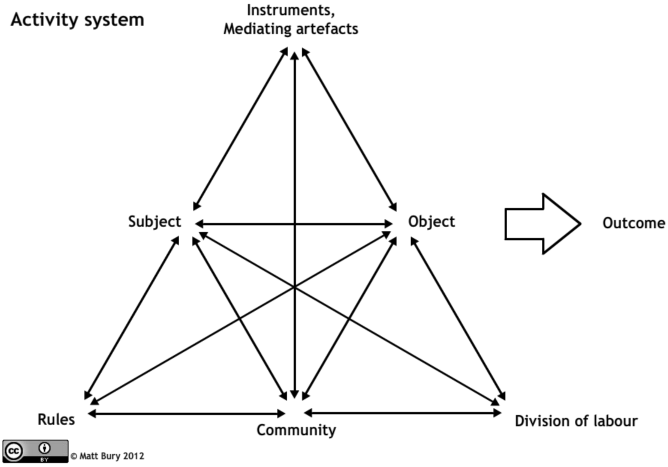


Figure 1. Engeström's activity theory

A change in one of the nodes in the system might affect other nodes. In activity theory, this is called 'disturbances in the system' (Engeström, 2000), which might consist of contradictions and may change potentials within the activity. The identification of contradictions in an activity system might help to identify the causes of problems in an activity and may be used in modelling new solutions. An example of this in activities for people with intellectual disability might be a change in health status and ability to work. People with intellectual disabilities often have a higher prevalence of health problems and diseases, especially with ageing (Beange & Durvasula, 2001; Cooper, Melville, & Morrison, 2004; Siperstein et al., 2014; Sutherland, Couch, & Iacono, 2002; van Schrojenstein Lantman-de Valk & Walsh, 2008). This might lead to varying work capacity. It is important to continuously assess and evaluate a person's functional level and ability to work. Is the employee able to perform the work task? Is the person able to cope at work? If not, work tasks or working time need to be changed or adjusted. This might affect all current instances in the system, and it requires collaboration between the parts to solve the disturbances or contradictions.

Engeström's activity system may be used both on micro and macro levels. If we see daily activities and all the correspondents needed to activate people with intellectual disabilities in their daily life as one system, activity theory might be useful in mapping necessary functions or nodes of the activation or employment process, and consequently also in identifying barriers.

A figure of the model including daily activities for people with intellectual disabilities placed in Engeström's activity system is presented on the next page (page 9), and used as a framework and theory in this thesis

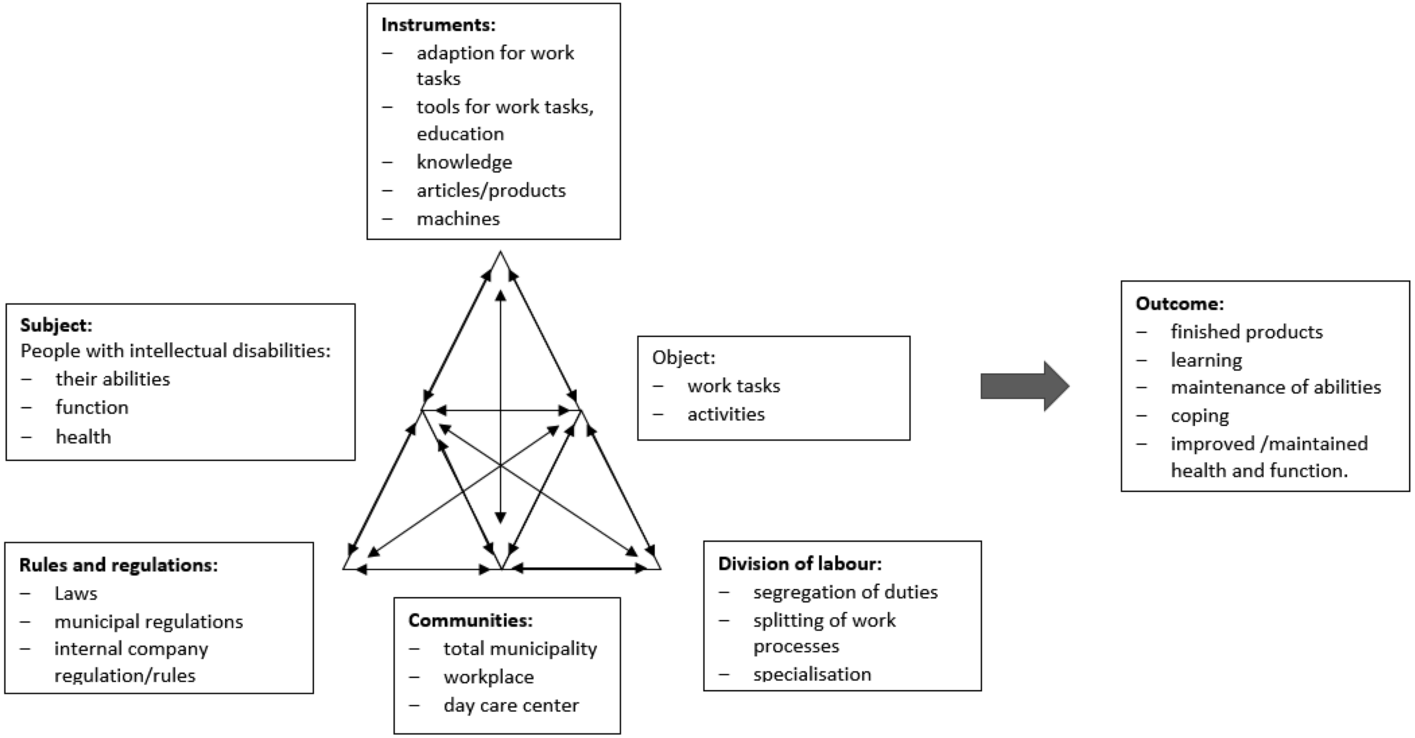


Figure 2. Daily activities for people with intellectual disabilities placed in Engeström’s activity system

Adults with intellectual disabilities (subjects) may have different abilities, functional levels, and health. These are individual factors, and the system must therefore be seen individually with a focus on one person with an intellectual disability. Their ability to work or to participate in activities might vary and will therefore affect their possibilities to perform work tasks and activities (objects).

To be able to perform different work tasks and activities, a person uses different instruments. They will use their individual skills and what they have learned, both through experiences in private and at school. Additionally, they might need to use machines to perform a work task, and there also might be a need for adaption/facilitation of work tasks to support the person to be able to complete a task. People with intellectual disabilities may also need help with transportation to and from the activities.

The subjects are part of a bigger system, and in the overall process of employment, we find the community, which may be the municipalities. The municipalities constitute elements in the decision regarding what the possibilities are for work and other activities. The municipalities have different numbers of positions at supported workplaces, and the work tasks differs between the workplaces. The municipalities have rules and regulation, some internal and some given by the Norwegian government. Supported employment is regulated by the Working Environment Act (2005), which applies to all employees, but internal rules and regulations might vary. An example of differences between the companies is that when an employee reaches 67 years of age, a regular age pension will replace the disability pension (National Insurance Act, 1997). Some people who receive age pensions but want to work are allowed to, even though the companies lose their governmental financial aid for work support, while others are forced to retire.

Division of labour is defined by how work is distributed within the workplace, and the workplaces often have a hierarchic work-force with a manager, leaders, and staff associated with specific work tasks. Each worker may have a specific work task or could be part of a bigger work process. For people with intellectual disabilities, the abilities to perform different work tasks differ, and facilitation of the work process and the combination of the appropriate work-force is essential to succeed in production. The end-product might be one of the outcomes in the activity system, but this may also lead to improved skills, function, or health for the subject. Indeed, for an ageing person with an intellectual disability, the goal of an activity is not to always to improve function or skills, but to prevent loss. The goals of activities will also differ between activities, but should always include a goal of meaningfulness. Additionally, in both sheltered and open employment, workers are expected to meet certain production requirements (NOU, 2012: 6), while outcome in day care does not necessarily consist of products, but are more person-centred.

In employment and participation in day care for people with intellectual disabilities, many units are involved in the activity system, and they must collaborate and work towards the same goal to achieve successful activity.

1.1.1 Antonovsky's sense of coherence

Salutogenesis was introduced by the American medical sociologist Aaron Antonovsky at the end of the 1970s (Vinje, Langeland, & Bull, 2017). The central aspect in Antonovsky's theory of salutogenesis is the importance of the experience of good health and well-being, which is achieved through a *sense of coherence* (SOC). SOC includes the three dimensions comprehensibility, manageability, and meaningfulness. These three components work together and forms an experience of sense of coherence. (Antonovsky & Sagy, 1986). Comprehensibility includes a feeling that the activities in life should be structured, predictable, and explicable. For activities to be manageable the person needs to have available resources to meet the demands, and the activity must be meaningful by giving the person challenges and be engaging (Antonovsky, 1987b).

For all people in employment and day care, it is important to experience a sense of coherence, and for this, there is a need for the work tasks to be understandable, manageable, and meaningful. According to Antonovsky's principle, daily activity is health-promoting for the individual when the person has the resources to manage the tasks and sees value in performing the activity. Meaningful daily activities are therefore important for health and quality of life. For most people with intellectual disabilities, facilitation is required to experience work as meaningful, which depends on individual resources, competence, and possibilities for development.

A more holistic, resource-oriented focus is also reflected in new biopsychosocial models, for example, the ICF model, developed by the World Health Organization (WHO).

1.1.2 The International Classification of Functioning, Disability, and Health

The first systematic classification of the consequences of disability was issued by WHO in 1980 and was called *the International Classification of Impairments, Disabilities and Handicaps* (ICIDH) (World Health Organization, 1980). The idea of the classification system was to turn the focus away from diseases to impairments, and from loss of functioning, defined as lack of ability to perform a normal activity, to individual resources (McDougall, Wright, & Rosenbaum, 2010).

In 2001, WHO approved The International Classification of Functioning, Disability and Health (ICF) as the international standard to describe the measure of health and disability, and it became a supplement to the medical diagnosis system ICD. This was built on the previous classification system, but the shift in focus in the debate between medical and social accounts of determinants of disability called for an updated version (Üstün, Chatterji, Bickenbach, Kostanjsek, & Schneider, 2003). The new version reflected a move in philosophy from a focus on consequences of disease and limitation in abilities to a focus on functional and structural integrity, activity, and participation, which means a focus on resources and abilities (World Health Organization, 2001). In the ICF model, environmental and other personal factors were added; the model integrates major medical and social models of disabilities based on the biopsychosocial model of human functioning and disabilities (Üstün et al., 2003).

ICF organises information into two parts: *functioning and disability* and *contextual factors* (World Health Organization, 2001), where functioning and disability include:

- Body functions and structures that describe the actual anatomy, physiology, and psychology of the human body;
- Activity, which describes the execution of a task or action by the individual and includes communication, interpersonal interaction, self-care, learning, and applying knowledge; and
- Participation, which involves the person's involvement in a life situation.

Contextual factors include:

- Environmental factors, which are factors outside the person's control such as the physical, social, and attitudinal environment;

- Personal factors influencing the individual’s experience of disability, age, and gender are also factors that may affect function, and they are included in personal factors. Even though personal factors are included in the model, they are not classified in ICF.

The following diagram (Figure 3) represent the model of disability that is the basis for ICF, and the interactions between the factors.

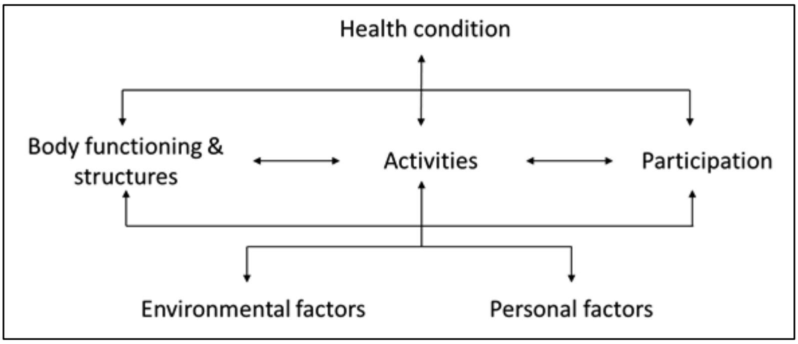


Figure 3. The interactions of the ICF components

In 2001, the ICF measures of functional level were included in the IPLOS registry for classification in the assessment of functioning (The Norwegian Directorate of Health, 2018a).

1.2 Definitions

1.2.1 Intellectual disabilities

The definition of intellectual disabilities used in this thesis is medical diagnoses from ICD-10 for people with congenital or early acquired cognitive impairment. Intellectual disability is a collective term referring to a set of diagnoses with cognitive impairment as the common factor (World Health Organization, 2016). The cause of intellectual disabilities may occur before, during, and after birth, and they are in most cases considered a lifelong condition (Harris, 2006; Maulik, Mascarenhas, Mathers, Dua, & Saxena, 2011; The Norwegian Directorate of Health, 2019; World Health Organization, 2016). Health care specialists sets the diagnoses by assessing abilities, language skills, self-care abilities, social competence, and physical abilities; in addition, intelligence quotient (IQ) must be under 70, and the condition must have occurred before 18 years of age.

The number of people with intellectual disabilities is uncertain, but a meta-analysis of prevalence estimates that about 1% of the world population have an intellectual disability, with higher prevalence in low- and middle income countries and lower in high income countries (Maulik et al., 2011). A Norwegian white paper assumes that 1.5% is a reasonable estimate for intellectual disabilities in Norway, which gives an estimate of 80,000 people (Ministry of Children, 2012-2013). Nevertheless, only 0.45% of the population over 16 years old in Norway (19,438 out of 4,330,608) are registered with a diagnose of intellectual disability (The Norwegian Directorate of Health, 2019). People with intellectual disabilities are, nonetheless, not a uniform group. Their assumptions and needs for services and support can be highly individual (Cooper et al., 2004; Eagar et al., 2006; Darragh McCausland et al., 2010).

1.2.2 Daily activities

Daily activities are, in this thesis, considered to be organised regular activities in daily life, such as day care activities and different types of employment. Day care centres are defined as publicly financed, community-based centres with daily activities registered in the Norwegian Information System for the Nursing and Care Sector (IPLOS). In Norway, day care centres provide services to people who need support for personal care, social support, activation, and training in activities of daily living (ADL), adapted to individual functional abilities (The Norwegian Health and Care Service Act, 2011).

In the general population, day care is most commonly used by elderly people with a need for organised activities (The Norwegian Directorate of Health, 2020a). Day care for elderlies in the general population and people with intellectual disabilities are mostly segregated. For people with intellectual disabilities, day care may be a place for activisation for all age groups with disabilities that make it difficult to work or participate in any kind of supported employment. People in day care need to have an individual decision regarding need for care registered in IPLOS (The Norwegian Directorate of Health, 2015). The number of people registered in community-based day care is considered to be valid since a report from The Norwegian Directorate of Health describes an expected low level of underreporting (2020a). The content of day care is not clearly defined and may vary between different day care centres.

Many people with intellectual disabilities are able to work, but the majority need facilitation and support to succeed in employment (Khayatzadeh-Mahani et al., 2019; Kirsh et al., 2009; Kocman, Fischer, & Weber, 2018; Rose et al., 2005; Siperstein et al., 2014). Since people with intellectual disabilities are mainly employed through employment services, employment type was defined as being registered in Statistics Norway as participants in sheltered or open employment. Sheltered employment is individually facilitated work in a sheltered environment, while open employment is facilitated work with support in mainstream employment (The Norwegian Labour Market Act, 2004). In terms of content, sheltered employment has a clearer profile compared to day care, with the production of goods and services that generates income. Only companies that meet these conditions receive governmental funding. This means that to be able to work in sheltered or open employment, workers are expected to meet certain production requirements. People in the different types of supported employment receive an additional wage on top of their disability pension, subsidised by NAV (NOU, 2012: 6).

1.2.3 Functional level

Functional level is an important variable in research on employment since it affects the ability to perform different activities, including day care and employment. The only registration of individual functional level in registries in

Norway is in the IPLOS registry, and functional level in this thesis is therefore based on these registrations. Functional level is only registered for people receiving community-based services in Norway, and it is used to map the need for support and services (The Norwegian Directorate of Health, 2018a).

This registration is based on ICF and is specifically suitable to assess and describe a person's ability to perform different activities of daily living, regardless of diagnoses (The Norwegian Directorate of Health, 2020b). The registrations include 16 variable activities of daily living, including assessments of difficulties in social functioning, cognitive functioning, self-care, and ability to perform household tasks (Beyrer, Otnes, & Karlsen, 2018). In addition, the variable of function includes a score on vision and hearing. A score from 1–5, *no difficulty* to *extreme difficulty*, is given regarding the ability in the different areas. In IPLOS, the total score is reported by means of all the questions and placed into three main groups of functional level: high (≤2), moderate (>2–3) and low (>3) (The Norwegian Directorate of Health, 2015).

IPLOS data is obtained from all applicants for social and municipal services. Registration of functional level in IPLOS systematises and highlights the need for services. A guide for registration has been published to secure equal understanding and registrations, regardless of the registrant's background or in which municipality the assessment and registration were performed (The Norwegian Directorate of Health, 2015). The guide includes guidelines for the use of professional assessment. Case managers in NAV offices and service providers in the municipalities perform the registration of functional level, which means that who is actually performing the assessment of functional level might vary between municipalities.

1.2.4 Retirement

Retirement is most commonly described as a shift from paid employment to senior life. Most people with intellectual disabilities do not engage in mainstream paid work; nevertheless, are to be considered retirees upon leaving comparable positions in later life (Cordes & Howard, 2005; Judge, Walley, Anderson, & Young, 2010; Stancliffe, Wilson, Gambin, Bigby, & Balandin, 2013). In this thesis and in paper I, retirement therefore 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.

There is a shift from disability pension to age pension when people reach 67 years. In the general population, retirement is flexible, and people may take out their age pension from 62 years of age but are free to also work after reaching 67 (The Norwegian Labour Inspection Authority, 2016). Since most people with intellectual disabilities receive disability pensions, this means there is a gap between the right to retirement pension between the general population and people with intellectual disabilities.

The right age for retirement is often difficult to define, especially for people with intellectual disabilities. Ageing is affected by the degree of intellectual disability, additional diseases, and other disabilities (Janicki & Deb, 1994; Patja, Iivanainen, Vesala, Oksanen, & Ruoppila, 2000). Ageing is the process of becoming older, and increases risk for diseases, and decrease in physical function, and sensory impairments (de Dieuleveult, Siemonsma, van Erp, & Brouwer, 2017; Jaul & Barron, 2017; McDonald, 2019). For some people with disabilities, ageing can start as early as 30-35 years (Bittles et al., 2002; Janicki & Deb, 1994; Zigman, 2013). There is a need for continuous assessment of function at earlier ages to be able to detect decreased levels of function and early signs of ageing. Possible early ageing also entails a need for flexibility in retirement age for people with intellectual disabilities.

2 Aims of the thesis

The aim of this thesis is to increase knowledge about the status of the employment and day care situation, as well as the experience of transition to retirement for people with intellectual disabilities, in Norway. More specifically, the objectives are to explore:

- Reasons for retirement, experiences with the transition to retirement, people's activities as retirees, and how they experience their new situations as retirees (Paper I);
- Association between age, gender, functional level, and hospital admissions with employment or attendance in publicly financed, community-based day care centres for adults with mild intellectual disabilities in Norway (Paper II);
- Association between age, gender, education, registered diagnoses, and functional level with employment and day care for employment for people with intellectual disabilities (Paper III).

3 Methods

The project has a multi-method design, with a qualitative study including interviews of retirees with intellectual disabilities and two quantitative registry-based studies with linked, individual population-based data.

Paper I: Qualitative interviews with seven retirees with intellectual disabilities.

Papers II and III: Quantitative analysis of registry data.

The papers will be described separately in the following chapters.

3.1 Paper I

3.1.1 Sample

Seven people with intellectual disabilities who had retired from sheltered employment one to two years earlier were recruited.

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 sample was 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 researcher if interested in participating in the project.

Inclusion criteria were individuals with intellectual disabilities, with diagnoses confirmed by a supervisor at a sheltered workshop, and the ability to communicate verbally in Norwegian. In addition, the informant must have previously worked in a sheltered company, retired one to two years prior to the study, be over 40 years old, and able to recall events from a minimum of three years earlier. Finally, informants could not have any serious illnesses. After four months, eight participants were recruited. One was later excluded due to lack of confirmation of a diagnose of intellectual disability.

The final sample consisted of four men and three women aged 42 to 68 years with various activities and activity levels after retirement, and the retirement ages varied from 40 to 67. Four of the participants had mild intellectual disabilities; one had moderate disabilities, and two had Down syndrome with moderate intellectual disability. Five lived in shared accommodations; one lived with parents, and one lived with a brother.

3.1.2 Data collection

Semi-structured, in-depth interviews were conducted to gather information about the retirees' subjective experiences and feelings. In-depth interviews are considered a suitable method for gathering information on personal experiences (Kvale, 2002; Legard, Keegan, & Ward, 2003). Using a semi-structured interview guide also allows the researcher to ask control questions and solicit clarifying statements about unclear responses in order to prevent misunderstandings (Kvale, 2002; Malterud, 2008; 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. The guide was then tested using a group interview with five employees with intellectual disabilities at a sheltered company. This provided the opportunity to test questions and use of words, and the interview guide was adjusted to the interviewees' understanding.

The interviews were conducted by a Ph.D. candidate who is a nurse, with a master's degree in nursing science, experienced in working with people with intellectual disabilities. The participants were informed that they could withdraw from the study at any time during the project. They were also given the possibility to contact the project manager to receive more information or if they needed to talk both prior to and after the interviews, which were conducted during a period of three months.

The interviews took place in environments familiar to the participants to ensure that they felt safe in the interview situation. Six of the interviews took place in the homes of the respective participants, and one took place at a participant's activity centre. Interviews at home enabled observing the individual's surroundings in order to establish contact and build trust in the interview situation (Ellingsen & Kittelsaa, 2010). Establishing a comfortable environment for the interviewee can help the interviewer obtain useful and reliable information. Two of the interviews were conducted alone with the interviewees, whereas another interview was conducted with a guardian present and the last four with caregivers present. To make the interview situation most similar to normal conversations and ensure that the participants' experiences remained in focus, guardians or caregivers were encouraged to allow the participants to speak freely and not to interrupt as long as the participant did not express a desire for help.

3.1.3 Ethics and data protection

This project was approved by the Norwegian Social Science Data Services (NSD) in February 2013. All participants were able to give consent themselves, but NSD additionally required written consent from their guardians. Written informed consent, with short sentences and simple language, was obtained from the participants through guardians or caregivers and additionally a person of trust, as requested by the Norwegian Social Data Services (Appendix A). Written information about the project was also provided prior to the interviews, both in an easy-to-read version (Appendix B) and a version for caregivers and guardians (Appendix C). Additionally, information was given orally by the interviewer prior to the interviews to secure the participants' understanding.

The recorded files of the interviews were encrypted and stored on a secure server. Interviews were transcribed, 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 it was fully written out from 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 participants' names and contact information was securely locked in a filing cabinet and shredded after analysis ended.

Anonymity and confidentiality for the participants were essential goals of the project. This was explained and guaranteed to the participants by explaining the secure storing of audio files and that no identifying data would be published. Both audio files and transcribed text were deleted after the completed analysis.

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.

3.1.4 Analysis

The transcribed interviews were analysed using Malterud's (2012) method of systematic text condensation, a modification of psychological phenomenological analysis developed by Giorgi (Giorgi, 1985, 2009). The method is a four-step process condensed into main categories to fit the meanings, and it focuses on the exact descriptions of the experiences of the interviewees, aiming to reduce the personal interference and preconceptions of the researchers (Malterud, 2012). The final categorisation resulted in four main categories focusing on the experiences of ageing and the transition to retirement:

- Health status before and after retirement,
- Self-determination and satisfaction before and after retirement,
- Knowledge on ageing and retirement, and
- Needs for activities and social interaction.

3.2 Paper II

3.2.1 Sample

The sample in paper II consisted of all adults between 18-67 years of age registered in NAV's registry of disability pensions with mild intellectual disability as the reason for the disability per 31.12.2013. The Norwegian Labour and Welfare Administration recommended basing the present study sample on individuals registered in 2013 because this year was considered the most complete and valid year available for diagnosis registrations, including intellectual disabilities. The diagnose code system ICD-10 was used for inclusion, and it included the code F70 – mild mental retardation, hereafter referred to as mild intellectual disabilities in this thesis.

The eligible study population originally consisted of 2,471 adults with mild intellectual disabilities, alive, and aged 20 to 69 per 31.12.2015. Individual data from Statistics Norway (SSB), the Norwegian Information System for the Nursing and Care Sector (IPLOS), and the Norwegian Patient Registry (NPR) were linked by means of unique personal identification numbers. Data from 2015 were used in the analyses because this was the most recent available year for employment status. The dataset had almost no missing values.

Functional level is only registered for people receiving public community-based services in Norway. People registered with services with missing registration of functional level were excluded (*n* = 59; 2.4%). Due to irrelevance to the research questions, people registered in education were excluded (*n* = 30). The work category *other measures* (wage subsidies, work practice, and clarification of ability to work; *n* = 12) was ambiguous. A comparison of Bayesian Information Criterion (BIC) between models including and excluding this category was performed. BIC assesses the overall fit of a model and may compare models, and BIC identifies the model that is more likely to have generated the observed data. The model with the smaller BIC is preferred, i.e., if BIC1 – BIC2 < 0, model 1 is preferred. If BIC1 – BIC2 > 0, the second model is preferred. If the difference in BIC is 0–2, the evidence is considered week, 2–6 positive, 6–10 strong, and >10 very strong. A difference of 131 in BIC provided very strong support for the models without the category *other measures*, and the category was therefore excluded.

Hence, the final sample included in the analysis in paper 2 consisted of 2,370 adults with intellectual disabilities, including 96% of the potentially eligible population (see Figure 4).

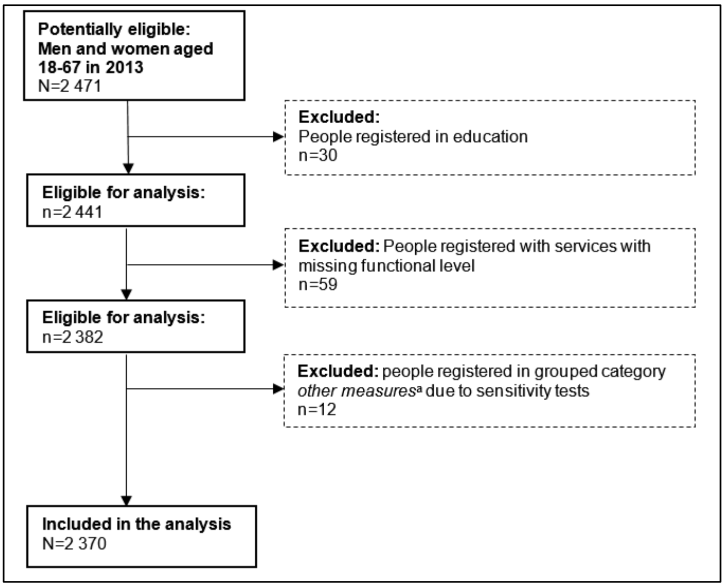


Figure 4. Flow chart for study population paper II

[a] Other measures included the following employment measures: wage subsidies, work practice and educating, and clarification of ability to work.

Additionally, a stratified and randomly selected sample representative of the general population consisting of 18,612 people aged 41 to 67 provided comparative descriptive statistics for overall employment rate and participation in day care in Norway. After exclusion, using the same criteria as for the sample of people with mild intellectual disabilities, the total sample of the general population was *N* = 13,063.

The sample from the general population was only used to compare descriptive statistics due to differences in some variables, making comparison of logistic regression models difficult.

3.2.2 Data collection

Data from Statistics Norway (SSB), the Norwegian Information System for the Nursing and Care Sector (IPLOS), and the Norwegian Patient Registry (NPR) were linked by unique identification numbers by SSB. Variables included in paper II are employment status, functional level, gender, age, and hospitalisations. See Table 1 for the variables' categorisation.

Table 1 Variables and categories in paper II

Employment status (SSB 31.12.2015)	Not employed or in day care Day care Sheltered employment Open employment
Age group (SSB 31.12.2015)	20–31 32–41 42–51 52–63 64–69
Gender (SSB 31.12.2015)	Men Women
Functional level (IPLOS 31.12.2015)	Low Moderate High Not registered
Diagnosis of intellectual disability (NAV 31.12.2013)	Hospital admissions None Psychiatric admissions only Somatic admissions only

3.2.3 Ethics and data protection

The study was approved by The Norwegian Regional Ethics Committee (REK) in September 2014 and by the Norwegian Data Inspectorate (NSD) in June 2015. Additionally, the study was approved by all included registries, and exemption from the duty of secrecy was given by the respective registries. All data presented secure anonymity. In addition, when linking the datasets, SSB secured all variables' anonymity by categorising or deleting variables that were a threat to anonymity. Data from the registries were stored electronical on a secure server, with access only for the project manager and the head of research on disabilities.

The project did not involve disadvantage on individual, group, or community levels since the project indirectly collects data anonymously through registries. The results will be positive for policy and, hopefully, for practice in planning employment, day care activities, and retirement for people with intellectual disabilities.

3.2.4 Analysis

Descriptive statistics were used to describe the sample. Logistic regression models were used to examine the association between the covariates (age, gender, functional levels, and hospital admissions) and the outcome variable of employment status (per 31.12.2015). Binary logistic regression was used when the dependent variable had two outcomes (employed/in day care or not), whereas multinomial logistic regression was used when a dependent variable had more than two outcomes (no employment/day care, day care, sheltered employment, or open employment).

When an outcome variable is categorical, logistic regression is a suitable method for analyses (Fugleberg, Småstuen, & Tufte, 2018; Hosmer, Lemeshow, & Sturdivant, 2013). The results of the logistic regressions in this study were presented as odds ratios (OR). When interpreting odds ratios, 1 indicates no effect/difference in odds; odds ratio over 1 means exposure associated with higher odds of outcome, while odds ratio under 1 means lower odds of outcome (Long & Freese, 2014). Two-tailed P-values less than 5% were considered significant.

Odds has the form: $\frac{p}{1-p}$, where p is a probability that an event will occur. Odds ratio is the ratio of two odds, for example the odds in women (1) divided by the odds in men (2): $\left(\frac{\mathrm{p1}}{1-p}\right):\left(\frac{p2}{1-p2}\right)$ (Hosmer et al., 2013). This means that reference values (value of comparison) for each categorical variable must be chosen in logistic regression. In paper II, the reference category in analysis was set to the group with highest likelihood of employment: those with high functional level, and no hospital admissions. All analyses were adjusted for all the predictor variables age, gender, functional level, and hospital admissions. All comparisons consisted of the different employment statuses compared with not being registered in employment or in day care.

In the analysis, the age variable was treated as a continuous variable as this had the best model fit according to BIC compared to age a categorical variable.

In the dataset, among those with mild intellectual disabilities, 49% did not receive community-based services and, consequently, were not registered with functional level. To be able to include these in the analyses, a separate category was therefore added, which indicate they were not registered with community-based services.

Analyses were carried out in STATA/IC version 15.1.

3.3 Paper III

3.3.1 Sample

The full sample of all people registered with intellectual disability as the reason for disability pension per 31.12.2013 between 18 and 67 years old per 31.12.2013 were drawn from NAV's registry of disability pensions. The diagnose code system ICD-10 was used for inclusion. Since some diagnoses might include both people with and without intellectual disabilities, only diagnoses of high probability of intellectual disabilities were included.

The full sample included people registered with:

- Mental retardation (F70–F79),
- Disorders of psychological development (F84.0, F84.1, F.84.2, and F84.4),
- Down syndrome (Q90), and
- Chromosomal abnormalities, not elsewhere classified, with high probability of intellectual disability (Q91.1–Q91.4).

For a complete list of included and excluded diagnose groups see Appendix D.

People registered in education as a main daytime activity (*n* = 188) were not relevant for the present research questions and were thus excluded. The oldest age group was excluded due to possible inclusion of retirees in this age group (*n* = 1,177). The category of other measures in employment status (wage subsidies, work practice, and clarification of ability to work) (*n* = 40) was also excluded due to differences in the measures included and could not be compared.

A total of 377 (2.6%) of people registered with municipal services lacked registration of functional level. A difference of 496.245 in BIC provided very strong support for a model without people registered with services that lacked registration of functional level, and they were excluded (*n* = 377).

Hence, the final sample included in the analyses consisted of 12,375 people aged 18 to 67, registered with intellectual disabilities based on our inclusion criteria (Figure 5).

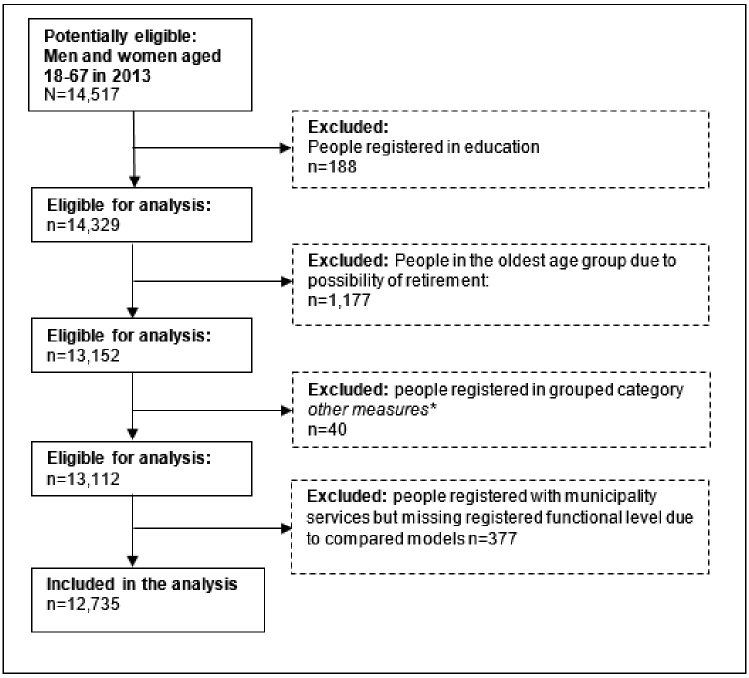
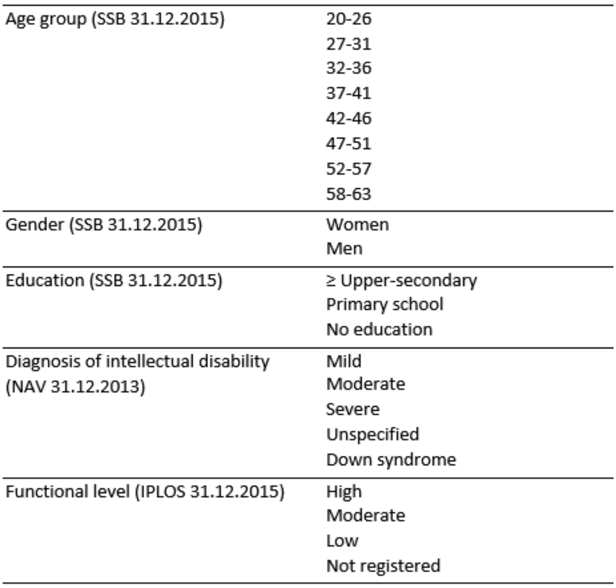


Figure 5. Flow chart for study population paper III
* Other measures included the following employment measures: wage subsidies, work practice and education, and clarification of ability to work.

3.3.2 Data collection

Data from SSB, IPLOS, and NAV were linked by SSB. Variables included employment status, age, gender, educational level, diagnose of intellectual disability, and functional level. See Table 2 for the variables’ categorisation.

Table 2 Variables and categorisation included in analysis in paper III



Age group (SSB 31.12.2015)	20-26 27-31 32-36 37-41 42-46 47-51 52-57 58-63
Gender (SSB 31.12.2015)	Women Men
Education (SSB 31.12.2015)	≥ Upper-secondary Primary school No education
Diagnosis of intellectual disability (NAV 31.12.2013)	Mild Moderate Severe Unspecified Down syndrome
Functional level (IPLOS 31.12.2015)	High Moderate Low Not registered

3.3.3 Ethics and data protection

The ethics and data protection were the same for paper II and paper III. Please see chapter 3.2.3, Ethics and data protection, page 26.

3.3.4 Analysis

To assess the association between covariates and the four-level employment status outcome variable, a multinomial logistic model was applied using employment type (or participation in day care) as reference. The results are presented as odds ratios (OR). All covariates (employment status, age, gender, education, functional level, and diagnose of intellectual disability) were included to control for possible confounding. Age was treated as a continuous variable, while all other covariates were categorical. A sub-analysis comparing employment or participation in day care among those with Down syndrome versus other diagnoses was performed. A Hosmer-Lemeshow test of goodness-of-fit (BIC) was used to check for interactions between functional level and age group as well as between functional level and diagnose of intellectual disability. There were no interactions between covariates, and thereby no interaction terms were included in analyses. The goodness-of-fit test supported simplifying the model by treating age as a continuous variable in the analyses. Two variables on living arrangement were initially included in the dataset, but due to inconsistency the variables were considered as unreliable and therefore excluded.

All analyses were performed in STATA/IC version 15.1.

3.4 The process of access to registry-based data

The process of application and accessing the registry-based data, used in paper II and III was long and complicated. The submission of the first application was 18th of June 2014 and the final delivery of data with description of the variable was 28th of September 2017, thus over three years. The long process of receiving the data was the result of several causes: changes in the project that required new approvals from REK and NSD, long processing times for applications, problems with anonymisation of data, and lack of documentation of codes in the dataset.

Because all data from IPLOS must be anonymous in the researchers' hands, some variables had to be excluded, for instance residence/municipality, which could have provided interesting information about differences between municipalities. All included variables had to be categorised to secure anonymity. This was most problematic for the age variable. Since the sample was drawn in 2013, and data for the analyses was from 2015, there was a displacement in age span. For the oldest age group, with ages 63-69 in 2015, this means that the group may include some retirees. For this reason, the oldest group was included in paper II but excluded in paper III.

The original project protocol also included people above retirement age. But, since the sample was drawn from NAV's registry of disability pensions, this limited the sample to people under 67 years since people above 67 years receive age pensions and are not registered in the same registry. A chronological table of the process of access to the registry-based data is added in the appendix (Appendix E).

4 Results

4.1 Results from Paper I

In the qualitative interviews of the retirees, the participants experienced the retirement process and transition as abrupt, and they lacked knowledge about retirement and self-determination in the retirement process. Still, they experienced that retirement had a positive impact on their health, and, retrospectively, they had a positive attitude toward their retirement.

Prior to retirement, nearly all participants described that their level of function did not correspond to their ability to perform work tasks and that they experienced pain and tiredness. They also experienced decreased coping skills at the end of their working lives. This despite that they felt their workplaces had facilitated work tasks and work schedules fitting their level of function and limitations. The activity level and the desire for activities varied for the participants. Social interactions were important for them, but some also reported a decreased need for social contact as retirees because of increased tiredness. All participants experienced either equal or increased satisfaction after retirement. Some also reported increased self-determination when they became retirees.

The results show that retirement is a complex process for people with intellectual disabilities, as well as for the general population. Increased knowledge about ageing and retirement and a more self-determined process might increase the chances of a positive experience of retirement.

4.2 Results from Paper II

In the total sample of 2,370 with intellectual disabilities, 67.9 % were registered neither in day care nor in employment., 6.5 % were registered in day care, 20.9% in sheltered employment, while only 4.7% were registered in open employment. People without registered functional level; i.e. not registered with public services, had the highest rate of people registered neither in employment nor day care, with 81.0%.

Employment for people with mild intellectual disabilities decreased with age and with lack of registration of functional level. Age did not impact participation in day care. Those with hospital admissions were less likely to be employed, especially if they had a combination of both psychiatric and somatic admissions, compared to those without hospital admission. The likelihood of participation in open employment and day care increased with both types of hospital admissions. Day care participation was more common in women than in men, whereas men were somewhat overrepresented in sheltered employment. There were no gender differences regarding open employment.

4.3 Results from Paper III

Of the total sample of 12,735, 51.7% were registered neither as employed nor in day care, 22.2% were registered in day care, 23.4% in sheltered employment, and 2.7% in open employment.

Employment decreased with age, and there were differences in employment status between diagnoses; the prevalence of employed was highest for people with Down syndrome and lowest for people with mild intellectual disability. Women were more often being registered in day care than men, but sheltered employment were more common in men. Attendance in open employment did not differ between men and women. Being registered with a high functional level or no functional level registered decreased the likelihood for employment, as well as being registered with higher educational level.

5 Discussion

An aim of the Norwegian welfare system and national regulations is to facilitate work inclusion (Ministry of Children, 2012-2013; Ministry of Labour and Social Affairs, 2002-2003). The right to work is equal for all (Ministry of Labour and Welfare, 2010; United Nations, 2006; Working Environment Act, 2005). However, for most people with intellectual disabilities, work support is needed to enter the labour market (Brotherton, Stancliffe, Wilson, & O'Loughlin, 2016; Khayatzadeh-Mahani et al., 2019; Olsen, 2003; Siperstein et al., 2014). The facilitation and support needed may depend on the target groups as well as the different activities and work tasks. The need for facilitation may also differ with ageing. The aim of this thesis is to increase knowledge about the status of the employment and participation in day care, and the association of functional level, age and gender. Paper II looks specifically on people with mild intellectual disability, and also include the association with hospital admissions. Paper III included all people registered with intellectual disabilities, and added an aspect of educational level and the association with employment and participation in day care. Additionally, paper I aims to increase knowledge of the experience of transition to retirement for people with intellectual disabilities.

Despite these political resource-oriented regulations and goals of an inclusive labour market, paper III shows that the employment rate and participation in day care is low for people with intellectual disabilities, with over 52% not being registered in employment or day care. Results in paper II reveal that that the situation for people registered with mild intellectual disabilities is even worse, with 68% registered neither in employed nor in day care. The employment rate was especially low for people with mild intellectual disabilities who did not receive public services in the communities, which means functional levels were not registered, and over 80% of them are not registered in employment or day care. These results showing a low employment rate are in line with previous research (Holwerda, van der Klink, de Boer, Groothoff, & Brouwer, 2013; Joshi, Bouck, & Maeda, 2012; Stancliffe, McGlinchey, McCallion, & McCarron, 2018).

The results in both quantitative studies (papers II and III) reveal decreased employment rate at higher ages, which was expected because of the increased risk of poorer health with ageing (World Health Organization, 2015). However, the studies find a surprisingly high proportion of people registered without employment or day care, especially for people with mild intellectual disabilities presented in paper II, where over 80% of those over 42 years old were registered without employment or day care. This may indicate that they are either falling out of employment at an early age or, alternatively, younger people with intellectual disabilities are prioritised in supported employment.

In paper II hospital admissions are used as an indicator of health status, and negative associations are found between employment status and somatic and psychiatric hospital admissions for people with mild intellectual disabilities, particularly for people having both types of admissions. It is natural for people to have decreased work capacity when ill, but not having employment may also cause poor health. The findings in this study support the need for meaningful activities, and early interventions when health is decreasing may be crucial for work inclusion. In Antonovsky's salutogenesis and theory of sense of coherence at work, health promoting consequences of work are subjects, and experience of comprehensibility, manageability, and meaningfulness in work tasks is important (Antonovsky, 1987a). The theory also emphasises that having the resources to perform an activity or a job, is essential to being able to build a sense of coherence. Use of the ICF model may be a way to assess and evaluate functional levels, which often decrease with poorer health. The sense of coherence may also be modified by the work environment. Both the ICF model and Engeström's activity system may be useful in mapping factors of the work environment (Engeström, 2000; Foley, Dyke, Girdler, Bourke, & Leonard, 2012; McDougall et al., 2010). Depending on the cause of decreased health, measures can be initiated to prevent permanent exit from work or activity (Bambra & Eikemo, 2009; Curnock, Leyland, & Popham, 2016; Heggebø, 2016).

The unclear definition of activities in day care may also cause different practice in decision making in the municipalities. A FAFO report (Mandal, 2008) states that employees of NAV experience boundaries between permanently adapted work and municipal activities as unclear. This means there is a risk that people who are offered municipal day care centres would rather be offered employment with support, and vice versa. A clearer and more consistent definition of the content of activities in day care may provide more predictable and meaningful activities for people with intellectual disabilities. Activities in supported employment, like sheltered employment, also overlap with activities in day care. We see an increase in requirements for production in supported employment. It is also difficult to compare statistics on day care and supported employment because statistics on supported employment are only available at the county level. Research also shows that 20% of participants with day care services and intellectual disabilities in Norway met the criteria for supported employment (Reinertsen, 2012).

Additionally, papers II and III reveals that the number of people without any daily activities is high. This may indicate that there are unmet needs for employment and day care for people with intellectual disabilities and that some people in day care have abilities to participate in supported employment and may also experience higher levels of meaningfulness and benefit more from employment than day care. This is in line with findings in study III were people registered with high functional level have a lower probability of participating in day care and employment. In addition, only the right to meaningful activities in life is stated in the municipal regulations, not participation in daily activities. Recently, a Norwegian report presented large variations between Norwegian municipalities in day care services, both in terms of content and scope (The Norwegian Directorate of Health, 2020a). Reasons for the variations might be differences in the organisation of services, population size, geographical distances to services, and prioritisation of resources. Of day care services, 76% reported having participants with intellectual disabilities, and 54.5% of day care services reported having mainly people with intellectual disabilities as their target group (The Norwegian Directorate of Health, 2020a). There are reasons to believe that differences in who assesses and registers level of function in the municipalities may also influence which services are offered to individuals. Unequal services offered in the municipalities and different practices of registrations may be problematic and might increase inequalities between people with intellectual disabilities living in different parts of Norway, and this may increase differences in health and well-being.

However, there is no definitive answer as to what meaningful activities entail, as this must be customised individually. Research shows that employees in sheltered employment value different aspects of employment. Some value the social aspect, while others experience work identity, pride of work, and being useful (Olsen, 2003). The variances in need for activities also were found in the interviews with the retirees in paper I. Additionally, what gives an experience of sense of coherence in activities is not static and must be continuously evaluated and adapted. A salutogenic approach, using the ICF model and activity theory, may be useful in the employment process for people with intellectual disabilities to be able to adapt activities to their resources and functions and for activities to be experienced as comprehensible, manageable and meaningful for the individual.

The results in paper III also reveal differences in employment and day care status according to age and diagnoses. The proportion of people in both day care and employment decreased with age, and people with Down syndrome had much higher odds of getting into daily activities. Differences between diagnoses may also be seen in laws for daily activities. Starting the 1st of January 2020, the Norwegian municipalities are required to offer day care to people with dementia. Even though this does not mean that there is an individual right for day care for people with dementia, it shows differences between diagnoses since there is no such requirement for people with intellectual disabilities. Meaningful activities are as important for all (Antonovsky, 1987a; Antonovsky & Sagy, 1986; Saunders & Nedelec, 2014), including people with intellectual disabilities, and the rights for activities should not be based on diagnoses. In the general population, we see an increase in day care participation with age, while paper III reveals a decrease with age for people with intellectual disabilities. There may be many factors affecting this difference, but it is hard to believe that the need for daily activities is much lower for ageing people with intellectual disabilities compared to the general population, and most likely a larger proportion would benefit from participation in day care.

However, diagnosis codes from ICD-10, which are biomedical concepts of disability, are problematic and inappropriate for describing individual abilities and resources. Medical diagnoses alone cannot answer questions about the need for services or support. Assessments of functions through the ICF model are more accurate predictors of abilities and resources with which to map individual possibilities for work inclusion or participation in day care. Additionally, the model includes social, psychological, and environmental factors, which also affect these possibilities. Assessment of functional level is used to map ability to work in the Norwegian system of work support. However, the negative effect of having a higher level of function found in papers II and III indicate that there are some missing links between the assessment of functional level and daily activities and employment. With this resource-oriented focus, it is also questionable whether a diagnosis of intellectual disability automatically generates a disability pension through exemption from functional assessment by law (Mandal, 2008; Wendelborg & Tøssebro, 2018).

The result found in paper III, that having a higher level of education did not affect employment status, is surprising and differs from previous international studies where higher employment rates for people with intellectual disabilities with upper-secondary school education were found (Papay & Bambara, 2013; Shandra & Hogan, 2008). However, the variable on educational level was highly skewed towards low educational level (*n* = 9,911), and may have affected our results on association between educational level and participation in daily activities. Nevertheless, the groups registered with high educational level and no education were of sufficient size (high educational level; *n* = 905, no education; *n* = 1,919) and may indicate that the link between the school system and supported employment services in Norway is weak. A Norwegian research project recently revealed that more people are entering open employment from community-based day care than from school and sheltered employment (Wangen, 2019). These interesting findings, together with the findings in paper III, reveal a need for increased focus on the transition from school to employment and that in an activity system, this factor seems to be one of the barriers to employment for people with intellectual disabilities, an observation also supported by other studies (Lysaght et al., 2012; Papay & Bambara, 2013; Shandra & Hogan, 2008). Several international studies supports the finding on the gap in the transition between school and employment as one of the barriers for work inclusion (Arvidsson, Widén, & Tideman, 2015; Gillan & Coughlan, 2010; Landmark, Song, & Dalun, 2010; Test et al., 2009). A literature review from 2012 supports using ICF as a framework for a better understanding of the transition, makes it easier to compare research on the theme, and might be a useful tool for highlighting the gap (Foley et al., 2012).

The most common work tasks and activities in day care centres and sheltered employment are traditional crafts (Olsen, 2009). In addition, sheltered employment includes manual work and small-scale industrial production (Mandal, 2008). This distinction may be one reason for the difference between genders for people with intellectual disabilities found in both papers II and III, with increased likelihood for participation in day care for women and in sheltered employment for men. Both this distinction and the work tasks seem old-fashioned and may constitute part of the prejudice regarding what tasks people with intellectual disabilities are able to perform. On the other hand, argument on the positive side claims that people with intellectual disabilities like and wish for manual and traditional routine work tasks (Olsen, 2003). Either way, it is important that the work tasks are individually adapted and meaningful for the individual.

NAV's duty to assess the work-related assistance needs of users is stated in the Labour and Welfare Administration Act (2006), section 14a, while their duty to clarify the users' overall needs is stated in section 15, second paragraph of the Act. A Norwegian study on rights for assessment in NAV concludes that gathering NAV's overall responsibility for clarification of needs in the same section may contribute to more targeted mapping and assessment.

The conventional understanding of work, where results and economic growth are central, is a challenge for work inclusion for people with intellectual disabilities. This may come at the expense of holistic understanding and inclusion. Sheltered workshops report an increased demand for production, which may provide advantages for employment related to other diagnoses considered to be associated with higher work resources than are intellectual disabilities, and may be one reason for the low work inclusion found in papers II and III. Additionally, the technological development and digitalisation may also affect employment for people with intellectual, both in positive and negative direction (Khanlou, Khan, Vazquez, & Zangeneh, 2020; Warhurst & Hunt, 2019).

Due to the mixed category of *other measures,* the results in paper III say little about inclusion in mainstream employment. Indeed, this category included only 40 people with intellectual disabilities, which is less than 1% of our sample. Statistics from 2008 show that 3% were employed in supported employment in mainstream companies (Reinertsen, 2012). This indicates that the proportion in mainstream employment has drastically decreased during the last decade. Reasons for low inclusion in mainstream employment may include lack of formal competence and scepticism among employers, but also that other diagnoses are prioritised in other support measures directed at the mainstream labour market (Reinertsen, 2012; Wendelborg & Tøssebro, 2018).

From a perspective of inclusion, supported employment in sheltered workshops is segregated from mainstream employment and therefore barely visible in the public space. Increased participation in mainstream employment for people with intellectual disabilities might, in the long term, change the view on their ability to work and thus increase work inclusion. However, inclusion in mainstream employment requires individual facilitation. If not, there is a danger of reinforcing people with intellectual disabilities to be different and experience inadequate coping, which may lead to reduced quality of life and health.

However, work inclusion is not only about having a job. Inclusion also requires active participation and a subjective experience of being included (Nordahl, 2015). This also applies to inclusive employment for people with intellectual disabilities, and it is often about experiencing social acceptance and being part of a community. Using Engeström's activity system may help identify contradictions and misfits between elements in the system (Engeström, 2000). On an individual level, it is important to focus on the person's own opinions and experiences to promote comprehensibility, manageability and meaningfulness, which is supported by findings in a study on motivation for employment in Norwegian adults with mild intellectual disabilities (Garrels & Høybråten, 2019). On a more systematic, community-based level, the system may be used to map barriers and facilitators in the employment process for people with intellectual disabilities. An example of problematic elements in a community-based activity system is a lack of adequate supported employment services or lack of other alternative activities.

With increased age, the ability to work may be affected (Brooke & Taylor, 2005; Harvey, 2001; Martorell, Gutierrez-Recacha, Pereda, & Ayuso-Mateos, 2008). Senior policy has received considerably greater attention in the mainstream labour market in the last decades, for example with increased facilitation for loss of function and an extra week of vacation (The Norwegian Labour Inspection Authority, 2016). This does not seem to apply equally to people with intellectual disabilities. Searches for literature on senior politics for people with intellectual disabilities in Norway, yield no specific results. With the early onset of ageing for some people with intellectual disabilities, many may benefit from early intervention with increased facilitation. The quantitative research in paper II and III revealed a marked decrease in employment with increased age.

Older adults with intellectual disabilities still need meaningful activities in their lives. In The Vienna Declaration, ”Ensuring a society for all ages: promoting quality of life and active ageing” (United Nations Economic Commission for Europe, 2012), one of the senior policy areas, consists of activities throughout all life stages through flexible, life-cycle corporate and human resource management and research-based labour market policies. Concerns about too few activities for seniors have emerged in the literature as well as in our study on retirement (McDermott &

Edwards, 2012; Wadsworth, Harper, & McLeran, 1995). More focus on senior policies is needed to extend their working life, and increased offers of other opportunities for activities, like day care centres, should be considered in the municipalities. The interviews in paper I revealed an experience of abrupt retirement. A sudden transition can make the days feel meaningless for the retirees, and they miss activities that provide a sense of coherence. This may be prevented by a gradual withdrawal from work and for some, a transition to other activities like day care, and they might experience a smoother and more positive transition.

A longitudinal study from France (Westerlund, Kivimäki, Singh-Manoux, Melchior, & Ferrie, 2009) shows that older employees with poorly adapted working conditions experienced deteriorating health as they came closer to retirement age. After retirement, they experienced clearly improved health. The study also shows that simple adaptions at work such as reduced working hours, extended vacations, and less physically demanding work tasks for the older adults can postpone retirement. Deterioration of health before retirement and improved health afterwards were also expressed by some of the retirees in the interviews in paper I.

Decisions concerning retirement are difficult for most people (Fouquereau et al., 2018), and it may be even harder for people with intellectual disabilities. For retirees to be able to take the right decisions for themselves, the process requires good self-awareness and knowledge about retirement and its possibilities. The results in paper I revealed a lack of knowledge in the process for some of the retirees. A Swedish research in group homes for people with intellectual disabilities also revealed lack of understanding of ageing and pointed out a need to raise issues and increased guidance in ageing for people with intellectual disabilities in policy documents (Kåhlin, Kjellberg, & Hagberg, 2016). For people who have been employed for much of their lives, it might be difficult to imagine a change in activities. This might be one of the reasons for the retirees’ experience of an abrupt transition to retirement presented in paper I.

With a changed level of function and poor health, many may benefit from retirement or transition to other activities, which was confirmed by some of the retirees in paper I. This reveals the importance of mapping current resources and needs, to find comprehensible, manageable and meaningful activities to promote an increase in their quality of life. Still, it is reasonable to assume that some older adults with intellectual disabilities have good health and want to work. This may sometimes be problematic since disability pensions automatically shift to age pensions at the age of 67. The different practices in sheltered workshops may lead to different practice within the group of people with intellectual disabilities, and between people with intellectual disabilities and the general population, where retirement is more flexibly regarding age. The age limits in the Norwegian national social insurance system vary from the age limits in the Public Age Pension Reform, which came into force in 2011. In June 2020, the government established a committee to evaluate the pension reform to look at possible adjustments to ensure the pension system is financially sustainable. This also includes an evaluation of the age limits in the pension system in connection with the disability pension system (Ministry of Labour and Social Affairs, 2020). This may affect the rights of people with intellectual disabilities to postpone retirement in the future.

Additionally, the retirees in paper I especially valued the increased self-determination after retirement, a finding supported by several previous studies (McDermott & Edwards, 2012; Nota, Ferrari, Soresi, & Wehmeyer, 2007). Increased self-determination and knowledge may contribute to a feeling of more control; retirees might be more secure in the process, which may facilitate for a smoother transition to retirement.

5.1 Strenghts and limitations in the theories

There may be issues in modelling activity systems, so it is difficult to ensure that every area affecting the activity is included. Additionally, it might be difficult to distinguish between the different nodes in the system, and the connection between them. Activities in a workplace may be considered both individual or collective, like in the municipalities, and it may be difficult to distinguish. The object, goals and personal motivation for engaging in an activity will, as for everyone, differ between people with intellectual disabilities, and may be difficult for the individ and the nearest relatives, friends and service providers to identify. Therefore, it might be difficult to place activities for people with intellectual disabilities in one activity system. The activity theory might also have limited scope according to cultural diversity. Culture, personal backgrounds, and ethnicity may be seen as mediating artefacts. These factors may be easier to include in the ICF model, where the environment affects abilities.

A criticism of the ICF-model is that there are lack of classification of categories for personal factors (Granlund, Eriksson, & Ylvén, 2004). Additionally, in the ICF model, the assessments are seen from the perspective of what functional level is considered as the norm. Positing what is ‘normal’ may serve to stigmatise the impaired individual as ‘not normal’ or as deviant or deficient (Abberley, 1987; Hahn, 1986; Pfeiffer, 2000). However, the model’s meaning in use actually presents a positive approach with a focus on abilities and resources, not on disabilities. The ICF model is also seen as universal in including all people through the basic idea that all humans are at risk of acquiring impairment and chronic illnesses (McDougall et al., 2010), with an increased probability with ageing (Bickenbach et al., 2003).

The limitations in the theories might be decreased by using them together as a framework for daily activities for people with intellectual disabilities.

5.2 Strenghts and limitations in methods

5.2.1 The qualitative research

The sample in the qualitative study was small, giving us only the interviewees’ experiences, which cannot be generalised. In addition, the study was retrospective. But the in-depth interviews gave us good insight and valuable information about the experiences of retirement for the retirees in the study. This gives us indications of what to focus on in the transition from work to retirement for people with intellectual disabilities, and might help others in the retirement process in the future.

Even though an interview guide was followed, there is always a chance that interviews may be biased by the researcher’s previous experiences, which may affect questioning and interpretation of the interviewees’ experiences, and be a weakness in studies using interviews for data collection. This bias could be decreased by including another researcher, both in the interview setting and in the analysis. Another common bias in interviews with people with intellectual disabilities is ‘yes-saying’ or acquiescence (Barron, 2002; Heal & Sigelman, 1995; Tøssebro, 1989). People with intellectual disabilities may tend to respond to questions in a way they think is expected or desired. To reduce the chance of this bias, open-ended questions were asked, and questions seeking ‘yes’ and ‘no’ answers were avoided during interviews included in the present qualitative study.

5.2.2 The quantitative research

The strengths of the two quantitative, registry-based studies were the large sample sizes, which included all people registered with intellectual disabilities between 20 and 69 years of age in NAV’s registry of disability pensions.

The cross-sectional design of the quantitative data analysis precludes causal interpretations of the results. However, the results of the analysis based on the registry-based data used in this thesis helps highlight different factors that may increase or decrease the odds of participation in day care and supported employment. Registrations in the system are aimed at being equal but may differ due to human assessment and registrations. This means one cannot be sure that variables and classifications are given the same meaning in the registration process, depending on how the variables are defined. Most of our variables are quite clear and therefore, sound measures of the entities they are expected to assess. However, the data set also includes some variables with lower probabilities of validity, especially in level of function and the diagnoses of intellectual disabilities.

The requirements by IPLOS for anonymous data are to protect the recipients of services in the municipality. Research on IPLOS data may, nevertheless, be important for increased knowledge in many areas. The strict requirement for anonymity may limit the research, and a fuller picture of the employment and day care situation could be revealed without this requirement. Additionally, the long process of retrieving registry-based data is problematic due to the data becoming old and sometimes outdated before publication. The status of employment and day care for people with intellectual disabilities has not changed significantly since 2015, and it may be assumed that the results of our study are still representative. In May 2018, the law on data protection in the European Union (EU) and the European Economic Area (EEA), the General Data Protection Regulation (GDPR), came into effect (European Commision, 2018). With this, the responsibility for privacy and data protection shifted from the Data Protection Authority to the individual companies. Instead of approval from REK and NSD, a Data Protection Impact Assessment (DPIA) must be performed in all research projects (The Norwegian Data Protection Authority, 2018).

Another change in the application of data is that starting in August 2017, IPLOS data were included in the Norwegian Registry for Primary Health Care (NRPC), drafted by The Norwegian Directorate of Health (2018b). This registry includes data from people who have applied for, received, or previously received health and care services in the municipalities. This also simplified the process of application of data from IPLOS and linkage with other registries, especially in case of changes in the project. In this project the data collection took excessive time, but hopefully, future research will experience an easier and faster process.

The registry-based studies only include people in publicly financed community-based services and people registered in supported employment in sheltered workshops. Other types and arrangement of services also exist: support persons, personal assistance, and support from voluntary organisations, for example. The largest proportion of non-municipal organisations in Norway is composed by the anthroposophical, with ten establishments (Sosialterapeutisk Forbund [The Association of Social Therapeutic Practice], 2020). The anthroposophical living and activity arrangements receive public operating grants, either from the state or the municipalities, but are not registered as employment in Statistics Norway nor as community-based day care in IPLOS. About 300 adults and children live in these villages, and the main diagnoses of people living there is intellectual disabilities. Some of these participate in employment and other daily activities similar to day care centres and sheltered employment, but, to our knowledge, no statistics on this are published. Yet, this means that adding the proportion of people with intellectual disabilities in this setting to our registry-based data would not significantly affect the percentage of people in day care or employment in Norway.

Despite these limitations, the study is still relevant and important. The quantitative study reveals low work inclusion and participation in day care for people with intellectual disabilities, which is also supported in recently published international studies (Khayatzadeh-Mahani et al., 2019; Darren McCausland et al., 2020; Stancliffe et al., 2018).

5.3 Implications for practice and research

A suggestion based on an overall interpretation of the results of the three papers is that more structured follow-up systems for individuals with intellectual disabilities are warranted. Even though the municipalities may have follow-up systems, it seems that abilities and needs for work are not caught and measures are not taken. Continuous evaluation of needs, wishes and functional levels will increase the possibility of capturing changes that may impact the desired and appropriate level of daily activities for each individual. A focus on what is comprehensible, manageable and meaningful for individuals with intellectual disabilities might increase the possibilities to facilitate activities that improve experienced health and quality of life. The results might additionally help to inform future policies in the area of inclusion in employment for people with intellectual disabilities.

Using Engeström's model (Engeström, 2000) to map the different factors affecting the possibilities of activities for an individual, combined with an individual holistic approach, in combination with the use of the ICF model to promote individual resources, may ease the process of adapting daily activities to functional levels, skills and interests. For the individual, this may impact the experience of sense of coherence in life, and, in the long run, affect the health of those with intellectual disabilities.

The lack of a significant association of education and employment also indicates that there is a gap between the school system and the support system for work inclusion. Better systems and more cross-sectional collaboration in the transition from school to employment might increase the employment rate for people with intellectual disabilities.

Follow-up studies are required to increase the knowledge regarding employment and activities for people with intellectual disabilities, to get a fuller picture of barriers and facilitators to employment. It is important to include factors on both individual and community level, and more multi-method studies are needed. Studies on older people with intellectual disability are scare. Further studies should include a larger sample from the older adult population of people with intellectual disabilities, and in future registry-studies this requires the inclusion of a sample from the registry of age pension. It could also be interesting to investigate participants in sheltered employment in general and compare people with intellectual disabilities with other included diagnose groups.

There is need for further studies on retirement for people with intellectual disabilities, and future studies may be prospective and longitudinal to increase the understanding of retirement for this group. Both in research on employment and retirement a measure of comprehensibility, manageability and meaningfulness for the individuals might be useful to increase the knowledge on their own experience of the activities. A scale measuring SOC might be useful to be able to compare data from different time points (Antonovsky, 1993).

In 2020, the COVID-19 virus affected the unemployment rate in Norway, significantly increasing the rate of people registered fully or partially unemployed by 16th of June 2020 to 10.8% (NAV, 2020). NAV expects even increased unemployment, with a top by the end of 2020 (Meisingset & Hogna, 2020).This might, additionally, lead to increased challenges in work inclusion for people with intellectual disabilities, and need further research.

6 Conclusion

This research presented in this thesis contributes to new knowledge about facilitators and barriers for employment and day care participation for people with intellectual disabilities in Norway. In addition, the research provides new insights regarding experiences of retirement for this group.

Despite a low unemployment rate in the general population throughout the study period, the results of the included registry-based studies show both low employment rates and low participation rates in day care for people with intellectual disabilities. These negative findings especially hold with increased age, and people without registered functional level. The latter is worrisome because it may indicate that people with intellectual disabilities who do not receive any services from the municipality may not get the support they need to be included in work or day activities. People registered with high functional level also had a significantly lower likelihood of employment than people with a low level of function. It is likely that many in this group had the ability to work and would benefit from partaking in work life. This implies that there is a need for increased focus on how to enhance inclusion in work-related activities, especially for people not registered with services in the municipalities and people registered with a high functional level. Additionally, results in paper II revealed lower likelihood for people with a history of hospital admissions. Health promotion and detecting diseases at an early stage may prevent people falling out of the labour market.

Being registered with a higher educational level deceased the likelihood for employment in paper III. Hence, contrary to the general work force, for people with intellectual disability, these results indicate that there is a gap in the transition between the school system and employment services. Differences between diagnoses were also revealed, with a notably higher likelihood of employment for people with Down syndrome than other diagnoses of intellectual disabilities. This might indicate that other diagnosis groups are more invisible than Down syndrome, which therefore increases the probability of falling out of the municipal system and employment. The difference between diagnoses may also reflect a poor ability to work for certain groups, but the low rate of participation may also be due to unknown causes, and further research is needed. In line with resource-oriented policies and regulations, these results indicate a need for more focus on resources and ability to participate in employment as well as a need for more standardised assessments.

The results in the qualitative study imply a need for more knowledge about ageing and retirement for people with intellectual disabilities, including an increased focus on self-determination, to facilitate experiences of a positive transition. This thesis discloses the importance of focus on the right balance of activities for retired older adults with intellectual disabilities to prevent unnecessary decline in health.

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Paper I

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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

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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, Søderstrøm 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.

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Employment and attendance in day care centres for people with mild intellectual disabilities – do age, gender, functional level or hospital admissions matter?

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Abstract

Background Workforce inclusion is an important political goal in many countries. However, nearly 70% of Norwegians registered with mild intellectual disabilities (IDs) are not registered employed or attending in day care centres. This study investigates the association between age, gender, functional level and hospital admissions with employment or attendance in public financed, community-based day care centres for adults with mild IDs in Norway.
Method This study is based on data from a linkage of the national population-based registries from 2013 to 2015: Statistics Norway (SSB), the Norwegian Information System for the Nursing and Care Sector (IPLOS) and the Norwegian Patient Registry (NPR). The sample consisted of 2370 adults registered with a mild ID, receiving disability pension in Norway, aged 18–67 years. Binary and multinomial logistic analyses, adjusted for age, gender, functional level and hospital admissions, were performed.

Results In 2015, 45.7% and 19.6% of the samples aged 20–31 and 52–63 years, respectively, were registered as employed or in day care centres. Participation in day care is a public service registered in IPLOS, which requires registration of functional level, while attendance in employment support is registered in SSB, where functional level is not registered. Compared with people registered with a high functional level, the probability of being employed or in day care centres was lower for people without registration of functional level. People with hospital admissions were less likely to be employed, especially if they had both psychiatric and somatic hospital admissions. People were less likely to attend day care and open employment only if they had a combination of both types of hospital admissions. Attendance in day care centres was less likely for men than women.
Conclusions Older people with mild ID, without registered functional level (meaning not receiving public community-based services) and with a history of hospital admissions were significantly less likely to be employed or participate in day care centres. The clear association between not being employed or attending day care centres and not having one's functional level registered implies there is a need for increased focus on how to enhance work participation

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among people with mild IDs who are not within the system of receiving public services.

Keywords ageing, day care, employment, functional level, hospital admissions, intellectual disability

Introduction

Norway is part of the Nordic welfare states, where high degree of employment and equal opportunities in the labour market is central in governmental policy. Workforce inclusion is an important political goal, in line with many other countries, and includes people with intellectual disabilities (IDs) (Ministry of Labour and Social Affairs 2002, p. 126; WHO 2011). The rights for people with ID to live an active life, use their resources and work inclusion are enshrined in laws, legislation and political strategies (Ministry of Labour and Social Affairs 2002; Ministry of Children 2012). Day care centres are alternative daily activities for people with IDs.

However, there is a gap between policy and practice in employment and participation in day care for people with IDs, reflected in the relatively low rates of people employed or in day care in Norway (Hvinden 2004; Halvorsen *et al.* 2016; Kuznetsova *et al.* 2017). In 2015, 25.7% of people with mild IDs, aged 20–69, were employed and 6.3% participated in day care in Norway (Engeland and Langballe 2018), compared with 70.7% and 0.2% in the general population (Statistics Norway 2015a). International statistics also report low employment rates for adults with IDs, with a range between 34% and 47% (Australia, Canada, the UK, the USA and Finland) (Taanila *et al.* 2005; Lysaght *et al.* 2015).

The WHO (2011) estimates that 1–3% of the population have IDs. However, in Norway, only 0.4% of the population is registered with an ID (Søndenaa *et al.* 2010), and as in the world in general, the exact number of people with mild IDs in Norway is unknown.

Individuals with mild ID are often able and willing to work (Parmenter and Knox 1991; Li 2004; Katz and Lazcano-Ponce 2008), and employment for people with IDs may entail better opportunities for independent living, meaningful social participation and enhanced self-confidence (Dixon and Reddacliff 2001; Kober and Eggleton 2005; Li *et al.* 2006; Jahoda *et al.* 2008; Lysaght *et al.* 2012). Unemployment is associated with poor mental and physical health (Bartley *et al.* 2006; van der Noordt, IJzelenberg, Droomers & Proper, 2014; Heggebø 2016), but little is known whether this is actually the case for people with IDs (Milner *et al.* 2014; Curnock *et al.* 2016).

Disability pension is granted in Norway when work capacity is considered low and there is no prospect of improvement. Almost all people with IDs in Norway receive disability pension when they reach 18 years, without assessment of functional level (Proba 2016), while 9.4% of the general population receives disability pension and requires assessment of workability (Statistics Norway 2019). The local offices of the Norwegian Labour and Welfare Administration (NAV) cooperate with the central government for solutions to increase the employment rate, into mainstream employment or through measures for people with difficulties entering the labour market (NOU, 2016). This includes people with IDs, even if disability pension is granted.

Despite the overall goal of improving access to mainstream employment and open employment, recruitment has been limited for people with IDs in Norway (Spjelkavik *et al.* 2012; Proba 2016). Tuckerman *et al.* (2012) found the same negative trend in Australia. Even though employment support is available, a Norwegian study reported that daily activities for people with IDs are mainly limited to day care centres or sheltered employment (Engeland and Langballe 2018). Research has also found a negative trend in employment rate and attendance in day care in Norway over the last decades (Kittelsaa and Tøssebro 2013).

Research on quality of life in employment for people with IDs shows that people in sheltered and open employment report better quality of life than people in day care, while no significant differences were found between open and sheltered employment (Reinertsen 2015). In contrast, a study from New Zealand found better quality of life for people with high functional level in open employment compared with sheltered employment (Kober and Eggleton 2005).

Studies from Scotland, Spain and the USA indicate that factors like functional level, physical condition, psychiatric disorders and age impact work participation (McDermott *et al.* 1999; Cooper *et al.*

2; Martorell *et al.* 2008). In addition, external factors like access to employment and public services, integration and attitudes towards people with IDs may affect the possibility to work (Ellenkamp *et al.* 2016; Wendelborg *et al.* 2017). Some studies found that employment is strongly impacted by severity of the disability and that people with mild ID have a significantly higher chance of employment than adults with moderate and severe IDs (Hum and Simpson 1996; Wilkins 2004). In relation to gender differences, research varies. McDermott *et al.* (1999) found that probability of employment was higher for men than women, while Martorell *et al.* (2008) found no differences.

Research on employment status/day care participation in association with health and functional level among people with ID is scarce, and to the authors' knowledge, no research exists concerning people with mild ID. Based on a unique large, population-based sample, with linked national registry data, this study investigates whether age, gender, functional level and hospital admissions are associated with employment and participation in day care centres for people with mild IDs in Norway. Better knowledge of the employment situation for people with mild IDs may help policy makers and service providers increase participation in work-related activities for this group.

Method

Study population

Mild ID is defined based on the diagnosis criteria in ICD-10, coded F70, which includes significant impairment of cognitive and adaptive functioning with an intelligence quotient ranging between 50 and 69 (WHO 2016).

The eligible study population consisted originally of a total of 2471 adults registered with mild IDs in the disability pension register in Norway, aged 18–67 at 31.12.2013, alive per 31.12.2015. Individual data from Statistics Norway (SSB), the Norwegian Information System for the Nursing and Care Sector (IPLOS) and the Norwegian Patient Registry (NPR) were linked by means of unique personal identification numbers. Data from 2015 were used in the analyses (most recent available year for employment status), sample aged 20–69. The number of missing values in the dataset was very low.

In Norway, functional level is only registered for people with public community-based services. People registered with services, with missing registration of functional level, were excluded prior to the analyses (59 individuals; 2.4%). People registered in education ($n = 30$) were excluded as well, because of irrelevance to the present research questions. A sensitivity test between models including or excluding the category of *other measures* (wage subsidies, work practice and clarification of workability; $n = 12$) showed no significant differences and therefore excluded.

Hence, the final sample included in the analyses consisted of 2370 people with a mild ID, which is 96% of the potential eligible population (Fig. 1).

In addition, a stratified and randomly selected sample representative of the general population of $N = 18\ 612$ people aged 41–67 provided comparative descriptive statistics for overall employment rate and participation in day care in Norway. Using the same exclusion criteria as for the sample in the present study with mild IDs, the total sample of the general population in the analysis was $N = 13\ 063$.

Study variables

Employment and attendance in day care centres

Because of the low rate of people with IDs in mainstream employment without support, employment type was defined as being registered as a participant in the facilitated employment measures, sheltered and open employment, in Statistics Norway. Sheltered employment includes individual facilitation in a sheltered workshop, while open employment refers to mainstream employment with support (Labour Market Act 2004). Employment services are administered as public or public–private partnerships, and employees in sheltered and open employment generally receive an additional low wage subsidised by the Norwegian Labour and Welfare Administration, on top of their disability pensions (NOU, 2012).

Day care centres are public financed, community-based activity centres, registered in the Norwegian Information System for the Nursing and Care Sector (IPLOS). Day care centres in Norway provide services to people who need support for personal care, social support, activisation, training in activities of

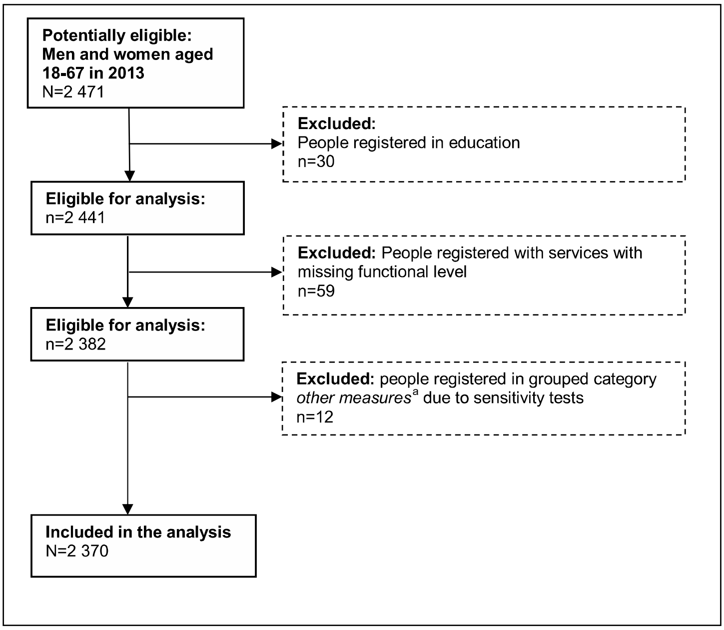

Figure 1. Flow chart for study population. [a]*Other measures* included the following employment supports: wage subsidies, work practice and educating, clarification of workability.

daily living and so on. Participation in day care activities aims to stimulate and increase coping with activities adapted to their individual functional abilities (Public Health Act 2011). Day care for people with IDs in Norway is often segregated from centres or wards with clients who have other diagnoses. Activities and tasks in sheltered employment and day care often overlap. A difference between sheltered employment and day care is that workers in sheltered employment are expected to meet certain production requirements, while people at day care centres do not have such requirements (NOU, 2012).

The registered employment status and attendance in day care variables in this study were grouped into four categories: not employed/not in day care, day care centre, sheltered employment and open employment. All were conducted per 31.12.2015 from Statistics Norway and IPLOS.

To avoid double registration of persons registered with more than one type of activity, the highest level of activity was preferred in the analyses. Eighteen people were registered in both day care and sheltered employment and registered with sheltered employment for the analyses. Three people were listed in day care and open employment and registered with open employment for the analyses.

Age, gender, functional level and hospital admissions

Information about age, gender, functional level and hospital admissions was included in the analyses on employment status.

Because of the threat to anonymity, age was categorised by SSB into five categories (Table 1). We found no deviation from linearity and treated age as continuous in the logistic analyses.

Functional level is based on a summary of 15 variables registered in IPLOS assessing ability to perform activities of daily living in order to map the need for public community-based services, regardless of diagnosis. The 15 variables include social functioning, cognitive functioning, self-care and

Table 1 Descriptive statistics of employment type by age, gender, functional level and hospital admissions

	Not employed or in day care		Day care		Sheltered employment		Open employment		Total	
	n	%	*n*	%	*n*	%	*n*	%	*n*	%
Age										
20–31	522	54.3	75	7.8	286	29.7	79	8.2	962	100
32–41	387	71.0	31	5.9	106	19.4	21	3.9	545	100
42–51	291	81.1	7	1.9	53	14.8	8	2.2	359	100
52–63	276	80.4	24	7.0	*	*	*	*	343	100
64–69	133	82.6	16	10.0	12	7.5	0	0.0	161	100
Gender										
Men	785	66.1	65	5.5	279	23.5	58	4.9	1187	100
Women	824	69.7	88	7.4	217	18.3	54	4.6	1183	100
Functional level										
Low	139	58.1	59	24.7	36	15.1	5	2.1	239	100
Moderate	302	50.2	74	12.3	192	31.9	34	5.6	602	100
High	218	61.2	20	5.6	96	27	22	6.2	356	100
Not registered	950	81.0	—†	—†	172	14.7	51	4.3	1173	100
Hospital admissions										
None	1017	65.0	86	5.5	369	23.6	92	5.9	1564	100
Psychiatric admissions only	67	65.0	13	12.6	18	17.5	5	4.9	103	100
Somatic admissions only	437	73.7	44	7.4	98	16.5	14	2.4	593	100
Both psychiatric and somatic	88	80.0	10	9.1	*	*	*	*	110	100
Total	1609	67.9	153	6.5	496	20.9	112	4.7	2370	100

†People without registered functional level cannot be registered in day care.

*Because of number <5 in some cells, numbers are replaced with an asterisk to ensure anonymity.

ability to perform household tasks (scored from 1 to 5, *no difficulty* to *extreme difficulty*). The mean score of all questions is categorised into three main groups: *high* (≤2), *moderate* (>2–3) and *low functional level* (>3). Registration of functional level in IPLOS includes only people receiving public services, which include attendance in day care centres but not work support (Gabrielsen *et al.* 2011). Almost half (49.5%) of people with mild IDs are not registered with community-based services, that is, not registered with functional level. Hence, this was added as a fourth category.

Hospital admissions may be an indicator of poor health and are a risk factor for unemployment (Bartley *et al.* 2006; Bambra and Eikemo 2009). In this study, hospital admissions registered in the Norwegian Patient Registry during 2013–2015 were divided into four categories: no hospital admissions, psychiatric admissions only, somatic admission only or having both psychiatric and somatic hospital admissions. Psychiatric hospital admissions entail hospital admissions due to psychiatric health problems or illnesses. Somatic hospital admissions entail hospital admissions due to medical illnesses or physical health problems.

The study was approved by the Regional Committees for Medical and Health Research Ethics (REK; September 2014), the Norwegian Data Inspectorate (NSD; June 2015) and by all included registries.

Statistical analyses

Descriptive statistics were used to describe the sample. Logistic regression models were used to examine the association between the covariates (age, gender, functional levels and hospital admissions) and the outcome variable of employment status. Binary logistic regression was used when the dependent variable had two outcomes (employed/in day care or not), whereas multinomial logistic regression was used when a dependent variable had more than two outcomes (no employment/day care, day care, sheltered employment or open employment). The reference categories in both logistic models were no employment/day care, high functional level and no hospital admissions. All analyses involved comparisons of these groups and were adjusted for age, gender, functional level and hospital admissions.

Analyses were carried out in STATA/IC version 15.1.

Results

Descriptive statistics

In the total sample of 2370 people with mild IDs, 49.9% were women. As shown in Table 1, 67.9% of the sample were not registered employed/not in day care, 6.5% were registered in day care centres, 20.9% in sheltered employment and only 4.7% in open employment. In comparison, 70.7% of the general population in the same age group were registered as employed, 0.3% in sheltered employment and <0.1% in open employment, while 0.2% were registered in day care (Statistics Norway 2015a).

Concerning people aged 20–31 with mild IDs, 45.7% were registered as employed or in day care centres, while 69.9% of the general population aged 20–39 were employed (Statistics Norway 2015b). The corresponding figure among people aged 52–63 was 19.6% for people with IDs and 66.6% in the general population aged 55–66 (Statistics Norway 2015b). Employment in sheltered and open employment clearly decreased with age for people with mild IDs, while attendance in day care centres increased for the two oldest age groups. Still, the overall rate of people not employed/not in day care decreased by age.

Of the 2370, 1173 (49.5%) of our study population were not registered with public services, that is, not registered with a functional level. This group was registered with the highest rate of people as neither employed nor in day care, with 81.0%. In comparison, 50.2% of people with moderate and 61.2% with high functional levels were not registered as employed or in day care.

Regarding hospital admissions, 34.0% were admitted at least once during 2013–2015, and the number of people with somatic hospital admissions was almost six times higher than psychiatric.

There was a similar trend in the rate of hospital admissions for the general population as for people with mild IDs, with 30.0% admitted at least once in the same period. Indeed, the rate of people with somatic hospital admissions, not registered as employed, was lower than for people with IDs, with 73.7% for people with IDs compared with 28.9% in the general population. The unemployment rate for those who had previous psychiatric hospital admissions was 65.0% for people with IDs compared with 61.6% for the general population. For those registered with both psychiatric and somatic hospital admissions, the rate of people not being employed or in day care increased for both people with IDs and the general population, 80.0% and 87.0%, respectively.

Association between employment and attendance in day care, age, gender, functional level and hospital admissions

As shown in Table 2, higher age decreased the odds of employment or attendance in day care. There were no significant differences between genders.

The odds of being employed were 33% higher for people registered with a moderate functional level compared with those with a high functional level (odds ratio = 1.33, 95% confidence interval = 1.01–1.77) and 67% lower for people not registered with any functional level (odds ratio = 0.33, 95% confidence interval = 0.25–0.43). There were no significant differences between people registered with low and high functional level.

People registered with psychiatric or somatic hospital admissions separately were less likely to be employed compared with those without any admissions. A combination of both admission types substantially lowered the likelihood of being employed.

When comparing different types of employment and day care versus not being employed or in day care, age did not impact participation in day care centres in this study (Table 3). However, higher age was associated with lower odds of both sheltered and open employment.

Men were underrepresented in day care and somewhat overrepresented in sheltered employment, while there were no gender differences regarding open employment.

Regarding functional level on employment type, those with a low functional level were five times more likely to participate in day care centres compared with those with a high functional level, while they were less

Table 2 Logistic regression, odds ratio (OR) of being registered as employed or participation in day care

OR of being registered employed/day care to not employed/not in day care			
	OR	**(95% CI)**	***P*-value**
Age	0.82	(0.79–0.86)	<0.001
Gender[†]			
Women[‡]	—	—	—
Men	1.04	(0.86–1.25)	0.698
Functional level[†]			
High[‡]	—	—	—
Moderate	1.33	(1.01–1.77)	0.045
Low	1.23	(0.87–1.75)	0.246
Not registered	0.33	(0.25–0.43)	<0.001
Hospital admissions[†]			
None[‡]	—	—	—
Psychiatric admissions only	0.48	(0.31–0.75)	0.001
Somatic admissions only	0.67	(0.53–0.84)	<0.001
Both somatic and psychiatric admissions	0.23	(0.14–0.38)	<0.001

[†] Fully adjusted analyses.

[‡] Reference group.

Table 3 Multinomial logistic regression odds ratio (OR) on employment type (sheltered or open) or participation in day care

OR of day care, sheltered and open employment to not employed/not in day care									
	Day care			**Sheltered employment**			**Open employment**		
	OR	**(95% CI)**	***P*-value**	**OR**	**(95% CI)**	***P*-value**	**OR**	**(95% CI)**	***P*-value**
Age[†]	0.95	(0.88–1.01)	0.105	0.81	(0.78–0.85)	<0.001	0.65	(0.58–0.73)	<0.001
Gender[†]									
Women[‡]	—	—	—	—	—	—	—	—	—
Men	0.63	(0.44–0.91)	0.013	1.20	(0.96–1.49)	0.094	0.97	(0.66–1.45)	0.900
Functional level[†]									
High[‡]	—	—	—	—	—	—	—	—	—
Moderate	2.73	(1.60–4.66)	<0.001	1.17	(0.85–1.61)	0.325	0.76	(0.42–1.36)	0.351
Low	5.02	(2.88–8.77)	<0.001	0.58	(0.37–0.91)	0.019	0.31	(0.11–0.87)	0.026
Not registered	—[§]	—[§]	—[§]	0.36	(0.26–0.48)	<0.001	0.47	(0.27–0.81)	0.006
Hospital admissions[†]									
No[‡]	—	—	—	—	—	—	—	—	—
Psychiatric admissions only	0.72	(0.37–1.40)	0.338	0.42	(0.24–0.72)	0.002	0.56	(0.21–1.46)	0.232
Somatic admissions only	1.02	(0.67–1.56)	0.911	0.64	(0.49–0.83)	0.001	0.36	(0.20–0.66)	0.001
Both somatic and psychiatric admissions	0.46	(0.22–0.94)	0.033	0.19	(0.10–0.37)	<0.001	0.08	(0.01–0.58)	0.013

[†] Fully adjusted analyses.

[‡] Reference category.

[§] People without registered functional level cannot be registered in day care.

likely to participate in sheltered employment and open employment. Those with a moderate functional level were also significantly overrepresented in day care compared with those with high function, while there were no significant differences in participation in sheltered or open employment for this group.

Compared with people with a high functional level, people not registered with any functional level were less likely to be registered in sheltered employment and in open employment.

Those with only a history of psychiatric hospital admissions were less likely to participate in sheltered employment. By contrast, there was no significant association between having psychiatric hospital admissions and attendance in day care or open employment. Also, those with somatic hospital admissions were underrepresented in sheltered employment, as well as in open employment. People with both somatic and psychiatric hospital admissions were significantly underrepresented in all employment types.

Discussion

In this large registry-based study of people with a mild ID, we found that being employed or attending day care centres was significantly associated with younger age, a moderate functional level and not having somatic or psychiatric hospital admissions.

Decreased employment rate at higher ages was expected because of the increased risk of poorer health with ageing (WHO 2015). However, this study finds that over 80% of people with mild IDs over 42 years old were registered without employment or day care was surprising. This indicates that people with a mild ID are falling out of employment at an early age or, alternatively, that younger people have an excessively higher chance of gaining employment compared with those middle aged and older.

For people with a mild ID, supported employment services may be essential to succeed in the open labour market, and co-worker support increases the job placement rate in open employment (Farris and Stancliffe 2001; Rose *et al.* 2005). Xu and Stancliffe (2017) claim that mainstream employment decreased the rate of depression for people with IDs compared with those in other employment arrangements.

The link between unemployment and poor health is well known (Bartley *et al.* 2006; Bambra and Eikemo 2009; van der Noordt *et al.* 2014). Being employed or partaking in organised day care activities may improve coping practices for people with mild IDs. This may, in the long run, be positive for health, decrease the chances of sickness and maintain the ability to work or actively participate in society. Hospital admissions can be used as an indicator of health status; this study finds negative associations between employment status and somatic and psychiatric hospital admissions for people with mild IDs, particularly if they have both types of admissions. Decreased work capacity is natural when getting ill, but not having employment may also cause poor health. These findings support that health promotion and early interventions may be crucial to maintain employment and that it is essential to strive for better work inclusion. Reasons for the high rate of unemployed people with mild IDs day care should be studied.

It is important to assess a person's functional level to find the right type of employment. Support centres and service providers need a structured system to match individual abilities, resources and rights. Previous research reports that the more severe the disability, the lower the work participation (Hum and Simpson 1996; Wilkins 2004); this was not supported by the results in this study. In contrast, as much as 61.2% of people with mild IDs with high functional level are registered without employment or day care. Moreover, this study finds that employment is significantly lower for people with a high functional level compared with people registered with a moderate functional level. This means that many of the people registered with high functional level may have unused resources and are able and willing to work.

This study also found that the risk of unemployment is much higher for people with mild IDs without public services and consequently does not have their functional level registered. This may be because most people with IDs receive a disability pension without an assessment of functional level, are never in contact with service providers, and no consideration of workability is performed. Other reasons for the high rate of unemployment among people with high functional level and people without registered functional level might include insufficient awareness of opportunities, support and public services in the community, as well as a lack of trust in the service system and differing family beliefs regarding the political aims of employment. Alternatively, limited public services resources might also affect the status of activities. Additionally, our findings support the previous literature: The gap between policy and practice in employment for people with mild IDs still exists (Hvinden 2004; Halvorsen *et al.* 2016; Kuznetsova *et al.* 2017). These results imply a societal need for an increased focus on people with mild IDs, especially for those not receiving public services who have perhaps fallen through the gaps of public systems that provide help with work inclusion.

Our study partly supports the findings of McDermott *et al.* (1999) on gender differences in employment. No overall significant difference was found between men and women in employment, but results showed that more women than men attended day care. This might indicate that women are more easily allocated in day care centres than men. Traditionally, there have been more 'women's assignments' in day care, such as needlework and weaving, which might be a reason for the higher proportion of women. However, men may also benefit from participation in day care centres, and service providers should make efforts to equalise gender differences in all types of employment.

We need strategies on both organisational and individual levels to facilitate employment for people with IDs. Employment services are important actors in increasing the employment rate for this group, and support and motivation in these agencies might increase the likelihood of employment (Rose *et al.* 2005; Cheng *et al.* 2018). Additionally, political guidelines and economic frameworks for public services should facilitate employment for people with IDs.

There is also a new opportunity for employment for people with IDs in Norway in which they have mainstream employment in such service sectors as hotels and restaurants (the so-called *ALL IN*). People included in this project receive approximately 20% of the tariff salary from their respective employers, in addition to their disability pension. Currently, 49 people with IDs are employed through this project (per 04.06.2019), and the project aims to employ 1000 people by 2027 and should be included in future research. Increased mainstream employment may result in more positive societal attitudes towards people with disabilities. Farris and Stancliffe (2001) found that co-workers of people with IDs in open employment valued them more after attending a co-worker training course. A more positive attitude towards people with IDs and their resources might in turn increase the possibilities for work in open employment.

Strengths and limitations

A strength of the study is that the analyses were based on a large dataset including the total population with mild ID receiving disability pension, with a low number of missing values, which give a high statistical power.

However, the number of people with mild ID without being registered is unknown. In most countries, it is difficult to identify people with an intelligence quotient at the border for diagnosis of mild ID (Søndenaa *et al.* 2010; Maulik *et al.* 2011). Another limitation is that this study only utilised people registered in public day care centres and in sheltered or open employment. There could be persons employed who are not registered in the employment services, for example, to avoid taxes or because family or friends offer jobs and do not think registration is necessary. However, most likely the number in this category is low because of the financial resources and support that follows registration in employment services.

Both random and systematic errors in registry-based data may affect the study's reliability. However, the probability for errors in registry-based data is generally low, and testing of Statistics Norway's event database confirms the low probability of error. The functional level should be assessed and registered the same way. Indeed, bias may occur because level of function is assessed by employees in public service centres, and differences may exist.

Limitations also include relying on unconventional age spans to secure anonymity. Displacement in age groups due to the population draw date (2013) to analysis (2015) indicates that some retirees might be included in the oldest age group. But, with a total of 161 in the oldest age group, that number is probably low. Differences in employment between 2013 and 2015 were checked by a sensitivity test. Although better model fit was found for 2015, the results showed higher probability of employment for the oldest age group in 2013 (the sample all younger than retirement age) compared with the same group in 2015. Indeed, the results showed the same for the second oldest age group, which makes it difficult to distinguish between an actual decrease in employment and inclusion of people naturally retired (>67 years old). Age as a continuous variable could have yielded more precise analyses, but the results still indicate trends. Further research may also include a time series to see a fuller picture of employment.

Moreover, there may be other hindrances to employment, such as work or day care offers in the municipality, prejudice from workplaces against the workability of people with IDs or the idea that it takes a lot of resources to have employees with IDs. Future research may include other variables affecting employment, including additional sociodemographic variables, differing public services and health measures to get more complex knowledge on employment for people with mild IDs.

Conclusion

To our knowledge, this is the first study to investigate the association between employment and attendance in day care and age, gender, functional level and hospital admissions among people with mild IDs using national registry data. The data are representative for adult Norwegian inhabitants registered with a mild ID who received disability pension in 2013–2015. The analyses are based on employment status in 2015.

The study found that older people with mild ID, without registered functional level (meaning not receiving public community-based services) and with a history of hospital admissions were significantly less likely to be employed or participate in day care centres. More women than men attend day care centres. The strong, negative association between lack of work or day care and not being registered with a functional level was particularly surprising and puzzling. This reveals a need for assessment of functional level to capture people without public community-based services and for an increase of necessary support for inclusion in meaningful work or other daytime activities. Additionally, many people registered with a high functional level are neither employed nor in day care, and the probability is high that many with resources to work are excluded from the labour market.

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Conflict of interest

To all authors knowledge, there are no conflicts of interest.

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Paper III

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Participation in employment and day care for adults with intellectual disabilities: Equal access for all?

A Norwegian registry-based study

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Abstract

Background: The employment rate for people with intellectual disability is low. This study aims to increase the knowledge about the association between age, gender, diagnosis, functional level, educational level, and daily activities for adults with intellectual disabilities.

Method: A multinomial logistic analysis was applied to registry data on 12,735 adults with intellectual disabilities from the Norwegian Information System for the Nursing and Care Sector (IPLOS) and Statistics Norway (SSB).

Results: Higher likelihood of employment and day care participation was associated with younger age, but differed between genders and diagnoses. High functional level and not having a functional level registered decreased the likelihood for employment. Educational level was not associated with employment.

Conclusions: Insight into differences between people with intellectual disabilities, might inform policy makers on action needed to prevent inequalities. A more standardised assessment of ability to work might promote participation in daily activities.

Keywords: Intellectual disabilities, employment, day care, inclusion, education, functional level

Introduction

As part of the Nordic welfare model, Norway aims for equal access to health and social services, equal possibilities for independent lives, and equal opportunities to enter the labour market, including people with intellectual disabilities (Ministry of Children, 2012-2013; Ministry of Labour and Social Affairs, 2002-2003; NOU, 2016: 17). Equal rights to employment for people with intellectual disabilities are also included in the UN's *Convention on the Rights of Persons with Disabilities* (United Nations, 2006, Article 27). Nonetheless, a decline in employment and day care participation has recently been recorded among people with intellectual disabilities in Norway (Engeland & Langballe, 2018; Søderstrøm & Tøssebro, 2011), and in 2015, more than half of this group were registered as neither employed nor in municipal day care (Engeland & Langballe, 2018). A similar downward trend has been observed internationally (Lysaght, Šiška, & Koenig, 2015; Taanila, Rantakallio, Koiranen, Von Wendt, & Järvelin, 2005).

Meaningful activities, positively impact our health, quality of life (QOL), and well-being (Bartley, Ferrie, & Montgomery, 2006; Fleming, Fairweather, & Leahy, 2013; Heggebø, 2016; McCausland, McCallion, Brennan, & McCarron, 2020; van der Noordt, Jzelenberg, Droomers, & Proper, 2014). Schalock's (2002) model of quality of life includes perceptions, behaviours and conditions that reflects a persons' well-being. Employment and day care activities should therefore be situated in models of quality of life.

Employment for people with intellectual disabilities is often defined in a broader way than for the general population. An official Norwegian report, on how to improve the rights of people with intellectual disabilities, defines work as activities that add values related to the production of goods and services (NOU, 2016: 17, p. 72). In Norway, 71% of the general working population were employed in 2015, and only 0.2% under the age of 67 were registered in day care (Statistics Norway, 2015). However, only 25% of people with intellectual disabilities in Norway were registered as employed and 21% as participants in day care (Engeland & Langballe, 2018). Disability pension is close to automatically granted at the age of 18 by the Norwegian Labour and Welfare administration (NAV) to people with a diagnosis of intellectual disability, most often without an assessment of their functional level. In 2013, about 14,800 people with intellectual disability received disability pensions (Engeland & Langballe, 2018), and 97% of adults registered with intellectual disability in Norway received a disability pension (Wendelborg & Tøssebro, 2018). The same year, only 9% of the general population received a disability pension in Norway (Ellingsen, N. Lindbøl, & Mølster Galaasen, 2014), which requires an assessment of ability to work (Labour and Welfare Administration Act, 2006; National Insurance Act, 1997).

NAV is also responsible for providing employment support to people with difficulties entering the Norwegian labour market. Those with intellectual disabilities are most often employed in sheltered workshops with individually facilitated work tasks, while very few acquire employment in the open labour market (Engeland & Langballe, 2018), a situation also found internationally (Verdonschot, de Witte, Reichrath, Buntinx, & Curfs, 2009). People with intellectual disabilities may be a valuable employment resource, but they often struggle to find and maintain jobs (Kirsh et al., 2009; Lysaght, Ouellette-Kuntz, & Lin, 2012). For people unable to work, participation in day care centres may be an alternative activity.

Factors associated with the ability to work in the general population are education, age, motivation, health status, and functional level (Harvey, 2001; Rongen, Robroek, Schaufeli, & Burdorf, 2014). Previous studies on the predictors of employment for people with intellectual disabilities have focused on political regulations and systems, demographic factors such as age, gender and educational level, and personal factors such as motivation and self-esteem (Foley, Dyke, Girdler, Bourke, & Leonard, 2012; Timmons, Hall, Bose, Wolfe, & Winsor, 2011). The increased prevalence of health problems with ageing (McDonald, 2019; World Health Organization, 2015) decreases the likelihood of employment in older age, an effect that is also expected to be present for people with intellectual disabilities (Siperstein, Heyman, & Stokes, 2014).

A diagnosis of intellectual disability should not in itself affect employment status; nevertheless, the degree of intellectual disability might affect one's functional level (McGlinchey, McCallion, Burke, Carroll, & McCarron, 2013). Research indicates that a higher level of function increases the likelihood of employment (Martorell, Gutierrez-Recacha, Pereda, & Ayuso-Mateos, 2008; McCausland et al., 2020), and that the ability to manage activities of daily living were the best predictors of success in work for adults with intellectual disabilities (Eagar et al., 2006; McCausland et al., 2020).

In general, higher education indicates better opportunities in the labour market (Ali & Jalal, 2018; Harvey, 2001). Studies on people with intellectual disabilities also report a positive association between completion of upper-secondary school and competitive employment (LoBlanco & Kleinert, 2013; Papay & Bambara, 2013; Shandra & Hogan, 2008). The Norwegian Education Act (The Education Act, 1998) provides the right to individually customised teaching and special education. From primary school through upper secondary school, people with intellectual disabilities may attend ordinary or specialised schools. Individually, customised higher education for people with intellectual disabilities is not available in Norway (NOU, 2016: 17).

The gender gap in the general labour market has steadily declined the recent decades, but statistics still reveal a higher full-time employment rate for men than for women (van der

Lippe & van Dijk, 2002). Research on gender differences in employment for people with intellectual disabilities is scarce and the results are contradictory (Martorell et al., 2008; McCausland et al., 2020; McDermott, Martin, & Butkus, 1999; Umb-Carlsson & Sonnander, 2006). No research exists on gender differences regarding employment for people with intellectual disabilities living in a Norway.

The varying research results on employment and day care for people with intellectual disabilities indicate a need for a more comprehensive understanding of the facilitators for daily activities for this group. Gaining a thorough understanding of employment and activities for those with intellectual disabilities is complicated by differences within subgroups, such as gender or diagnosis of intellectual disability. Awareness of the role of intersectionality, first described by Crenshaw (1989), may also promote equal rights and refine decision- and policy-makers- perspectives on individuals' abilities to perform work tasks and activities. This nuance in understanding might increase the possibilities of employment and participation in day care for people with intellectual disabilities, and their quality of life.

To the authors' knowledge, the present study is the first to explore employment and participation in day care, combining the association with age, gender, educational level, diagnosis of intellectual disability, and functional level for people with intellectual disabilities. No previous research has combined all these variables in any region. Furthermore, by exploring registry-based data for a large sample of people with intellectual disabilities in Norway, this study aims to increase the knowledge of employment and day care participation for this group.

Method

The study had a cross-sectional design and was based on registry data. Data for 2015, the most recent year available, from two national population-based registries, the Norwegian Information System for the Nursing and Care Sector (IPLOS) and Statistics Norway (SSB), were used for the analysis. The data were linked by means of unique personal identification numbers, specifically for this study.

The study was approved by the Regional Committees for Medical and Health Research Ethics (REK, ref. 2014/1158) in September 2014, by the Norwegian Data Inspectorate (NSD, ref. 40853/7/LT/LR) in June 2015, and by the examined registries.

Study population

The eligible study population comprised 14,329 of people registered with intellectual disabilities in the Norwegian Labour and Welfare Administration register of disability pension, between 18 and 67 years of age on 31.12.2013, and alive per 31.12.2015. The population was drawn in 2013, as recommended by the NAV registry, which considers 2013 to be a year with a high number of registered diagnoses of intellectual disabilities.

In Norway, a diagnosis of intellectual disability is defined by the International Classification of Diseases version 10 (ICD-10) (World Health Organization, 2016) and determined by a health care specialist. For the aims of this study, only diagnoses with a high probability of intellectual disability were included: mental retardation (F70–F79), disorders of psychological development (F84.0, F84.1, F.84.2, and F84.4), Down syndrome (Q90), chromosomal abnormalities, and disorders not classified elsewhere with a high probability of intellectual disability (Q91.1–Q91.4).

People with intellectual disabilities registered as being involved in education as their main daytime activity (*n* = 188) were not considered relevant for the present study and were excluded from the analysis. The oldest age group (64 to 69 years) was excluded because of the likelihood of displacement in the age groups between the time of the inclusion in 2013 and the analysis of status in 2015, which indicated a possibility of retirees in this age group (*n* = 1,177). People in other types of facilitated employment (wage subsidies, work practice, and clarification of ability to work) (*n* = 40) were also excluded because the group included types of facilitation methods that differed and could not be compared.

Of those registered with community-based services, 377 (2.6%) people lacked any registration of their functional level. A comparison of models supported the model without that category. Thus, these 377 was excluded from the analysis.

Hence, the final sample included in the analyses comprised 12,735 people with intellectual disabilities, which corresponds to a response rate of 88% of the potential eligible population (Figure 1). The dataset analysed in this study had no missing values.

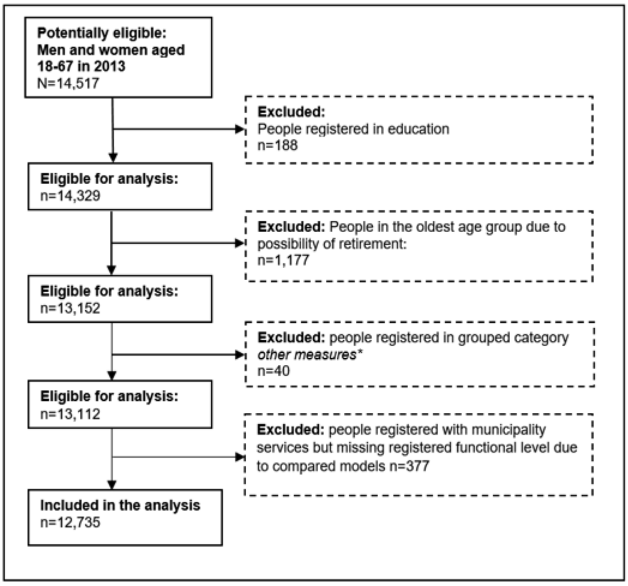

Figure 1. Flow-chart for study population

*Other measures included the following employment measures: wage subsidies, work practice and education, clarification of ability to work

FIGURE 1. Flowchart for study population

Study variables

Outcome variable

Since people with intellectual disability are mainly employed through employment services, employment type was defined as being registered in Statistics Norway as participants in sheltered and open employment. Sheltered employment is defined as individual facilitated work in a sheltered environment, whereas open employment is facilitated work with support in mainstream employment (Labour Market Act, 2004). In both work settings, workers are expected to meet certain production requirements and receive a limited salary in addition to their disability pension, subsidised by the Norwegian Labour and Welfare Administration (NOU, 2012: 6).

Day care centres are defined as publicly financed, community-based centres with daily activities registered in the Norwegian Information System for the Nursing and Care Sector (IPLOS). In Norway, day care centres provide services to people who need support for personal care, social support, activation, and training in activities of daily living (ADL), adapted to individual functional abilities (Norwegian Health and Care Service Act, 2011).

To avoid duplicate registrations of persons registered with more than one type of activity, the type of activity, that with the highest level of activity, was selected for the analyses. A total of 149 people was listed in both day care and sheltered employment and were registered with sheltered employment in the analyses. Fifteen were listed in both day care and open employment and were registered with open employment in the analyses.

The most recent year for employment status in Statistics Norway and participation in day care registered in IPLOS, both by 31.12.2015, was used for the main analyses, when the sample population was 20 to 63 years old.

The outcome variable had four levels: no registered employment/participation in day care, day care, sheltered employment, and open employment.

Predictor variables

The predictor variables were chosen based on prior evidence from research, theories about factors having a possible impact on employment, and the accessibility of data from the registries. All predictor variables were categorical and included age, gender, educational level, diagnosis of intellectual disability, and functional level. Age, gender and educational level were derived from SSB per 31.12.2015.

Educational level was grouped into three categories according to the highest completed level: *no education, primary and secondary school,* and *upper-secondary school or higher*. Primary and secondary school are hereafter referred to as low educational level and upper-secondary school or higher as high educational level.

Diagnosis of intellectual disability was defined as a registered diagnosis of intellectual disability being the cause for a disability pension. The diagnoses were grouped into five categories by SSB: *mild* (F70), *moderate* (F71), *severe/profound intellectual disability (*F72 and F73) (hereafter referred to as severe), *unspecified intellectual disabilities* (F78–79, F84.0–F.84.2, F84.4, and Q91.1–Q91.4) or *Down syndrome* (Q90). The group with unspecified disabilities included people with the diagnoses *unspecified* and *other intellectual disabilities* (88 %) as well as diagnoses with few individuals in order to secure anonymity (12 %). Of note, Down syndrome differs from the other diagnostic groups of intellectual disabilities as the other diagnoses describe either the degree of intellectual disability or is unspecified. In contrast, people with Down syndrome are registered within the same group, although they may have different degrees of intellectual disability.

Functional level is registered (in IPLOS) for people who receive community-based services by assessing their ability to perform different activities of daily living regardless of diagnosis. These registrations include assessments of difficulties in social functioning, cognitive function, self-care and ability to perform household tasks. The overall functional level is scored according to three main groups, high (≤2), moderate (>2–3) and low functional level (>3), by means of the total score of all questions (scored 1–5, *no difficulty* to *extreme difficulty*). Since day care is a community-based service, a functional level is registered for all people in day care. A functional level for people in employment with support is registered only if they receive any other community-based services (Proba, 2016). In our dataset, 27 % (3,444 of

12,735) of those with intellectual disabilities do not receive community-based services and consequently are not registered with a functional level. Therefore, a fourth category of people not registered with a functional level was added, which means they are not registered with community-based services.

Statistical methods

To assess the association between predictor variables and the four-level employment status outcome variable, a multinomial logistic model was applied, using employment type or participation in day care as the reference. Results are presented as odds ratios (OR). All predictor variables were included to control for confounding. Two-tailed p-values less than 5 % were considered significant. A sub-analysis with Down syndrome coded as a dichotomous variable (yes/no) was performed.

Interactions between functional level and age group, and between functional level and diagnosis were also tested by using the Hosmer–Lemeshow goodness-of-fit test, which supported the exclusion of both interactions. The goodness-of-fit test also supported simplifying the model by treating age as a continuous variable in the analyses.

Post-tests showed that the model in the analyses contributed to 34% of the precision in employment and participation in day care for people with intellectual disabilities (Nagelkerke's $R^2 = 0.34$), while the validity test for the model gave no indication to reject the model (Hosmer–Lemeshow $p > .01$).

All analyses were performed in STATA/IC version 15.1.

Results

Descriptive statistics

Of the total sample of 12,735 (45% women), 22.2% were registered in day care, 23.4% in sheltered employment, 2.7% in open employment, and 51.7% neither employed nor in day care (Table 1). Employment/day care participation decreased with age. The prevalence of people in sheltered employment decreased by 10 percentage points from the youngest age group (age 20–26) to the oldest (age 58–63). Compared to sheltered employment and day care, the prevalence of people in open employment was significantly lower, with 5.7% in the youngest age group and only 0.3% in the oldest age group attending open employment. Women were more likely to be in day care than men, whereas men were more often employed in sheltered workshops compared to women.

Most people with intellectual disability (77,8%) had education at the primary and secondary school level only. Under 0.1% were registered with a level of upper-secondary school or higher, and 68.2% in this group were registered neither as employed nor as participants in day care. Under 0.2% were registered with no education.

Among the participants, 54.8% were diagnosed with an unspecified intellectual disability. The prevalence of not being registered in employment or day care was highest for people with mild intellectual disability (66.4%) and lowest for people with Down syndrome (26.2%).

Of those registered with high functional levels, 55.4% were registered as neither employed nor in day care. The prevalence for moderate and low functional levels were almost the same (38.8% and 39.4%, respectively). The rate of people registered as neither employed nor in day care was especially high among those without a registered functional level (79.8%).

TABLE 1. Frequencies in different types of employment and day care regarding all predictor variables

† Registered in day care not possible without registered functional level

		Employment type									
		Neither employed/ nor in day care		Daycare		Sheltered employment		Open employment		Total	
		n	%	n	%	n	%	n	%	n	%
Total		6580	51.7	2822	22.2	2984	23.4	349	2.7	12735	100
Age group	20-26	866	41.5	589	28.2	515	24.7	118	5.7	2088	100
	27-31	630	42.5	326	22.0	442	29.8	85	5.7	1483	100
	32-36	624	46.4	302	22.5	380	28.3	39	2.9	1345	100
	37-41	750	51.0	321	21.8	370	25.1	31	2.1	1472	100
	42-46	893	54.8	340	20.9	373	22.9	23	1.4	1629	100
	47-51	843	55.6	294	19.4	352	23.2	26	1.7	1515	100
	52-57	966	57.8	356	21.3	327	19.6	22	1.3	1671	100
	58-63	1008	65.8	294	19.2	225	14.7	5	0.3	1532	100
Gender	Women	3017	52.7	1307	22.8	1258	22.0	147	2.6	5729	100
	Men	3563	50.9	1515	21.6	1726	24.6	202	2.9	7006	100
Education	≥ Upper-secondary	617	68.2	85	9.4	178	19.7	25	2.8	905	100
	Primary school	5108	51.5	1962	19.8	2545	25.7	296	3.0	9911	100
	No education	855	44.6	775	40.4	261	13.6	28	1.5	1919	100
Diagnosis of intellectual disability	Mild	1468	66.8	136	6.2	482	21.9	112	5.1	2198	100
	Moderate	251	48.9	91	17.7	144	28.1	27	5.3	513	100
	Severe	868	47.5	650	35.6	302	16.5	8	0.4	1828	100
	Unspecified	3675	52.6	1507	21.6	1631	23.4	170	2.4	6983	100
	Down syndrome	318	26.2	438	36.1	425	35.0	32	2.6	1213	100
Functional level	High	672	55.4	92	7.6	394	32.5	56	4.6	1214	100
	Moderate	1361	38.8	630	18.0	1369	39.1	145	4.1	3505	100
	Low	1800	39.4	2100	45.9	634	13.9	38	0.8	4572	100
	Not registered	2747	79.8	-[†]	-[†]	587	17.0	110	3.2	3444	100

Predictors of employment and participation in day care

Older age was negatively associated with participation in employment and day care, especially participation in open employment (Table 2). For men, the odds of being in day care was lower than for women (OR = 0.86, 95% confidence interval (CI) 0.78, 0.96) and higher for participation in sheltered employment (OR = 1.16, 95% CI 1.06, 1.28). No significant gender differences were found regarding attendance in open employment.

Education was inversely associated with the odds of being registered in day care and sheltered employment; compared to people with high educational level, the odds for people with low were higher for being registered in day care (OR = 1.44, 95% CI 1.11, 1.88) and sheltered employment (OR = 1.23, 95% CI 1.02, 1.48). People registered without education had a higher odds of participating in day care and lower odds of sheltered and open employment. People with upper-secondary school education or higher had a lower odds of being registered in sheltered employment compared to those with primary or secondary school education. There were no significant differences in participation in open employment for people with upper-secondary school education or higher compared to those with primary and secondary school or no education.

Compared to people with mild intellectual disability, those with other diagnoses of intellectual disability had higher odds of attendance in day care and sheltered employment. Severe intellectual disability and Down syndrome were the diagnoses with the highest odds of attendance in day care. People with Down syndrome had three times higher odds for participation in sheltered employment than those registered with mild intellectual disability (OR = 3.03, 95% CI 2.50, 3.67). There were no significant differences in open employment between the diagnoses.

People with a low or moderate functional level had higher odds of being registered in day care than those with a high functional level, with 6 times higher odds for those with a low functional level (95% CI 4.78, 7.63) and 2.8 times higher odds for those with a moderate functional level (95% CI 2.19, 3.54). Moderate versus high functional level was associated with higher odds for sheltered employment (OR = 1.45, 95% CI 1.25, 1.68). People with a low functional level had lower odds for sheltered employment (OR = 0.49, 95% CI 0.43, 0.60). Indeed, compared to people with a high functional level, those without a registered functional level had lower odds of sheltered employment (OR = 0.38, 95% CI 0.32, 0.44) and open employment (OR = 0.5, 95% CI 0.35, 0.69). People with low functional levels had the lowest odds of being registered in open employment. There was no significant difference in participation in open employment between those with high and moderate functional levels.

TABLE 2. Odds ratio of being registered in employment types and day care compared to not employed or in day care, fully adjusted for all predictor variables

	Day care			Sheltered employment			Open employment		
	OR	95% CI	p-value	OR	95% CI	p-value	OR	95% CI	p-value
Age	0.89	0.87–0.91	<0.001	0.90	0.87–0.92	<0.000	0.69	0.65–0.73	<0.000
Gender									
Women †	-	-	-	-	-	-	-	-	-
Men	0.86	0.78–0.96	0.005	1.16	1.06–1.28	0.001	1.19	0.95–1.49	0.121
Education									
≥ Upper secondary school †	-	-	-	-	-	-	-	-	-
Primary and Secondary school	1.44	1.11–1.88	0.007	1.23	1.02–1.48	0.027	0.78	0.51–1.20	0.265
No	1.78	1.35–2.36	<0.001	0.83	0.66–1.06	0.131	0.62	0.35–1.11	0.111
Diagnosis of ID ‡									
Mild ID†	-	-	-	-	-	-	-	-	-
Moderate ID	1.56	1.13–2.15	0.007	1.49	1.17–1.89	0.001	1.29	0.82–2.02	0.257
Severe ID	3.12	2.42–4.03	<0.001	1.65	1.34–2.03	<0.000	0.73	0.33–1.60	0.433
Unspecified ID	2.41	1.96–2.96	<0.001	1.47	1.29–1.67	<0.000	1.02	0.78–1.33	0.881
Downs syndrome	3.83	3.00–4.89	<0.001	3.03	2.50–3.67	<0.000	1.37	0.89-2.11	0.157
Functional level									
High †	-	-	-	-	-	-	-	-	-
Moderate	2.79	2.19–3.54	<0.000	1.45	1.25–1.68	<0.000	1.03	0.74–1.44	0.860
Low	6.04	4.78–7.63	<0.000	0.51	0.43–0.60	<0.000	0.23	0.15–0.35	<0.000
Not registered	- §	- §	- §	0.38	0.32–0.44	<0.000	0.50	0.35–0.69	<0.000

† Reference categories in the analysis
‡ ID = Intellectual disability
§ Registered in day care not possible without registered functional level

For people with Down syndrome, compared to other diagnoses of intellectual disabilities, the odds were 1.7 times higher of being registered as a participant in day care (95% CI 1.47, 2.03) and 2.2 times higher of being registered in sheltered employment (95% CI 1.86, 2.57).

Discussion

This large, national and registry-based study including adults with intellectual disabilities in Norway found low rates of employment and day care participation, which is in line with related international studies (Lysaght et al., 2015; Taanila et al., 2005). However, to our knowledge, no fully comparable research exists using national registry data and combining the association of employment, educational level, diagnosis of intellectual employment and functional level.

One important reason for the low rates of employment and day care participation in Norway might be the automatic granting of disability pension for people with intellectual disabilities (Wendelborg & Tøssebro, 2018). Although national policy is focussed on activation and inclusion, people who receive a disability pension are not required to engage in activation measures. Even in the organisation of day care, activities are not clearly defined. A clearer and more consistent definition of the content of activities in day care may provide more predictable and meaningful activities for people with intellectual disabilities. Most employed peoples with intellectual disabilities participate in sheltered employment. In Norway, there are far fewer jobs in sheltered workshops than there are people with a need for such supported employment. In addition, many sheltered workshops have a high production requirement, which may increase competition for candidates in sheltered employment. Among people with intellectual disabilities, those whose diagnoses involving a potentially higher capacity for production may be preferred (Brage & Thune, 2015; Engeland & Langballe, 2018).

Similar to the situation of the general population, our research confirms that older age decreases opportunities for employment. This might be a result of the naturally decreasing ability to work at an advanced age, but it may also be a result of newer, more inclusive policies that younger people now might benefit from (NOU, 2016: 17). Nevertheless, meaningful activities in life still impact the quality of life for elderly people, including people with intellectual disabilities, and should be strived for (Eakman, Carlson, & Clark, 2010; Engeland, Kittelsaa, & Langballe, 2018).

Our findings on gender differences in day care and sheltered employment are supported by McDermott's (1999) study on gender differences in employment, with higher attendance in day care for women than men, while more men were registered in sheltered employment. Research on employment for people with disabilities in general also finds lower employment rates for women than men (Kavanagh et al., 2015). Traditionally, activities in day care have been characterised by crafts (Olsen, 2009), while sheltered employment additionally includes manual work and small-scale industrial production (Mandal, 2008). This distinction might be one reason for the gender difference in employment among people with intellectual disabilities. These inequalities seem old fashioned and may constitute part of the prejudice and stigmatisation regarding what people with intellectual disabilities are capable of performing.

Previous research found higher employment rates for people with intellectual disabilities with upper-secondary school education (Papay & Bambara, 2013; Shandra & Hogan, 2008). Our results revealed challenges in obtaining employment for people with high education, especially in open employment. However, the variable was highly skewed towards low educational level (*n* = 9,911). This may have affected our results on association between educational level and participation in daily activities. Nevertheless, the groups registered with high educational level and no education were of sufficient size (high educational level; *n* = 905, no education; *n* = 1,919) to give us some indication that that the transition from upper-secondary school to employment is one of the barriers to employment for people with intellectual disability, which is also supported by other studies (Lysaght et al., 2012; Papay & Bambara, 2013; Shandra & Hogan, 2008). Additionally, several studies have shown that work experiences during upper-secondary school are significantly positively associated with competitive employment (Carter, Austin, & Trainor, 2012; Gold, Fabian, & Luecking, 2013; Joshi, Bouck, & Maeda, 2012;

LoBlanco & Kleinert, 2013; Papay & Bambara, 2013). This indicates that a more-flexible transition from school to employment might contribute to higher employment rates for people with intellectual disabilities.

Our results indicate that access to sheltered employment and day care differs among people according to their specific intellectual disability diagnoses. We may assume that the degree of intellectual disability is associated with the ability to work, indicating that work in open employment is more accessible for people registered with mild intellectual disabilities. Still, the results show that people with mild intellectual disabilities have fewer opportunities for activation in day care and employment compared to other diagnoses of intellectual disability. The result showing no significant differences in the likelihood of open employment based on the degree of intellectual disability is, therefore, surprising.

Additionally, a diagnosis of Down syndrome increases the probability of employment, especially for sheltered employment. The higher employment rate for this group be influenced by the case that Down syndrome is often a visual disability, in which chances of being registered in the municipality are higher and that an assessment of their functional level is therefore performed. Among the general population, Down syndrome is also one of the most well-known intellectual disabilities, which may also affect opportunities for work (Bittles, Bower, Hussain, & Glasson, 2007; Nota, Santilli, Ginevra, & Soresi, 2014). This indicates a stigmatisation of people with other diagnosis of intellectual disabilities by decision-makers or employers. The assessment of ability to work should always be based on the assessment of an individual's functional level and personal resources and not on the diagnosis.

The fact that employment was less likely for people with high functional levels and those without municipal services may indicate that employment for people with intellectual disabilities is not based on an assessment of functional level. The lack of such assessment may be a reason for the low employment rate for this group. Eagar et al. (2006) found that a short screening by teacher for ADL and behaviour before leaving school was sufficient to stream people with disabilities into a range of transition-to-work programmes. This indicates that a more systematic screening of functional level before leaving school might predict a higher employment rate for people with intellectual disabilities. Our study indicates that more people with intellectual disabilities have the capacity to perform work, probably in the open labour market, and this is supported by previous research by Martorell et al. (2008).

Implications for research

Although our findings show a very low probability of people with intellectual disabilities finding work in mainstream employment even with support, previous research differs regarding disabilities have the best employment practices for people with intellectual disabilities. Whereas Burge, Ouellette-Kuntz and Lysaght (2007) found that integrated employment was preferred in Canada, Reinertsen (2015) found no differences between employment with support in mainstream employment and sheltered employment in self-reported quality of life for people with intellectual disabilities in Norway. Further studies are needed on individual wishes and needs, on work and activities for people with intellectual disabilities, quality of life in different work settings, and self-determination in the employment process or other activities.

Future studies should also include more variables in order to provide a more complete picture of the topic. For instance, a study from the US reported that one of the most important predictors of the employment of people with intellectual disabilities is family expectations of employment when finishing school (Papay & Bambara, 2013). Cultural diversity, discrimination and engrained stereotypes about productivity might be barriers to employment. Further studies on these topics are needed. Additionally, research with a more intersectional perspective is warranted, as it would combine relevant aspects of employment to gain more specific insight to the role of group diversities in employment.

Strengths and limitations

The main strength of this study is its large, registry-based dataset with no missing values, including the total population of adults registered with intellectual disabilities in Norway. That consideration makes the study generalisable to Norway. Differences between countries in organising work for people with intellectual disabilities may complicate the possibilities of comparison. However, there are similarities among Nordic countries regarding employment and day care for people with intellectual disabilities, and therefore these results may be generalised with caution.

However, a limitation is that the number of unregistered cases with intellectual disabilities in Norway is unknown. People on the borderline for a diagnosis of intellectual disability are especially difficult to identify (Maulik, Mascarenhas, Mathers, Dua, & Saxena, 2011; Søndenaa, Rasmussen, Nøttestad, & Lauvrud, 2010). Additionally, only people registered in sheltered employment, open employment or community-based day care centres were included.

In general, there is a low probability of error in registry-based data, and a test of those errors in Statistics Norway’s event database was revealed to be low, which increases the reliability of the study’s results. The functional level is theoretically registered the same way in all municipalities, but there still might be some differences in the assessment and registrations. As a result of the exclusion of the oldest age group, the study lacks information on people above 63 years, which is also a limitation.

Norway has a welfare system that ensures welfare for its inhabitants, where laws and regulations secure the same rights for education and employment. Support systems and activisation services might vary between countries, and therefor the results are not generalisable to countries without the same codes and welfare system.

Despite these limitations, the results of the present study indicate the factors associated with employment status and participation in day care for people with intellectual disabilities.

Conclusion

This registry-based study among people with intellectual disabilities found that being registered as employed or in day care was associated with younger age, and differs by gender and diagnosis of intellectual disability, but not by educational level. Attendance in day care was more likely for women, while men were more likely to work in sheltered employment. People with a diagnosis of Down syndrome were more likely to be employed than adults with other diagnoses of intellectual disability. High functional level or not having one’s functional level registered lowered the likelihood of employment regardless of diagnosis. This study underscores that people with intellectual disabilities are rarely included in work-related activities aimed towards mainstream employment.

This study suggests systematic inequalities regarding age, functional level, gender and diagnosis of intellectual disabilities for the possibilities of employment and day care participation among people with intellectual disabilities in Norway. Standardised assessments of ability to work and improved routines for the transition from school to employment might increase the employment rate among this group. National and local studies are needed to identify those differences that policy-makers should address to ensure equal access to employment and day care for adults with intellectual disability.

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Appendix A

Written informed consent

Study I

Samtykkeskjema

Utviklingshemning og avgang fra yrkeslivet

Prosjektleder: Jeanette Engeland,
Tlf: 922 32 492
E-post: jeanette.engeland@aldringoghelse.no

Tenk igjennom før du bestemmer deg.
Andre vil ikke kjenne deg igjen i det som blir skrevet og sagt.
Lydopptakene vil bli lagt trygt inn på data
De slettes når prosjektet er ferdig.
Vennligst svar på setningene under.
Skriv under og gi arket tilbake til Jeanette,
enten på første møte eller før intervjuet.

Jeg vil være i prosjektet.	☐ **Ja**	☐ **Nei**
Jeg har fått informasjon både på ark og noen har fortalt meg om det.	☐ **Ja**	☐ **Nei**
Jeg har forstått informasjonen.	☐ **Ja**	☐ **Nei**
Jeg har forstått at jeg kan angre på deltagelse og at jeg ikke trenger å si hvorfor.	☐ **Ja**	☐ **Nei**
Jeg er enig i at intervjuene kan tas opp på lydopptaker	☐ **Ja**	☐ **Nei**
Jeg har snakket med noen jeg stoler på om at jeg sier ja til å være med	☐ **Ja**	☐ **Nei**

Min underskrift: ____

Underskrift til personen jeg har snakket med om at jeg vil være med:

____

Sted: ______________________ Dato: ______________________

Aldring og helse
Nasjonalt kompetansesenter

Appendix B

Information on project. Easy-to-read version

Study I

Å slutte på jobben

Hvordan er det å slutte å jobbe?
Dette vil jeg og mange andre
vite mer om.

Jeg vil snakke med deg som
sluttet å jobbe for ett til to år siden.
Jeg vil intervjue deg
for å lære mer om det å bli pensjonist.

Dette lurer jeg på:
Hva jobbet du med?
Hvordan var det å jobbe?
Hvordan har du det nå?

Det vi sier tas først opp på lydopptaker.
Så skriver jeg det inn på data.
Etterpå fjerner jeg det fra lydopptakeren.

Jeg kommer hjem til deg.
Du kan ha med en du kjenner godt.
Du bestemmer selv om du vil være med.

Vil du være med?
Ring meg eller skriv en e-post.
Telefonnummer og adresse står på neste side.

Jeg forteller mer om intervjuene.
Hvis du blir med, må du skrive under på et skjema.
Det er lov å si nei senere.
Da vil alt du har sagt bli fjernet.

Det du og mange andre forteller meg
skal jeg skrive i en liten bok.
Denne kan du og de du kjenner lese.
Den skal være ferdig 1. september 2014.
Jeg vil også fortelle om dette på kurs.
Jeg skal ikke fortelle eller skrive navnet ditt.

Ring meg hvis du lurer på noe.
Ring meg hvis du vil snakke.

Jeg håper du vil snakke med meg.
Jeg gleder meg til å treffe deg.

Vennlig hilsen
Jeanette Engeland
Tlf: 922 32 492
E-post: jeanette.engeland@aldringoghelse.no

Appendix C

Information on project. Version for caregivers and guardians

Study I

Utviklingshemning og avgang fra yrkeslivet

Flere personer med utviklingshemning blir i dag eldre. Vi vet for lite om hvordan det er for personer med utviklingshemning å slutte å jobbe; om det å bli *pensjonist*. Med pensjonist mener vi her personer som har sluttet å jobbe og trenger ikke være ved tradisjonell pensjonsalder. Prosjektet har som mål å få en økt forståelse av hvordan personer med utviklingshemning opplever det å slutte i varig tilrettelagt arbeid.

Vi vil derfor snakke med personer med utviklingshemning som har jobbet i varig tilrettelagt arbeid, men har sluttet for ett til to år siden.
De vil bli intervjuet og vi vil gjerne vite litt mer om hvilken jobb de hadde, hvordan de hadde det da de jobbet og hvordan de har det nå.

Dersom du kjenner til noen som kan være aktuelle for en slik studie bes du kontakte prosjektleder. Vi avtaler deretter et møte med vedkommende og en tillitsperson.
De vil få mer informasjon om prosjektet og han/hun kan bestemme seg om de ønsker å delta. De kan få betenkningstid.

Deltagerne bestemmer selv om de vil gjøre intervjuet alene eller om de vil ha noen med seg. Intervjuene vil foregå i deltagerens hjem. Vi ønsker å ta lydopptak av intervjuet. Dette blir lagret trygt på en datamaskin og slettes fra lydopptaker. Lydopptakene blir skrevet ut i tekstbehandlingsprogram og sammenlignet med de andre som har blitt intervjuet.

Alle opplysninger som blir samlet inn vil bli lagret uten personopplysning (avidentifisert). Det er kun 3 prosjektarbeidere som har tilgang til opplysningene. Personer som ønsker å delta kan når som helst trekke seg fra undersøkelsen, uten begrunnelse. Alle opplysninger vil da bli slettet umiddelbart.

Resultatet blir skrevet i en prosjektrapport og i artikkel. En lettlest rapport vil også bli utarbeidet. Deltagerne får alt publisert materiell. Det vil bli informert om prosjektet på konferanser og i kurs, uten personopplysninger. Forventet sluttdato for prosjektet er 01.09.2014.

Personer som ønsker å delta må han/hun fylle ut et samtykkeskjema sammen med en tillitsperson. Dette for å sikre at informasjon som er gitt er forstått.

Deltager og tillitsperson står fritt til å kontakte prosjektleder ved spørsmål eller behov for å snakke.

Vennlig hilsenJeanette Engeland
Tlf:: 922 32 492
E-post: jeanette.engeland@aldringoghelse.no

Aldring og helse
Nasjonalt kompetansesenter

Appendix D

List of included and excluded diagnoses of intellectual disabilities

Paper III

Inkluderte diagnoser i kobling av registerdata

Kategorisert	ICD-10	Diagnose	Spesifisert Diagnose	ICD9
Lett grad av utviklingshemning	F70	Lett psyk. utvh.		3170-317X
	F70.0	Lett psyk. utvh.	Ingen eller minimale atferdsproblemer	3170-317X
	F70.1	Lett psyk. utvh.	Betydelige atferdsproblemer som krever oppmerksomhet eller behandling	3170-317X
	F70.8	Lett psyk. utvh.	Andre spesifiserte atferdsproblemer	3170-317X
	F70.9	Lett psyk. utvh.	Uten beskrivelse av atferdsproblemer	3170-317X
Moderat grad av utviklingshemning	F71	Moderat ps. Utvh.		3180
	F71.0	Moderat ps. Utvh.	Ingen eller minimale atferdsproblemer	3180
	F71.1	Moderat ps. Utvh.	Betydelige atferdsproblemer som krever oppmerksomhet eller behandling	3180
	F71.8	Moderat ps. Utvh.	Andre spesifiserte atferdsproblemer	3180
	F71.9	Moderat ps. Utvh.	Uten beskrivelse av atferdsproblemer	3180
Dyp/alvorlig grad av utviklingshemning	F72	Alvorlig		3181
	F72.0	Alvorlig	Ingen eller minimale atferdsproblemer	3181
	F72.1	Alvorlig	Betydelige atferdsproblemer som krever oppmerksomhet eller behandling	3181
	F72.9	Alvorlig	Uten beskrivelse av atferdsproblemer	3181
	F73	Dyp ps. utvh.		3182
	F73.0	Dyp ps. utvh.	Ingen eller minimale atferdsproblemer	3182
	F73.1	Dyp ps. utvh.	Betydelige atferdsproblemer som krever oppmerksomhet eller behandling	3182
	F73.9	Dyp ps. utvh.	Uten beskrivelse av atferdsproblemer	3182
Downs syndrom	Q90.0	Kromosomavvik	Downs syndrom	7580-7580
	Q90.1	Kromosomavvik	Trisomi 21, mosaikk (mitotisk nondisjunksjon)	7580-7580
	Q90.9	Kromosomavvik	Uspesifisert Downs syndrom	7580-7580
Uspesifisert utviklingshemning	F78	Annen ps. utvh.		3189-319X
	F78.0	Annen ps. utvh.	Ingen eller minimale atferdsproblemer	3189-319X
	F78.1	Annen ps. utvh.	Betydelige atferdsproblemer som krever oppmerksomhet eller behandling	3189-319X
	F78.8	Annen ps. utvh.	Andre spesifiserte atferdsproblemer	3189-319X
	F78.9	Annen ps. utvh.	Uten beskrivelse av atferdsproblemer	3189-319X
	F79	Uspes ps. utvh.		3189-319X
	F79.0	Uspes ps. utvh.	Ingen eller minimale atferdsproblemer	3189-319X
	F79.1	Uspes ps. utvh.	Betydelige atferdsproblemer som krever oppmerksomhet eller behandling	3189-319X
	F79.8	Uspes ps. utvh.	Andre spesifiserte atferdsproblemer	3189-319X
Uspesifisert utviklingshemning	F79.9	Uspes ps. utvh.	Uten beskrivelse av atferdsproblemer	3189-319X
	F84.0	Autisme o.a.	Barneautisme	2990-2999
	F84.1	Autisme o.a.	Atypisk autisme	2990-2999
	F84.2	Autisme o.a.	Retts syndrom	2990-2999
	F84.4	Autisme o.a.	Forstyrrelse med overaktivitet forbundet med psykisk utviklingshemming og bevegelsesstereotypier	2990-2999
	Q91.1	Kromosomavvik	Edwards' syndrom og Pataus syndrom - Trisomi 18, mosaikk (mitotisk nondisjunksjon)	7580-7580
	Q91.2	Kromosomavvik	Trisomi 18, translokasjon	7580-7580
	Q91.3	Kromosomavvik	Uspesifisert Edwards' syndrom	7580-7580
	Q91.4	Kromosomavvik	Trisomi 13, meiotisk nondisjunksjon	7580-7580

Ekskluderte diagnoser på grunn av usikkerhet rundt utviklingshemning

F84	Autisme o.a.	Autisme	2990-2999
F84.3	Autisme o.a.	Annen disintegrativ forstyrrelse i barndommen	2990-2999
F84.5	Autisme o.a.	Asbergers syndrom	2990-2999
F84.8	Autisme o.a.	Andre spesifiserte gjennomgripende utviklingsforstyrrelser	2990-2999
F84.9	Autisme o.a.	Uspesifisert gjennomgripende utviklingsforstyrrelse	2990-2999
Q92.1	Kromosomavvik	Andre trisomier og partielle trisomier av autosomer, ikke klassifisert annet sted – Trisomi, mosaikk (mitotisk nondisjunksjon)	7580-7580
Q92.3	Kromosomavvik	Mindre partiell trisomi	7580-7580
Q92.8	Kromosomavvik	Andre spesifiserte trisomier og partielle trisomier av autosomer	7580-7580
Q92.9	Kromosomavvik	Uspesifisert trisomi og partiell trisomi av autosomer	7580-7580
Q93.2	Kromosomavvik	Monosomier og delesjoner fra autosomer, ikke klassifisert annet sted - Kromosom erstattet med ring eller disentrisk kromosom	7580-7580
Q93.3	Kromosomavvik	Delesjon av kort arm på kromosom 4 Wolff-Hirschorns syndrom	7580-7580
Q93.4	Kromosomavvik	Delesjon av kort arm på kromosom 5 «Cri-du-chat»-syndrom	7580-7580
Q93.5	Kromosomavvik	Andre delesjoner av del av kromosom Angelmans syndrom	7580-7580
Q93.8	Kromosomavvik	Andre spesifiserte delesjoner av autosomer	7580-7580
Q93.9	Kromosomavvik	Uspesifisert delesjon av autosomer	7580-7580
Q95.8	Kromosomavvik	Balanserte rearrangementer og strukturelle markører, ikke klassifisert annet sted - Andre spesifiserte balanserte rearrangementer og strukturelle markører	7580-7580
Q96.8	Kromosomavvik	Turners syndrom - Andre spesifiserte varianter av Turners syndrom	7580-7580
Q96.9	Kromosomavvik	Uspesifisert Turners syndrom	7580-7580
Q97.0	Kromosomavvik	Andre kjønnskromosomavvik, kvinnelig fenotype, ikke klassifisert annet sted - Karyotype 47,XXX	7580-7580
Q98.0	Kromosomavvik	Andre kjønnskromosomavvik, mannlig fenotype, ikke klassifisert annet sted - Klinefelters syndrom karyotype 47,XXY	7580-7580
Q98.1	Kromosomavvik	Klinefelters syndrom, mann med mer enn to X-kromosomer	7580-7580
Q98.3	Kromosomavvik	Annen mann med 46,XX karyotype	7580-7580
Q98.4	Kromosomavvik	Uspesifisert Klinefelters syndrom	7580-7580
Q98.5	Kromosomavvik	Karyotype 47,XYY	7580-7580
Q98.8	Kromosomavvik	Annet spesifisert kjønnskromosomavvik, mannlig fenotype	7580-7580
Q98.9	Kromosomavvik	Uspesifisert kjønnskromosomavvik, mannlig fenotype	7580-7580
Q99.2	Kromosomavvik	Fragilt X-kromosom	7580-7580
Q99.8	Kromosomavvik	Andre spesifiserte kromosomavvik	7580-7580
Q99.9	Kromosomavvik	Uspesifisert kromosomavvik	7580-7580

Appendix E

Chronological list of process of access to the registry-based data

Study II and III

Chronological list of process of access to the registry-based data

Date	Process
18.06.2014	Original application and protocol sent REK
17.09.2014	Approval from REK, and exemption from the duty of confidentiality is granted in the project
19.11.2014	Application for data access sent to NPR and IPLOS
21.11.2014	New protocol and application of change sent to REK, due to changes in sample and variables.
20.02.2015	Approval from NSD
09.03.2015	Approval from REK
30.04.2015	Application sent to SSB, in line with approvals from REK and NSD
26.05.2015	Approval from NPR
08.12.2015	Application on access to IPLOS data, sent to SSB
03.02.2016	Meeting with SSB and IPLOS to clarify variables and ensure anonymity. Some changes were needed, and new application of changes were sent to REK and NSD some days after the meeting.
07.03.2016	New approval from REK
24.05.2016	New approval from NSD
27.06.2016	SSB requires application to the NAV registry on access to data an exemption of duty of confidentiality in research, despite the request for anonymous data. The application was sent NAV the following day
15.08.2016	Approval of exemption of duty of confidentiality received from NAV, and sent SSB
23.08.2016	SSB confirmed that all approvals are received and ready to receive and link data from the different registries.
02.05.2017	Data files received from SSB. Some errors in the coding was detected, and code lists with descriptions are missing
28.09.2017	Final clarifications of sample and coding in the data set received by SSB

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