UiT The Arctic University of Norway

Faculty of Health Sciences

Physical performance, physical and perceived health, and the use of healthcare services in a population of adults with intellectual disability

The North Health in Intellectual Disability (NOHID) study

Monica Isabel Olsen

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Table of Contents

List of Tables

List of Figures

Abbreviations

P-15	POMONA 15 Health indicators
CP	Cerebral palsy
ASD	Autism spectre disorders
WHO	World health organization
ICD	International Statistical Classification of Diseases and Related Health Problems
CVD	Cardiovascular disease
IP	Individual Plan
GP	General practitioner
NOHID study	North Health in Intellectual Disability study
CHARM	Research Centre for Habilitation and Rehabilitation Models and Services, University of Oslo.
REDCap	Research Electronic Data Capture
SPPB	The Short Physical Performance Battery
TUG	The timed up- and-go test
OLS	The one-legged stance test
BMI	Body mass index
ABC-C	The aberrant behaviour checklist
GMFCS	Gross motor classification system
CFCS	Communication Function Classification System
OR	Odds ratio

List of papers

The following three manuscripts are included in this dissertation:

Paper I.

Monica Isabel Olsen, Marianne Berg Halvorsen, Erik Søndenaa, Bjørn Heine Strand, Ellen Melbye Langballe, Anders Årnes, Henriette Michalsen, Frode Kibsgaard Larsen, Wenche Gamst, Erik Bautz-Holter, Audny Anke. (2022). Factors associated with non-completion of and scores on physical capability tests in health surveys: The North Health in Intellectual Disability Study. *Journal of Applied Research in Intellectual Disabilities*, *35*(1), 231-242. https://doi.org/10.1111/jar.12942

Paper II.

M.I. Olsen, M.B. Halvorsen, E. Søndenaa, E.M. Langballe, E. Bautz-Holter, E. Stensland, S. Tessem & A. Anke. (2021). How do multimorbidity and lifestyle factors impact the perceived health of adults with intellectual disabilities? *Journal of Intellectual Disability Research*, *65*, 777-783. https://doi.org/10.1111/jir.12845

Paper III.

Monica Isabel Olsen, Eric Søndenaa, Ellen Melbye Langballe, Marianne berg Halvorsen, Per Wilhelmsen, Erik Bautz-Holter, Audny Anke. Use of health and dental care services in adults with intellectual disability in relation to age and intellectual disability levels. *In review*.

During the Ph.D. period I have also contributed to the following paper:

Michalsen, Henriette, Wangberg, Silje Camilla, Hartvigsen, Gunnar, Jaccheri, Letizia Muzny, Miroslav, Henriksen, André, Olsen, Monica Isabel, Thrane, Gyrd, Jahnsen, Reidun Birgitta, Pettersen, Gunn, Arntzen, Cathrine, Anke, Audny. (2020). Physical activity with tailored mHealth support for individuals with intellectual disabilities: Protocol for a randomized controlled trial. *JMIR research protocols*, *9*, e19213-e19213. https://doi.org/10.2196/19213

Abstract

Background and aim: People with intellectual disabilities have poorer physical and perceived health and less healthcare services access than the general population. Health-related aspects in adults with intellectual disabilities are under-investigated. Accordingly, this study aimed to investigate factors associated with non-completion of and scores on physical performance tests, physical and perceived health, as well as access to healthcare services in Norwegian adults with intellectual disabilities.

Methods: The North Health in Intellectual Disability (NOHID) study was a multicentre cross-sectional community-based study that used the POMONA-15 health indicators for data collection and some additional measures. In addition, the substudy which only involved participants from Tromsø, comprised the following physical performance tests: the Short Physical Performance Battery (SPPB), the Timed Up-and-Go (TUG) test and the One-Legged Stance (OLS) test. Body mass index (BMI) was measured.

Results: In the substudy, the completion rates for one or more of the measurements or tests among 93 Tromsø participants were 57%. Approximately 45% completed the SPPB and the TUG. The participants with a mean age of 34 years showed physical performance scores comparable with participants from the general population at the age of 80 years (paper I). In the main study, data from 214 participants in five municipalities in the north and central regions of Norway showed that multimorbidity was present in 79%, with weight disorders as the most frequent health condition. Obesity was more frequent in individuals with mild intellectual disability, whereas epilepsy and constipation were significantly more prevalent in individuals with severe intellectual disability. Perceived health was reported as 'good' by 79% of the subjects. A perceived health rating of 'poor' was associated with being a woman, intellectual disability level, number of physical health conditions, and lower motor functioning. A low activity level tended to negatively impact perceived health (paper II). The use of healthcare services was relatively high, although only 57% had undergone the recommended yearly health check in the preceding year. Cancer screening for women was rarely performed. Approximately half of the participants reported receiving specialised habilitation services the preceding year and very few had a functioning individual plan. The use of physiotherapy was low. As many as 94% had been to a dentist or dental nurse the preceding year, but 32% reported not having access to a dentist or dental nurse when needed. The experienced of poor dental health was reported by 39% (paper III).

Conclusion: The current study showed that despite recruitment problems it is feasible to conduct community-based health studies and physical capability tests in adults with intellectual disabilities in Norway. The study reveals a need to implement annual health checks as recommended in the national guidelines, with emphasis on individuals with more severe forms of intellectual disability. Physical performance was found to be poor among participants with intellectual disability, and tests should be part of annual health checks to monitor functional status and to guide prevention strategies. Women with intellectual disabilities, individuals with reduced motor function and those with more physical health conditions are at increased risk of lower perceived health. Also, a lack of physical activity tended to negatively influence perceived health. Therefore, more attention must be given to these individuals in terms of health-promotion efforts.

The quality of dental health care should be improved; although individuals with an intellectual disability made frequent use of dental care services, they still experienced poor dental health.

Health- promoting strategies involving the central lifestyle factors physical activity and nutrition should be prioritized for all adults with intellectual disabilities.

Norsk Sammendrag

Bakgrunn: Voksne med utviklingshemming har dårligere fysisk og selvrapportert helse og mindre tilgang til helsetjenester sammenlignet med generell befolkning. Dette har vært lite undersøkt i Norge.

Formål: Øke kunnskap om helse og fysisk funksjon hos voksne med utviklingshemming. Undersøke faktorer assosiert med gjennomføring av fysiske funksjonstester, samt fysisk og selvopplevd helse. Identifisere udekkede behov for helsetjenester.

Metode: Multisenter tverrsnittstudie med bruk av POMONA helseindikatorer. I en delstudie ble det målt kroppsmasseindex (KMI) og gjennomført fysiske funksjonstester: Short physical performance battery (SPPB), timed up-and-go (TUG) test, one-legged stance test (OLS).

Resultat: Delstudie: 93 deltakere, gjennomsnittsalder: 34.2 år, 58% menn. Over halvparten av deltakerne gjennomførte en eller flere målinger eller tester. Gjennomføringsrate for SPPB var 46%. Manglende gjennomføring var predikert av lav KMI og mer alvorlig grad av utviklingshemming. Testskårer var betydelig under referanseverdier for generell populasjon. Lavere skårer var assosiert med høyere alder, nedsatt grovmotorisk funksjon og mer alvorlig grad av utviklingshemming.

Hovedstudie: 214 deltakere, gjennomsnittsalder 36.1 år, 56% menn. Fordelingen av fysiske helsetilstander varierte med grad av utviklingshemming, 79% rapporterte multimorbiditet. Multivariate analyser viste signifikante assosiasjoner mellom dårlig selvrapportert helse og kvinnelig kjønn, dårligere grovmotorisk funksjon og flere fysiske helsetilstander. Mangel på fysisk aktivitet tenderte til å påvirke selvrapportert helse negativt.

Årlig helsesjekk ble gjennomført hos 57%. Flere deltakere med lett utviklingshemming enn med mer alvorlig grad hadde gjennomført helsesjekk og vært i kontakt med fastlege. Få (13%) hadde en fungerende individuell plan. Selv om 94% rapporterte at de hadde mottatt tannlegetjenester siste året, opplevede 39% dårlig tannhelse.

Konklusjon: Studien indikerte en lavere bruk av årlige helseundersøkelser enn anbefalt i nasjonale retningslinjer. Spesiell oppmerksomhet bør rettes mot personer med mer alvorlig grad av utviklingshemming. Fysiske funksjonstester bør inkluderes i helseundersøkelsene. Kvinner, de med redusert grovmotorisk funksjon, flere fysiske helsetilstander og lavt fysisk aktivitetsnivå, har økt risiko for dårligere selvopplevd helse. Kvaliteten på tannhelsetjenester

bør forbedres. Helsefremmende strategier innen livsstilsfaktorene fysisk aktivitet og kosthold bør prioriteres for alle personer med utviklingshemming.

1 Introduction

The current study which this thesis is based on is called the North Health in Intellectual Disability (NOHID) study. It was a population-based study of health, physical performance and health care services in youths and adults with intellectual disability in the northern and central regions of Norway. To our knowledge it was the first population-based study of its kind in the Nordic countries.

It is beneficial to first outline the historical background for the current organization of the services provided to individuals with intellectual disabilities. In Norway, individuals with intellectual disabilities were mostly confined to large institutions until the Responsibility Reform Act implemented deinstitutionalization between 1991–1996. The reform was initiated by the Lossius Committee, chaired by the psychiatrist Ole Petter Lossius. The intention was to give individuals with an intellectual disability better living conditions and quality of life. The main goal was to close large institutions and transfer the responsibility for individuals with intellectual disability from county municipalities (in Norwegian 'fylkeskommunen') to primary municipalities. The reform was based on the ideals of normalization and equal rights and intended to give individuals with intellectual disabilities the opportunity to choose where and how they wished to live and to participate in society in the same way as other people (Linaker & Nøttestad, 1998; Vik, 2021).

Deinstitutionalization is a term that is often used to describe the process of replacing long-term institutional care for people with intellectual disability with community care. This change started in the late 1960s in the United States, England, Canada, Australia, and Sweden (Chowdhury & Benson, 2011) and was effected in most Western countries during the last part of the twentieth century (Miettinen & Teittinen, 2014). The ideology behind this reform was the concept of normalization (Tøssebro et al., 2012), but policy and ideological differences within and between Western countries makes evaluation of its success difficult (Hall et al., 2021; Martínez-Leal et al., 2011).

In Norway today, the vast majority of adults with intellectual disabilities are cared for at home and their right to municipal health and care services is regulated by the Patient and User Rights law (Tøssebro & Wendelborg, 2019). The Lossius Committee argued that the quality of healthcare services in the institutions was poor and that it could not get worse in the primary municipalities. However, Linaker and Nøttestad (1998) monitored individuals with intellectual disability before and after they moved out of the institutions and reported poorer

physical and mental health for many of them after moving to the municipalities. Furthermore, they found that caregivers had inadequate knowledge of their clients' physical health and concluded that the organization of services for this group of clients' needed improvement (Linaker & Nøttestad, 1998; Nøttestad, 2004).

In the preceding decades, several international studies have shown that individuals with intellectual disabilities have poorer health and less access to health care services throughout life than the general population (Balogh et al., 2016; Emerson et al., 2016; Folch et al., 2018; Kinnear et al., 2018). Knowledge of how the health situation and health care services in Norway have been adapted for individuals with an intellectual disability is limited in Norway. The organization of such services is different in each country (Salvador-Carulla & García-Gutierrez, 2009). Several countries have national guidelines for following up on the health of people with intellectual disabilities (Casson et al., 2018; McConkey et al., 2015) but this was not true in Norway until recently (Norwegian Directorate of Health, 2021).

Health care services for individuals with intellectual disabilities have not been prioritized which is worrying considering the higher prevalence of lifestyle diseases compared with the general population (de Winter et al., 2012; McMahon & Hatton, 2020; Vis et al., 2012). Based on the four domains identified as health indicators in the European POMONA project (Perry et al., 2010) and inspired by the Figure 1 in Cocks et al. (2017), Figure 1 illustrates the health outcomes in this study and the possible impact of interconnected factors. As illustrated in the centre of Figure 1 this study focuses on the following health indicators as outcome variables: physical performance, physical health conditions, perceived health, and dental health, whereas the use of health and dental care services are investigated as part of the established health systems. Of further importance for health outcomes are the investigated lifestyle health determinants and the demographic factors of the participants with intellectual disabilities.

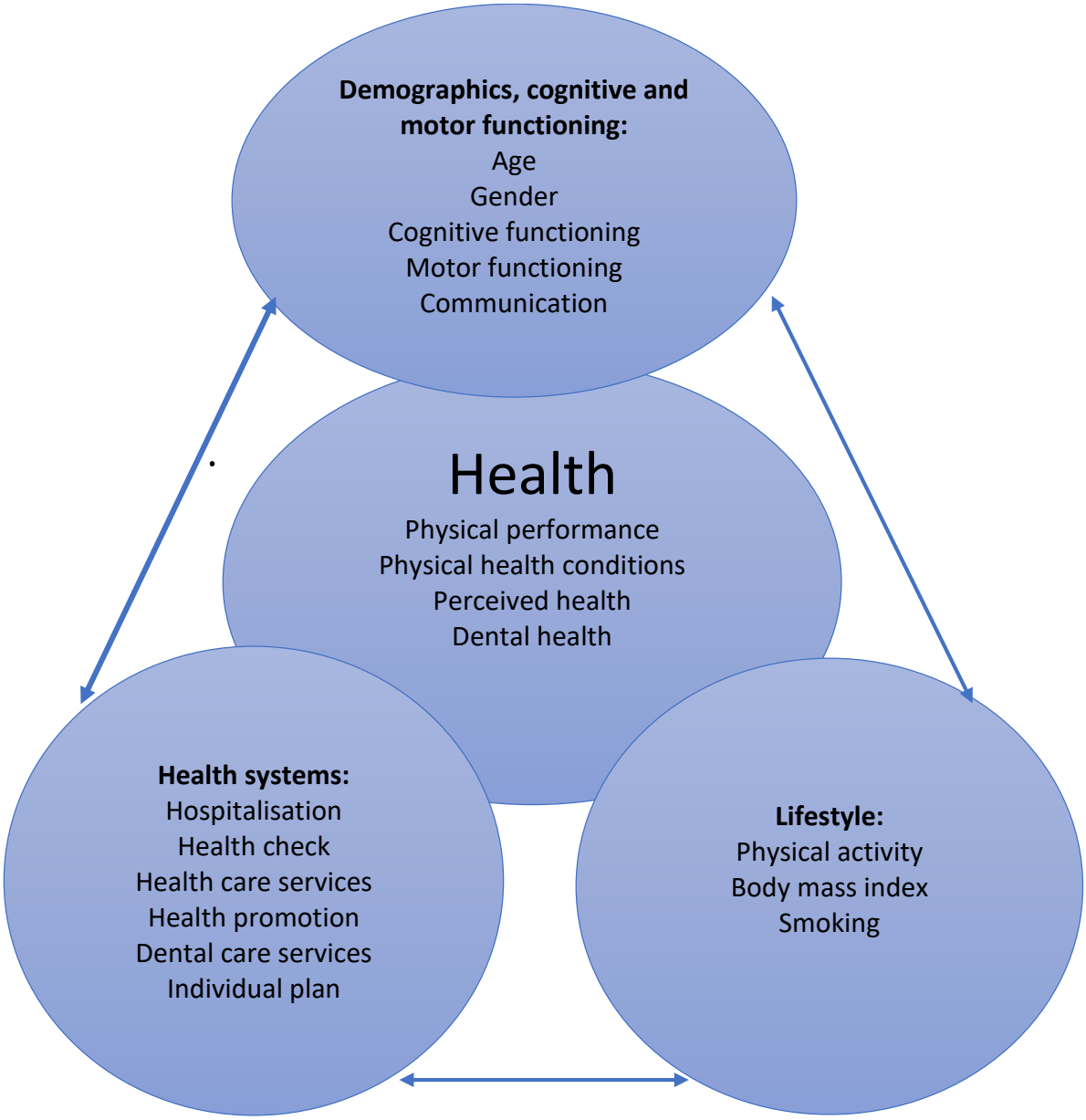

Figure 1. Health outcomes in the present study and possible interconnected factors.

1.1 The diagnosis of intellectual disability

Throughout the ages different terms have been used to describe people with congenital cognitive impairments. One such term was 'mental retardation', but it has been replaced by other terms, mainly 'intellectual disability'. An intellectual disability diagnosis requires 'significant limitations both in intellectual functioning and in adaptive behaviour as expressed in conceptual, social, and practical adaptive skills. This disability originates before age 18' (Schalock et al., 2010, p. 1). The intellectual functioning must be associated with more than two standard deviations below the population average (IQ < 70) (WHO, 2019). 'Developmental disabilities' is an umbrella term that includes other disabilities that are apparent during childhood in addition to eventual cognitive impairments (Schalock et al.,

2019). Other terms used for this condition are ‘intellectual developmental disability’ or ‘learning disability’(Carey et al., 2016; Schalock et al., 2019).

The prevalence of intellectual disability worldwide is estimated at between 1% and 3% of the general population with a male-to-female ratio of 2:1(Maulik et al., 2011; Patel et al., 2020). Although, in population-based studies, the reported percentages of adult male participants have varied between approximately 40%–57% (Cooper et al., 2015; Evenhuis et al., 2012; Folch et al., 2018; McCarron et al., 2017). The prevalence of individuals with intellectual disability in need of support in Norway is found to be 0.44% of the total population (Søndenaa et al., 2010). The aetiology of intellectual disability is mainly divided into genetic abnormalities and environmental exposure. For mild intellectual disability, some environmental and psychological risk factors have been reported (e.g. low socioeconomic status, residence in low-income countries, low maternal education, malnutrition, and inadequate access to healthcare), while a specific underlying genetic, biological or neurological reason, according to Patel et al. (2020), can be identified in 75% of individuals with severe intellectual disability. Chromosome defects, other genetic syndromes, brain malformations, neurodegenerative syndromes, congenital central nervous system infections, inborn errors of metabolism, maternal disease and exposure to toxins, and birth injury are the most common identified conditions (Patel et al., 2020). Cerebral palsy (CP) is a disorder of the development of movement and posture, causing activity limitations attributed to nonprogressive disturbances of the foetal or infant brain that may also affect sensation, perception, cognition, communication, and behaviour’ (Richards & Malouin, 2013). The epidemiology of concurrent intellectual disability in individuals with CP has not been comprehensively investigated, but Reid et al. (2018) reported a prevalence rate of 45%. ‘Autism spectrum disorders (ASD) is a complex developmental condition involving persistent challenges with social communication, restricted interests, and repetitive behaviour. The degree of impairment in functioning because of these challenges varies between individuals with autism, and not all have concurrent intellectual disability’ (American Psychiatric Association, n.d.). The presence of both intellectual disability and autism is estimated to be between 37–47% (Postorino et al., 2016; Rivard et al., 2015).

Human genetics and clinical research in the last decade have led to the identification of hundreds of genes responsible for intellectual disability disorders (Iwase et al., 2017). Around 25% of individuals with intellectual disabilities have a genetic syndrome (Karam et al., 2015). Down syndrome is a chromosomal disorder characterized by an extra chromosome 21 and

affected individuals usually have mild to severe intellectual disability (American Psychological Association, n.d.). 'The most common chromosomal cause for intellectual disability is Down syndrome, and the most common other genetic cause is Fragile X syndrome' (Lee et al., 2019, p. 1).

Intellectual disability is categorized into four levels; mild (IQ 50–69), moderate (IQ 35–49), severe (IQ 20–34) and profound (IQ 20 or below) (World Health Organization, 2019). Around 85% of individuals with intellectual disability are reported to have mild intellectual disability, while approximately 10% have moderate intellectual disability, 4% have a severe intellectual disability and 1% have profound intellectual disability (Patel et al., 2020). The reported distribution of intellectual disability levels has varied and approximately 27%–39% for mild intellectual disability, 24–46% for moderate intellectual disability, 19%–27% for severe intellectual disability and between 5% –18% for profound intellectual disability (Folch et al., 2018; Kinnear et al., 2018; Maltais et al., 2020). There are probably many individuals with a milder degree of intellectual disability that has not been diagnosed (Maulik et al., 2011), or do not need services, and thereby are not included in prevalence studies of individuals with intellectual disability.

The use of measured IQ (intelligence quotient) in determining an intellectual disability diagnosis has limitations as measured IQ does not always correlate with the level of adaptive function (Patel et al., 2020). Furthermore, it is not always possible to do a standardized test with an individual for various reasons (e.g., lacking cooperation skills, verbal comprehension). Therefore, adaptive function in terms of the conceptual, social, and practical domains must be considered (Tassé et al., 2019). As described by Patel et al. (2020) individuals with mild intellectual disability have challenges with complex language and academic skills. Most of them can learn basic skills in reading, writing and mathematics, but have problems with executive functioning (e.g., planning, organizing, abstract thinking). They mostly manage the skills needed for activities of daily living and can, with some support, function as valuable workers in many types of jobs. Individuals with moderate intellectual disability have notable problems in skills like reading, writing, mathematics and understanding age- and context-specific social norms. They need continuous positive support and will then maintain basic daily living and job skills. Individuals with severe intellectual disability may also have motor impairments and other associated conditions that further limit their intellectual and adaptive functioning. They have significantly limited language and communication ability and need support in all activities of daily living. Most of them can

communicate their preferences in relationships and some can, with appropriate social and visual or verbal support, do small jobs or activities. Individuals with profound intellectual disability have significant limitations in self-care, continence, communication and mobility. They are total care dependent, but most of them can with prompts and aids perform simple tasks. Severe and profound intellectual disabilities are differentiated based primarily on differences in limitations of adaptive behaviour because the validity and reliability of standardized intelligence tests are not yet clearly established (Patel et al., 2020; Tassé et al., 2019).

1.2 Health conditions in individuals with intellectual disability

1.2.1 Mental health

This study emphasizes the physical health and perceived health of individuals with intellectual disabilities. Other publications have also focused on the physical health of adults with intellectual disabilities (Evenhuis et al., 2001; Kinnear et al., 2018). However, mental health is an important part of the total health of an individual and we cannot go on without mentioning it. The risk for mental health disorders is much higher in individuals with intellectual disabilities compared with the general population (Cooper et al., 2015; Folch et al., 2018; McMahon & Hatton, 2020; Perera et al., 2019), and those with Sami background are found to have even poorer mental health (Gjertsen, 2019). The prevalence of mental illness is reported to be higher in individuals with milder forms of intellectual disability than in those with more severe forms of intellectual disability (Bhaumik et al., 2008; Mazza et al., 2020). The female gender predicts mental health conditions (Kinnear et al., 2019). Whether challenging behaviour is strongly associated with mental health disorders or not is an ongoing discussion in the field (Hove & Havik, 2008; Painter et al., 2018). Challenging behaviour was reported to be prevalent in 18.1% of individuals with intellectual disabilities (Bowring et al., 2017). Communication difficulties and a severe or profound intellectual disability diagnosis were the factors most related to challenging behaviour (Bowring et al., 2017). Polypharmacy was also found to be strongly related to living in a residential institution and reporting a mental health condition (O'Dwyer et al., 2016). Both multimorbidity and polypharmacy are strong predictors of mortality in people with intellectual disabilities (Schoufour et al., 2018). We have not investigated medication use in this study but acknowledge its importance for further studies.

1.2.2 Physical health conditions including multimorbidity

People with intellectual disability have higher levels of chronic conditions, more multimorbidity, earlier mortality and greater complexity identified in health needs compared to their peers without (Haveman et al., 2011; Hermans & Evenhuis, 2014; Hirvikoski et al., 2021; van Schrojenstein Lantman-De Valk, 2000).

Studies have reported divergent findings of the occurrence of physical health disorders. The Irish Longitudinal Study on Ageing (TILDA) and the Intellectual Supplement (IDS)-TILDA showed higher rates of chronic conditions for people with intellectual disability compared with the general population (McCarron et al., 2017). Cooper et al. (2015) found a significantly more prevalence of 14 out of 32 physical health conditions in individuals with intellectual disability compared with the general population. Epilepsy, constipation and visual impairment accounted for the largest difference, while hearing loss, eczema, dyspepsia, thyroid disorders and Parkinson's disease were more than twice as common in individuals with intellectual disability than in the control group. McMahon and Hatton (2020) reported that participants with an intellectual disability were more likely than the general population to have viral or infective diseases, mental health illnesses and behavioural problems, neurological disorders, diseases of the genitourinary system and malformations or genetic problems. The diseases that had a lower prevalence in people with intellectual disability were coronary heart disease, peripheral vascular disease, hypertension, atrial fibrillation, cancer and chronic obstructive pulmonary diseases (Cooper et al., 2015). Less prevalence of cancer among individuals with intellectual disability compared to the general population was also observed by McMahon and Hatton (2020), while hypertension, arthrosis, hypercholesterolemia, allergies and asthma were reported to be less prevalent in a Spanish study by Folch et al. (2018).

The World Health Organization (WHO) defines multimorbidity as the coexistence of two or more chronic conditions in the same individual (World Health Organization, 2016). In the literature different definitions of and ways of measuring multimorbidity make comparison across studies difficult. For example, van Timmeren et al. (2017) used the definition 'simultaneous occurrence of various health problems in the same person', while Hermans and Evenhuis (2014) used the definition 'the occurrence of two or more chronic conditions which may negatively influence daily functioning'. Tyrer et al. (2019) defined multimorbidity as 'two or more chronic conditions in addition to intellectual disability' and a similar definition was used by Kinnear et al. (2018). The inclusion of diseases also varied. van Timmeren et al.

(2017) used only physical health problems with prevalence rates above 25 % which included 15 diseases. A list of 20 conditions was reported by Hermans and Evenhuis (2014), while 19 chronic conditions were reported in the study by (Tyrer et al., 2019) and Kinnear et al. (2018) reported the 20 most reported diseases. The reported prevalence of multimorbidity varied from 61.2% (Tyrer et al., 2019), 71% (McCarron et al., 2013), 79.8% (Hermans & Evenhuis, 2014), and 98.7% (Kinnear et al., 2018).

Individuals with severe or profound intellectual disability were found to have more comorbidity (Folch et al., 2018), and a higher risk of neurodevelopmental conditions than people with milder forms of intellectual disability (Moreno-De-Luca et al., 2013; Schrojenstein Lantman-de Valk et al., 1997). The prevalence of visual impairment, epilepsy, constipation, ataxia, CP, osteoporosis, bone deformity, gastro-oesophageal reflux disorder and dysphagia were more prevalent among those with more severe forms of intellectual disability (Kinnear et al., 2018) compared to those with milder forms of intellectual disability. A pattern of five prevalent physical health disorders (visual impairment, constipation, epilepsy, spasticity, and scoliosis) was found in individuals with severe or profound intellectual disability and motor disabilities (van Timmeren et al., 2017). Obesity, hypertension and dorsalgia were more common among individuals with milder forms of intellectual disability (Kinnear et al., 2018). Folch et al. (2018) found that eye or ear problems, migraines, asthma, obesity, diabetes, hypertension and hypercholesterolemia were more prevalent in individuals with milder forms of intellectual disability.

Perinatal problems, motor disorders, and epilepsy are expected to be more prevalent in people with intellectual disability, as perinatal problems may have caused brain dysfunction which leads to intellectual disability, motor disorder, or epilepsy (van Schrojenstein Lantman-De Valk, 2000). A strong correlation between the degree of CP, intellectual disability level, and epilepsy prevalence has been found (Andersen et al., 2008; Vukojević et al., 2017; Zafeiriou et al., 1999).

Communication difficulties are common in individuals with severe or profound intellectual disabilities. Further limitations may occur if the intellectual disability is compounded by autism or by CP that affects controls of the muscles involved in speech, gesticulation, and grimacing. Some of these individuals may be essentially non-communicating (Kildal et al., 2021). Down syndrome, CP and autism are diagnoses that are registered in this study, but they are not regarded as a physical health condition.

The prevalence of diseases in people with intellectual disabilities may differ between countries and populations and investigating patterns of diseases across countries may contribute to better treatment and health (James et al., 2018). Results from Norwegian surveys of how physical health disorders are related to degree of intellectual disability in adults have not previously been reported (paper II).

1.2.3 Physical capability

Physical function is a well-established way of measuring biological age and is a biomarker of health and quality of life in older persons (Bergland et al., 2017; Oppewal & Hilgenkamp, 2019b). There have been few epidemiological studies on physical test performance in adults with intellectual disability and most have been done in the Netherlands (Hilgenkamp et al., 2013).

A large population-based cross-sectional study 'Healthy Ageing and Intellectual Disability (HA-ID) ,which included physical capability tests, was conducted in people with intellectual disability aged 50 and older (Evenhuis et al., 2012). People with intellectual disabilities often present below average on physical performance (Hilgenkamp et al., 2013). The concepts of physical performance, physical functioning, and physical capability are similar and are often used interchangeably. They describe the degree to which a person can manage the physical tasks of daily living (Cooper et al., 2011). The ageing process and related functional problems seem to have an earlier onset in people with intellectual disability, although they now live longer than before. This could lead to a loss of movement and balance skills, resulting in an increased risk of falls and, in turn, a higher risk of disability and loss of quality of life (Evenhuis et al., 2001; Torres-Unda et al., 2017).

Physical capability can be objectified by measuring grip strength, walking speed, chair rising and standing balance times, and is important for independent function or to prevent disability (Cooper et al., 2011; Hilgenkamp et al., 2013). These tests are often used with older adults. Individuals who do not complete physical capability tests in health surveys or who achieve markedly low scores on such tests may have health challenges (Oppewal & Hilgenkamp, 2019a) and could therefore be at risk of developing serious illness (Bergland et al., 2017). However, people with intellectual disabilities are often not included in these assessments.

Physical capability tests used in the general population rely on average cognitive and physical abilities, and even short physical performance batteries used for older adults cannot be

assumed to be suitable for the population with intellectual disabilities. Knowledge regarding the feasibility of instruments to measure physical fitness (capability) in older adults with an intellectual disability is lacking (Hilgenkamp et al., 2013). In the last decade, some instruments have been tested on the population with intellectual disability, such as the Short Physical Performance Battery (SPPB) (Oppewal & Hilgenkamp, 2018; Torres-Unda et al., 2017), the One-legged Stance test (OLS) (Blomqvist et al., 2012), and the Timed Up- and- Go (TUG) test (Alcántara-Cordero et al., 2020; Enkelaar et al., 2013). Recently the SPPB and the TUG test were used to establish reference values for the general population in Norway (Bergland & Strand, 2019; Svinøy et al., 2020), but have not before the present study been compared to scores in adults with intellectual disability. Factors associated with low scores on physical capability tests used in health surveys have rarely been investigated in adults with intellectual disabilities (paper I). Identifying individuals with intellectual disabilities who score low on physical capability tests would enable the implementation of preventive strategies to avoid falls and illness and promote health and quality of life (Finlayson, 2018).

1.2.4 Perceived health

Perceived health and self-reported health are synonyms. Both terms are used in the literature. In this study, we use the term perceived health. Objective health status was found to be consistent with perceived health in the general population (Wu et al., 2013), although it was more common for proxy responders to report on individuals with intellectual disability when their health was investigated (Emerson et al., 2016; Jin et al., 2020; Kinnear et al., 2019; Scott & Havercamp, 2018). According to Scott and Havercamp (2018), perceived health and caregiver-health reports were significantly related in individuals with intellectual disability in a study from the United States. Both rating methods (that is, self-reporting and proxy reporting) are common in studies involving individuals with intellectual disabilities (Jin et al., 2020; Kinnear et al., 2019).

Investigating perceived health in individuals with an intellectual disability is complex as many factors affect their health simultaneously (Jin et al., 2020). Several studies have reported poorer perceived health among individuals with intellectual disability compared with their peers without intellectual disability (Emerson et al., 2016; Kinnear et al., 2019). There is limited research on how multiple potential factors may influence perceived health in this population (Cocks et al., 2017; Jin et al., 2020). However, adults with an intellectual disability

are less likely than the general population to make healthy lifestyle choices such as healthy nutrition and participation in physical activity (Havercamp & Scott, 2015).

Few studies have investigated predictors for perceived health in adults with an intellectual disability. Jin et al. (2020) reported that obesity, smoking and a lack of physical activity predicted lower perceived health, while increasing age, financial hardship, smoking and living in a home of their own were predictors of low perceived health according to Cocks et al. (2017). Neither of these studies adjusted for the presence of physical health conditions.

The reported prevalence of good perceived health among participants with an intellectual disability varied from 78% in an Australian study (Cocks et al., 2017), 59.8% in an American study (Jin et al., 2020), and 48% in a Scottish study. The simultaneous associations between lifestyle factors and multimorbidity and perceived health ratings in the adult population with intellectual disability have not previously been reported.

1.3 Lifestyle factors

Determinants of health are the personal, social, economic and environmental factors that influence population status (Krahn & Fox, 2014). Of the health determinants emphasized by the POMONA group (Perry et al., 2010), the present study investigated the lifestyle factors of weight, physical activity and smoking (Figure 1) (paper I, Paper II).

Overweight and obesity are on the rise worldwide; these conditions are associated with health consequences such as cardiovascular disease, hypertension and type 2 diabetes mellitus (Williams et al., 2015). Several studies have reported a higher prevalence of obesity among adults with intellectual disability than in the general population (Flygare Wallén et al., 2018; Folch et al., 2018; Hsieh et al., 2014). A higher obesity rate was found to be associated with female gender, Down syndrome, certain medications, less moderate physical activity, and greater amounts of soda consumption in an American study (Hsieh et al., 2014). Obesity is reported to be more common among those with milder forms of intellectual disability (Ranjan et al., 2018), while underweight is more common among those with severe or profound intellectual disability (Hsieh et al., 2014). Whether a similar weight pattern is present in a Norwegian population sample of adults with intellectual disability was investigated in the present study.

Health consequences of overweight and obesity in adults with intellectual disabilities have been demonstrated. In a study from the United States, overweight and obesity were associated with an increased risk of sleep apnoea and type 2 diabetes in adults with Down syndrome, adults with autism and adults with intellectual disability and developmental disabilities. In addition, an increased risk of hypertension in overweight and obese adults with autism or intellectual disabilities has been observed (Ptomey et al., 2020). Furthermore, obesity may lead to less independence in activities of daily living and reduced community participation (Patterson et al., 2004).

The literature is consistent regarding the burden of overweight and obesity in adults with intellectual disability, and also there is consensus that overweight and obesity are preventable and modifiable health conditions (Prasher & Janicki, 2019). The impact of obesity on perceived health was shown by Jin et al. (2020), but not adjusted for the presence of other physical health disorders, as in the present study (paper II).

Physical activity is known to prevent numerous diseases and is also important in the treatment of mental health (Bull et al., 2020). Reviews from 2011and 2019 summarized the evidence for adults with an intellectual disability and found that physical activity positively affected balance, muscle strength and quality of life (Bartlo & Klein, 2011; Bouzas et al., 2019). Houwen et al. (2014) reviewed the evidence for the effectiveness of participating in movement-oriented activities for adults with severe or profound intellectual disability and found that all included studies reported beneficial effects in the motor domain, at least in the short term. However, several studies have suggested that physical inactivity is common in people with intellectual disability (Dairo et al., 2016; Stancliffe & Anderson, 2017) and reviews have indicated that lower intellectual capacity was a limiting factor for being physically active (Bossink et al., 2017; Dairo et al., 2016). The extremely low levels of physical activity in the population of people with intellectual disabilities are alarming (Hilgenkamp, Reis, et al., 2012). Furthermore, research among adults with CP has suggested a lower level of regular physical activity than in the general population (Waltersson & Rodby-Bousquet, 2017).

Smoking was found to be more prevalent among adults with disabilities or long-term health conditions than in those without in a study from the United Kingdom (Emerson, 2018). However, a review of the prevalence of smoking and other substance use in individuals with an intellectual disability found it hard to draw conclusions due to different methodological

issues in the reviewed studies (Huxley et al., 2019). Robertson et al. (2020) reported less self-reported smoking, alcohol and drug use among adolescents and young adults with mild to moderate intellectual disability than among their non-disabled peers. The current study will increase knowledge about the smoking situation among adults with intellectual disabilities.

1.4 Access to health care services

The Nordic countries established formalized services for people with intellectual disabilities during the second half of the nineteenth century and institutions were the preferred healthcare system during most of the twentieth century (Tøssebro et al., 2012). In the 1960s, this ideology changed due to criticism of the prevailing standards of institutional care as inhumane; the institutions were overcrowded, understaffed and isolating, standards inconsistent with those of the evolving welfare state (Hall et al., 2021; Tøssebro et al., 2012). Furthermore, the principle of normalization was affirmed by the United Nations Convention on the Rights of Persons with Disabilities (Bredewold et al., 2020) based on the assumption that living in a community-based environment with less restrictions was better for civil rights, fulfillment of social needs and general well-being (Chowdhury & Benson, 2011). Sweden was ahead of the other Nordic countries regarding normalization and gradually introduced group homes and community care. After Iceland decentralized in 2011, the local government was fully responsible for services to individuals with an intellectual disability in all the Nordic countries (Tøssebro et al., 2012).

In Norway today, the responsibility for organizing healthcare services for individuals with an intellectual disability is shared between GPs, standard medical specialties, and specialized multidisciplinary hospital-based mainly outpatient habilitation services. How healthcare services in Norway meet the needs of people with intellectual disabilities is largely unknown. Recently, new national guidelines for health and care services for persons with intellectual disability were published by the Norwegian Directorate of Health (2021) (in Norwegian: Gode helse- og omsorgstjenester til personer med utviklingshemming). The new guidelines describe what is considered to be good practice in important areas like person-centred care, life transitions, habilitation, health follow-up and cooperation with the family. It is the municipalities' responsibility that the national guidelines are followed, and that goals and measures are documented in an individual plan (IP) for each person with an intellectual disability. An IP is a statutory right for individuals in need of long-term coordination of

multiple services (Norwegian Directorate of Health, 2015), and the actual usage among adults with an intellectual disability is shed light on in the present study.

General practitioners (GP) are usually the first contact when adults with intellectual disabilities need health care. Many GPs have had no training in the special needs of this population resulting in barriers to high-quality health care for people with intellectual disabilities (Byrne et al., 2016; Fredheim et al., 2013). A study from the United Kingdom that compared the management of long-term conditions between adults with intellectual disability and the general population reported significantly poorer care among the former, despite more prevalent conditions (Cooper et al., 2017). In contrast, an Irish study reported significantly higher use of GP, public health nurse visits, and outpatient services among participants with intellectual disability compared with the general population (McCarron et al., 2017). The use of healthcare services was significantly lower for those with more severe forms of intellectual disability than those with milder forms of intellectual disability and the general population in a Canadian study (Maltais et al., 2020). Knowledge about contacts between adults with intellectual disability and GPs and the specialized habilitation services is not available in Norway and will be clarified in relation to level of cognitive functioning.

Byrne et al. (2016) reported that health checks were the only intervention to significantly increase health actions. The use of health checks to identify problems was highlighted, as was the need to evaluate their impact in the long run (Hanlon et al., 2018). Annual health checks in primary care for adults with intellectual disability have been incentivized by the National Health Service in England since 2009 (Carey et al., 2017), and in Norway the NAKU (In Norwegian: Nasjonalt kompetansemiljø om utviklingshemming) has informally recommended doing since 2007 (Ellingsen, K.E., 2007), although it has not been included in the official guidelines until recently (Norwegian Directorate of Health, 2021). The main objective of the present study is to explore the extent to which annual health checks are conducted in adults with intellectual disabilities.

The cognition of children with CP is being systematically followed up in Norway and Sweden, but not so for adults with CP. Recently there has been a focus on the cognitive impairment that many adults with CP experience and a protocol is developed for cognitive follow- up in adults (Stadskleiv et al., 2021). The information on how the use of healthcare services is in adults with concurrent intellectual disability and CP, in Norway is scarce.

There have not been large population-based studies in people with intellectual disabilities in Norway regarding healthcare services. Therefore, how healthcare services in Norway meet the needs of people with intellectual disabilities is largely unknown. The present study sought to investigate the use of healthcare services in the preceding 12 months according to national recommendations and in relation to age and intellectual disability level.

1.5 Oral health

Oral health and dental health are terms that are used interchangeably in the literature (Prasher & Janicki, 2019; Wilson et al., 2019). 'Oral health refers to the health status of the oral and related tissues and includes dental health' (Chadwick et al., 2018). Good oral health includes an individual's ability to eat, speak and interact without discomfort or disease and is important for personal well-being (Chadwick et al., 2018; Wilson et al., 2019).

A review by Wilson et al. (2019) found significantly poorer levels of oral health, more missing teeth, greater numbers of tooth extractions, more caries, fewer filled teeth and greater gingival inflammation in individuals with intellectual disability compared with non-disabled participants. In addition, they demonstrated less preventive dentistry and poorer access to services, and insufficient oral care practices were associated with an increased risk of caries (Wilson et al., 2019). Demographic variables that predicted poor oral health were the degree of intellectual disability, older age and living in an institution. Health and treatment related predictors for poor oral health were comorbidity and problems accessing dental services (Wilson et al., 2019).

In a Portuguese study that investigated the oral health-related quality of life of individuals with mild intellectual disability, more than half (54.9%) reported one or more oral health problems that had a major to severe impact on their quality of life. As many as three-quarters (76.9%) of the participants reported that oral health had an impact on their quality of life and 61.9% experienced pain (Couto et al., 2018). Furthermore, 7.2% of the sample never went to the dentist and only 28.4% had attended a dental appointment in the preceding six months. Only 18.8% went to the dentist for routine dental appointments. Higher self-perception of the need for dental treatment and having fewer teeth negatively affected the quality of life (Couto et al., 2018).

The literature agrees on the importance of regular dental check-ups to achieve and maintain good oral health; nonetheless, a daily dental hygiene routine is decisive (Chadwick et al.,

2018; Ward et al., 2019). Therefore, preventive oral actions are recommended in Norway's recent guidelines (Norwegian Directorate of Health, 2021).

The current study sought to explore how the use of dental care services is related to experienced access to dental care, mouth pain and the experience of good or poor dental health.

1.6 People with intellectual disability in research

Although people with intellectual disabilities are recognized as full citizens with equal rights to inclusion in society (Office of the United Nations High Commissioner for Human Rights, 2006; United States Congress, 2008), they are often excluded from medical research (Feldman et al., 2014). The literature is agreed on the necessity of including people with intellectual disabilities in health research to ensure that their specific health-related needs are captured and that interventions and services received are evidence-based and sound (Brooker et al., 2014; Feldman et al., 2014; Mulhall et al., 2018). The poorer health experienced by people with intellectual disability compared with the general population makes the exclusion of persons with intellectual disability from medical research problematic (Brooker et al., 2014; Feldman et al., 2014). According to Shankar et al. (2018), the under-representation of people with epilepsy and intellectual disability was found in research presented at all major conferences for either intellectual disability or epilepsy in the United States, the United Kingdom and Europe.

Feldman et al. (2014) investigated the inclusion of people with intellectual disabilities reported in high-impact medical journals. In addition, they considered whether modifications and accommodations to support the inclusion of persons with intellectual disabilities in the studies could have been made. Of the investigated studies, only 2% clearly included persons with intellectual disabilities, while more than 90% were designed in a way that automatically would exclude persons with intellectual disabilities.

Another systematic review on inclusion and identification of people in public health concluded that cohort studies passively excluded people with intellectual disability, while randomized controlled trials (RCTs) actively excluded this population (Brooker et al., 2014). In a review by Mulhall et al. (2018), the methodological and practical challenges involved in including people with cognitive impairments in RCTs were explored. Some of the reported barriers were clearly RCT methodology related, while others were specific to people with

cognitive disabilities. Health investigations and research involving individuals with intellectual disabilities face practical challenges like the problem of recruiting participants by engaging gatekeepers, obtaining informed consent and the ability to understand the questions in the outcome measures and to follow instructions (Brooker et al., 2014; Mulhall et al., 2018). Challenges may increase with more severe forms of intellectual disability and such individuals are often excluded from health screening and research (Brooker et al., 2014).

According to Doody (2018), gaining access to participants with an intellectual disability almost always involves going through gatekeepers or facilitators with the risk of excluding the least able due to over-protectiveness and gatekeeping on the part of service providers (Doody, 2018).

McMahon and Hatton (2020) argued that variations in prevalence of major health problems among people with intellectual disability reported across different studies, and how they were compared with people without intellectual disability (e.g., cancer and mental health problems), may be due to methodological reasons such as inconsistent definitions of intellectual disability, diverse diagnostic tools and small sample sizes. Although the literature is expanding, the lack of representative samples of people with and without intellectual disabilities continues to be one of the most important methodological limitations in intellectual disability research (McMahon & Hatton, 2020).

However, in recent years people with intellectual disabilities have been included in some population-based studies from Ireland (McCarron et al., 2013) and the United Kingdom (Perera et al., 2019), but no such studies have been performed in the Nordic countries. Furthermore, very few studies in the Nordic countries have investigated physical health conditions in a population-based setting among adults with intellectual disabilities.

2 Aims and objectives of the study

This is the first study in the Nordic countries to investigate physical performance, physical health and perceived health, and the use of healthcare services in a community-based study of adults with intellectual disabilities.

The main aim of the research project on which this study is based was to investigate physical capability tests scores, physical and perceived health, and to explore the use of health and dental care services in Norwegian adults with an intellectual disability.

The specific objectives of this study were as follows:

1) To assess completion rates, scores, and factors associated with non-completion and low scores on physical capability tests as part of a health survey administered to adults with intellectual disability (paper I).
2) To investigate lifestyle factors and multimorbidity as predictors of perceived health adjusted for age, gender and intellectual disability level (paper II).
3) To investigate the use of health care services in the preceding 12 months among adults with intellectual disability according to national recommendations and in relation to age and level of intellectual disability (paper III).
4) To investigate the use of dental care services in the preceding 12 months its association with age, gender, intellectual disability level, pain, access to dental care and perceived dental health in adults with intellectual disability (paper III).

3 Material and methods

3.1 Study design and setting

The North Health in Intellectual Disability (NOHID) study was a cross-sectional multicentric study involving people with intellectual disability living in five different municipalities in northern and central Norway. The study was led by the University Hospital of North Norway (UNN) in Tromsø in cooperation with St.Olav's Hospital in Trondheim.

The municipalities in the northern region were Tromsø, Balsfjord and Narvik, while Malvik and parts of Trondheim represented the central region. UNN functions as a local hospital for the inhabitants of the municipality of Tromsø, which has 71,590 inhabitants and covers an area of 2,521 km^2 , and the inhabitants of the municipality of Balsfjord, which has 5,593 inhabitants and covers an area of 1 497 km^2. The local hospital in the municipality of Narvik (17,000 inhabitants) is a part of UNN with its specialized habilitation team. Saint Olav's hospital in Trondheim is also the local hospital of the municipality of Malvik which has 13,371 inhabitants and covers an area of 168.4 km^2. The municipality of Trondheim has an area of 321.8 km^2 and 182,035 inhabitants.

3.2 Funding and registration

This study was funded as a PhD project from the DAM Foundation and initialized with financial support from the Research Centre for Habilitation Model and Services (CHARM). The study was preregistered at ClinicalTrials.gov with identification number NCT03889002.

3.3 Procedure and recruitment

Research assistants with a health professional background (research nurses, intellectual disability nurses and one physiotherapist) were employed in all the municipalities and were responsible for recruitment and data collection. 'Intellectual disability nurse' is the title used for professionals nurses (in Norwegian: vernepleier) with a three-year Norwegian university education in the care of and services for individuals with intellectual disabilities. All collaborators participated in regular Skype meetings to discuss progress, clarify questions and ensure quality in the data collection.

All individuals with a verified diagnosis of intellectual disability according to the International Statistical Classification of Diseases and Related Health Problems-10 criteria (WHO, 2019), aged 16 years or older and living in the previously defined areas, were invited to participate in the study. Although there were no predefined exclusion criteria, some exclusions were made based on reasons described in more detail elsewhere (paper II).

Potential participants were identified through 1) having been registered as previous recipients of specialized intellectual disability services at UNN or St. Olav's hospital in Trondheim, or 2) information available from the municipalities (receiving health care services).

All individuals aged 16 and above with an intellectual disability diagnosis and receiving health care services from the municipality are registered in the municipalities. We collaborated with the municipalities and the registers were checked to ensure that we got an overview of all eligible individuals and that no individual was counted twice (if registered both in the municipality register and the specialized habilitation register). This was checked using an ethically approved deidentified approach. Identified individuals were then contacted either by the municipality or by a project assistant in the form of an information letter regarding the study. When participants were identified through information from the municipalities, staff from the municipality contacted the individual with an intellectual disability before the researchers were involved.

Next of kin or service provider were contacted by telephone to inform them about the letter to be sent out. The intention with this was to ensure that someone who knew the individual with intellectual disability was aware that the letter was an invitation to participate in a health survey. From experience, we knew that some persons with intellectual disabilities might need help to understand the content of the letters, and that others might throw away or not open the letters. The telephone contact with the next of kin was approved by the Committee for Medical Research Ethics.

The NOHID study sought to disseminate information in several ways. In 2016, a pilot study was performed in the municipality of Tromsø to test recruitment and the use of questionnaires. The pilot study is described in a master's thesis by Christian Sørensen (2017). Experience from the pilot study suggested that collaboration with the municipality in recruitment would lead to a higher participation rate in the study. Administrative leaders of healthcare services for individuals with intellectual disabilities in the municipalities and the user organisations were informed. The study was promoted through the healthcare services for individuals with an intellectual disability in the municipalities and the specialized habilitation services. In addition, the study was promoted through regional television and radio news channels and via the hospital's internal newspaper.

The NOHID study sought to include individuals with all levels of intellectual disability irrespective of physical health conditions, motor functioning and communication functioning. Therefore, we strived to be flexible in how and where data collection took place. We stipulated that the questionnaire/interview could be held at a location suitable for the informants. Individuals with an intellectual disability were permitted to bring with them a support person or a family member who knew them well as we knew that some of the questions might be hard to answer. This was also important to ensure that the person with an intellectual disability was comfortable with the situation. Furthermore, if the person with an intellectual disability did not want to be present but allowed their next of kin or their healthcare provider to answer on their behalf, this was also accommodated. Since we wanted individuals with an intellectual disability to participate as much as possible, we made allowances such as taking a break when needed and allowing the individual with intellectual disability to participate in some but not all of the data collection.

3.4 Ethical considerations

Informed consent was obtained from the participants or their legal representative. The study was conducted according to the Declaration of Helsinki and approved by the Committee for Medical Research Ethics, Health Region North (2017/811), and the data protection officer at UNN.

There are several ethical challenges to be aware of when doing research involving individuals with an intellectual disability. Obtaining informed consent is one such challenge. This study collected sensitive information and attached great importance to safeguarding the individual's privacy, safety and rights. Therefore, the first contact was with a service provider or next of kin. Informed consent was obtained from the participant, when possible, otherwise a close family member or legal representative was asked to provide consent. Health professionals who were used as informants had to have known the individual with intellectual disability for at least one year. In addition, professionals needed approval from the individual or a legal representative. Participants were informed that they could withdraw from the study at any time without consequences. As mentioned previously, arrangements were made to involve the participant with an intellectual disability as much as possible in the study.

If the information obtained from the interview indicated the need for health actions, such actions were ensured.

3.5 Participants

A flowchart of the inclusion process for the main study (paper II and paper III) and the substudy (paper I) is presented in Figure 2.

Paper I: For this substudy, only inhabitants in the city of Tromsø were invited. Of 182 eligible individuals in the municipality of Tromsø, 93 participants consented to participate in the study, a participation rate of 51%. The mean age of the participants was 34.2 years (*SD* = 14) with a range of 17–78 years and 58% were men. The non-participants were significantly older with a mean age of 42 years (*SD* = 16), but the gender distribution was similar between the participants and the non-participants. In terms of intellectual disability levels, 33% had a mild intellectual disability, 24% had a moderate intellectual disability, 28% had a severe intellectual disability and 14% had a profound intellectual disability. Only 1% had an unknown intellectual disability level (paper I).

Papers II and III: In total 214 participants were included in the main study. In the northern region (the municipalities of Tromsø, Balsfjord and Narvik) the number of eligible individuals was 266; of these, 140 individuals participated in the study. Information regarding the number of eligible participants was not available in the central regions (the municipalities of Trondheim and Malvik) and only a representative analysis could be done in the northern region. The participation rate for the northern region was 53% and the mean age was 35.3 years (SD = 14.1) which was significantly lower ($p < .001$) than the mean age of the non-participants (M = 42.3 years, SD = 15.9). The participation was lower in the central region with 74 participants, but with a similar age and gender distribution as in the north. Of the 214 individuals with an intellectual disability who participated in the study, 56% were men. The mean age was 36.1 years (SD = 13.8) and ranged from 16 to 78 years. The distribution of intellectual disability levels was as follows: mild (39%), moderate (26%), severe (24%), profound (8%) and unknown (3%).

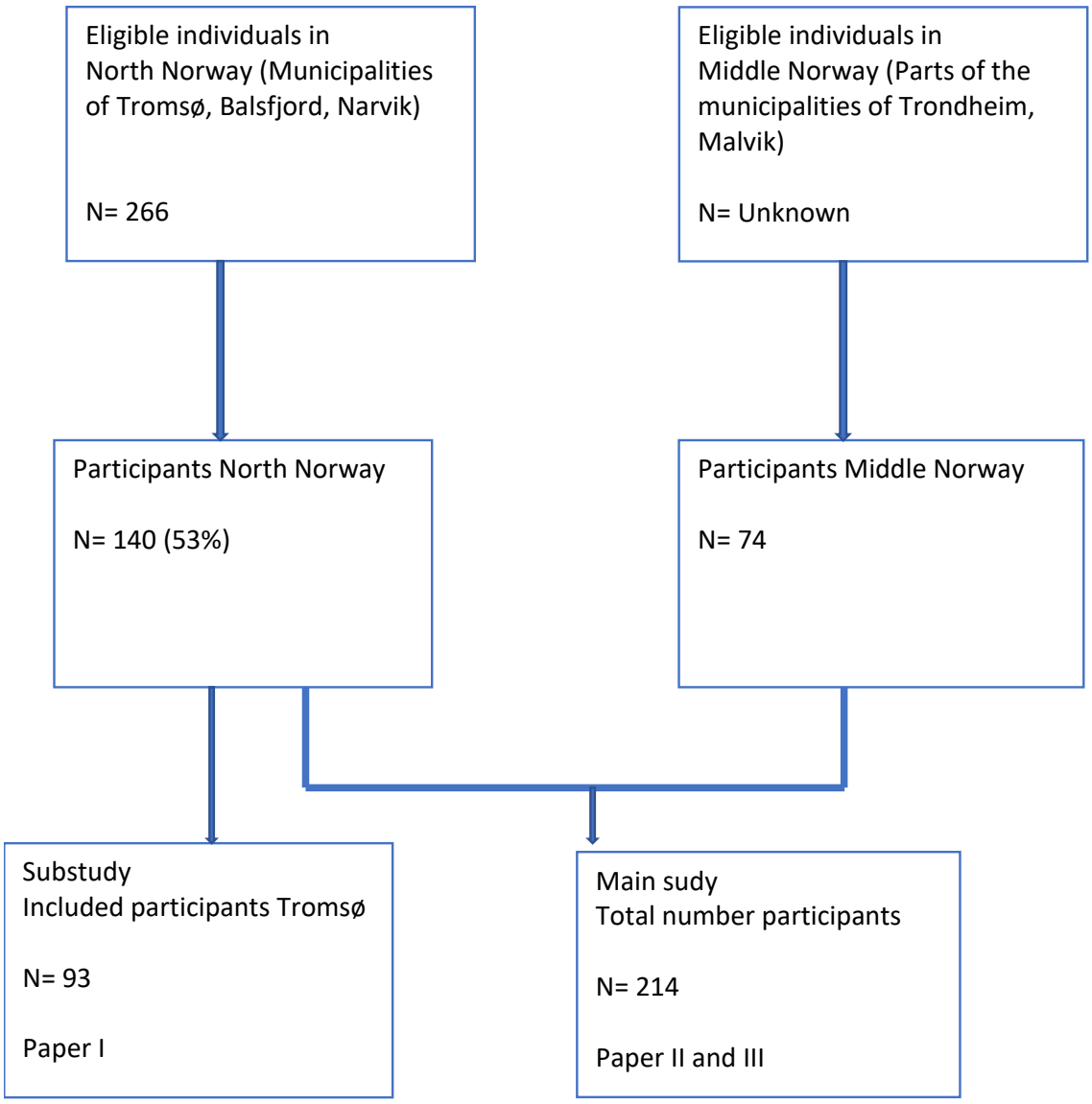

Figure 2 Flowchart of the study population

3.6 Data collection

Data collection took place between October 2017 and December 2019 using questionnaires and through structured interviews with participants or their next of kin, caregiver, or support person. Intellectual disability level and other health conditions were confirmed in the participant's medical record at the hospital. We also had permission to contact the participant's GP if necessary. In cooperation with the research unit at UNN REDCap, a web-based instrument (Research Electronic Data Capture, Vanderbilt University, Nashville, TN) was developed and used for data collection. All research assistants had access and could transfer data into REDCap regardless of geographical location.

The primary recommendation from collaborators after evaluation of the pilot study was to include some suitable tests of physical performance in the full study. The additional physical measurements and physical capability tests were investigated in a substudy only in the municipality of Tromsø for convenience reasons (paper I). We used much time to find a suitable location, order the necessary equipment and undergo training in the procedures. The Short Physical Performance Battery (SPPB), the Timed Up- and-Go (TUG), and the One-legged Stance (OLS) test were chosen for use as they were used in the Tromsø study (Jacobsen et al., 2012), found potentially suitable for the study population and made a comparison with reference values in a general population possible.

3.6.1 Measures and physical capability tests

Body mass index (BMI) was calculated as weight in kilos divided by height in metres squared and was grouped as follows: underweight (below 18.5 kg/m^2), normal (18.5-24.9 kg/m^2), overweight (25-29.9 kg/m^2) and obese (30 kg/m^2 or above) (Bailey & Ferro-Luzzi, 1995). Height and weight were measured on site or, when that was not possible, were based on self-reports. Height without shoes was measured with a stadiometer (Seca 206, Hamburg, Germany). Weight without shoes and outdoor garments was measured with a mechanical floor scale (Seca 761, Hamburg, Germany). For participants who were in a wheelchair or had difficulty standing on a small plate, a wheelchair weight (Seca 675, Hamburg, Germany) was used.

The Short Physical Performance Battery (SPPB) is a screening test originally designed to measure physical performance and predict disability in an older population (Guralnik et al., 1994). The SPPB mainly measures lower-extremity function and comprises three subtests. A score of 0 indicates the inability to perform the subtest, while a score of 4 indicates the highest level of performance. The battery tests are as follows: 1) static balance, tested with the feet in a side-by- side, semi-tandem and tandem position; 2) gait speed, as measured by two 4 m (13 ft) walking tests at the individual's habitual pace, with the best results of the two tests retained; and 3) lower limb strength, measured by the ability to rise from a chair with arms folded across the chest. The total score was the sum of the three test scores and ranged from 0 to 12 points; scores were grouped into *low* (0–6 points), *moderate* (7–9 points) and *high* (10–12 points) categories (Guralnik et al., 1994). In addition, raw scores on the gait speed (meter/seconds) and chair stands (seconds) are provided in this study.

The validity and reliability of the SPPB have been reported for older adult populations (Guralnik et al., 1994) and Norwegian populations (Olsen & Bergland, 2017). Norwegian reference values for the general adult population were recently established (Bergland & Strand, 2019). The SPPB has been used in people with mild and moderate intellectual disabilities (Torres-Unda et al., 2017). According to Oppewal & Hilgenkamp (2019a), the SPPB may be calculated from tests included in the fitness tests battery recommended for adults with intellectual disabilities.

The Timed Up-and-Go (TUG) test is a test of basic mobility skills (Podsiadlo & Richardson, 1991) that has been applied to people with intellectual disabilities (Enkelaar et al., 2013). The participants, who were seated, were instructed to stand up, walk three meters, turn around, return to the chair and sit down. The task was to be performed at an ordinary comfortable speed. The TUG time was measured in seconds (Podsiadlo & Richardson, 1991). The feasibility and reliability of the TUG were investigated in a Spanish study with individuals with Down syndrome and was found to be reliable with an intracorrelation coefficient (ICC) of 0.87 (Cabeza-Ruiz et al., 2019); it has also been used in adults with intellectual disability without Down syndrome (ICC > 0.8) (Cabeza-Ruiz et al., 2020).

The One-legged stance (OLS) test measures static aspects of balance (Springer et al., 2007). The participants chose one foot to stand on for as long as possible for a maximum of 30 seconds without moving the planted foot. They were allowed to move their upper body and the raised foot. The timing was stopped if respondents moved their planted foot or had to put their raised foot on the floor. If participants managed to keep their balance and felt safe, they were instructed to do the same with their eyes closed. The OLS has been found to have excellent interrater reliability in the general population (Springer et al., 2007) and good reliability with an ICC of 0.88 in individuals with mild and moderate intellectual disabilities (Blomqvist et al., 2012).

To complete the SPPB, the TUG and the OLS, participants had to be able to follow a basic set of instructions and to stand and walk independently. Walking aids such as a walker or stick could be used if necessary. We defined non-completers as participants who either did not attend the test appointment or failed to perform the tests but completed the questionnaires. The participants' mean test scores were compared to published normative mean values for the SPPB, the TUG, and the OLS (Bergland & Strand, 2019; Springer et al., 2007; Svinøy et al., 2020).

3.6.2 Procedure for the physical capability tests

The tests were administered by an experienced intellectual disability nurse or study nurses at the research unit at UNN. The intellectual disability nurse and the study nurses received training in administering the tests from a research technician (physiotherapist) who had carried out the same tests in the population-based Tromso study. Some adjustments to the test procedures were made in advance before the participants were investigated, based on experiences from earlier studies in the general population and the researchers' knowledge of individuals with an intellectual disability. In particular, the standard instructions for all the tests were adjusted and simplified. This was done on the physiotherapist's recommendation to ensure that participants were able to follow instructions easily.

A location for testing was made available by the habilitation services. The room was furnished with seating for the surveys and interviews and the equipment needed for performing the physical tasks was brought in. The equipment included a height measurement instrument and a chair and table for measuring blood pressure. Marks were made on the floor for doing the walking test and the TUG test. Later we received support from the research unit at UNN and were given access to a location at the research unit. For practical reasons we chose to move to this location.

The visits usually started with a short conversation in the sitting area where the participant and next of kin were offered lemonade, coffee, or tea. The purpose was to get the participant to relax and feel safe. The researcher provided information about the study and the tasks the participants were to perform. The participants were asked if they had any questions and if they were ready to start with the tasks.

The procedure was to first measure weight, height, upper arm circumference, waist circumference, and blood pressure. Upper arm circumference, waist circumference and bloodpressure results were not analysed as part of this study. Thereafter, the physical capability tests were carried out in a fixed order, first the SPPB, then the TUG, and lastly the OLS. The researcher demonstrated the task first and if the participant felt confident, they performed the demonstrated task. The procedures for these tests were followed and if the participant at any time wanted to stop, the task was ended. In some cases, the participants needed physical guidance to get into the right position.

After the examination the researcher noted the challenges and successes.

In the beginning, there were always two instructors (the researcher and a study nurse), one instructed the participant while the other recorded managed the time. In time, we realized that we did not need two people as long as the participant was accompanied by a support person.

3.6.3 Questionnaires

Data were collected using standardized questionnaires and interviews with individuals with ID or their family members or healthcare providers. The POMONA Checklist of Health Indicators (P15) for people with intellectual disability was used (Perry et al., 2010), in addition to the selected questionnaires. Data were also extracted from participants' medical records.

The P15 for people with an intellectual disability has been translated to Norwegian and validated (Perry et al. 2010). The P15 questionnaires were provided for this study from Professor Jan Tøssebro, NTNU. The following fifteen health indicators that comprise the P15 are divided into four main categories as follows (variables not analysed in this study are shown in italics):

1) Socio-demographics: age, gender, education, living arrangement, occupation, and *income*.
2) Health status: epilepsy, oral health, body mass index, mental health indicators (The ABC-C and *the PAS-ADD* checklist), sensory impairment, mobility and perceived health.
3) Health determinants: physical activity and *medication use*.
4) Health Systems: Hospitalization, contact with professionals/health checks, and health promotion.

An overview of the variables used in this study is presented in Table 1.

The P15 list of diseases included asthma, allergy, diabetes, cataract, hypertension, heart attack, stroke, chronic obstructive pulmonary, disease/emphysema, arthritis (osteoarthritis/rheumatoid arthritis), osteoporosis, peptic ulcer, cancer including leukaemia, migraine, or frequent headaches, constipation, thyroid disease, and epilepsy among others. Other frequent conditions registered were skin conditions and musculoskeletal disorders. Oral problems were indicated by pain in either the mouth or teeth.

Multimorbidity was defined as one or more physical health conditions in addition to a diagnosis of intellectual disability (WHO, 2016). A diagnosis of Down's syndrome, autism or CP was not counted as a physical health condition but was noted. Mental health conditions were not included in the operationalization of this study (paper II).

Perceived health was measured using the question, 'How is your health in general?' The question had five response options ranging from 'very good' to 'very poor'. The same question has been used in general population studies (Bennie et al., 2017; Wu et al., 2013) and in studies in which people with intellectual disabilities were included (Cocks et al., 2017; Kinnear et al., 2019). The variable was dichotomized into good health (very good or good health) or poor health (fair, poor, or very poor health) which has been reported in other studies (Cocks et al., 2017; Kinnear et al., 2019). The question was rated by the participant with intellectual disability, in collaboration with a family member or staff support person, or by a close representative alone.

The Aberrant Behavior Checklist- Community (ABC-C) is a 58 item scale designed to measure behaviour problems in people with intellectual disabilities *(Aman & Singh, 1994, 2017).* The items are grouped into five subscales: (I) Irritability (15 items), (II) Social Withdrawal (16 items), (III) Stereotypic Behavior (7 items), (IV) Hyperactivity/Noncompliance (16 items), and (V) Inappropriate Speech (4 items). Each item is rated on a four-point scale from 0 ('not a problem') to 3 ('the problem is severe'). The Norwegian version of the ABC-C was found to have satisfactory internal consistency, factor structure, and divergent and convergent validity (Halvorsen et al., 2019).

Intellectual disability levels were retrieved from medical records and were categorized as mild (IQ 50–69), moderate (IQ 35–49), severe (IQ 20–34), or profound (IQ less than 20) (WHO, ICD-10). For eight individuals without a degree of intellectual disability, the degree of intellectual disability was determined from information about adaptive functioning in cooperation with specialized intellectual disability health staff (Tassé et al., 2019).

The use of healthcare services was measured using the question 'Did you use this service during the last 12 months?'

The use of dental care services was examined with the following questions: 'How many times did you visit a dentist/dental nurse during the last 12 months?' and 'Do you have access to a dentist or dental nurse when you need one?'

Dental health was examined by the means of the following questions: ‘Do you have pain in your mouth or teeth?’ and ‘How is your dental health?’

The lifestyle factors physical activity, weight and smoking were investigated in this study. Physical activity level was measured using the question ‘In how much of your leisure time have you been physically active in the last year?’ The four response categories were: 1) ‘Participating in hard training or sports competitions regularly more than once a week,’ 2) ‘jogging and other moderate sport or heavy gardening for at least four hours each week,’ 3) ‘walking, cycling or other forms of light exercise at least four hours a week,’ or 4) ‘reading, tv or other sedentary activities.’ In addition, two further questions were used based on recommendations from the Norwegian Directorate of Health in 2019: ‘Are you physically active for at least 30 minutes each day (e.g., walking with a faster heart rate)?’ and ‘Do you work out enough to get sweat at least once a week?’ (Perry et al. 2010). Both questions had the following response categories: no, yes, and cannot answer.

The P15 was supplemented with the following instruments:

The Gross Motor Function Classification System (GMFCS) classifies gross motor functioning into levels 1–5, with lower levels indicating better function. The GMFCS was developed for children with CP (Palisano et al., 1997) and has high interrater reliability (McCormick et al., 2007). Individuals with motor function level 1 may have limitations in advanced motor skills (speed, balance) but generally, walk without limitations. Persons classified as level 2 usually need to use railings to climb stairs and can walk without aid but may occasionally use devices like crutches or a wheelchair. Persons classified as level 3 need to walk with devices inside and usually require a wheelchair outside. Levels 4 and 5 usually mean the need to use a wheelchair. The GMFCS has been used, but not validated, in studies of adults with an intellectual disability (Dijkhuizen et al., 2018). The GMFCS is considered the gold standard for classifying the severity of CP. ‘Gross motor function’ implies using large groups of muscles for maintaining balance, changing positions, and mobility (Russell et al., 2013; Størvold, 2018).

The Communication Function Classification System (CFCS) classifies communication function into five levels, with lower levels indicating better skills. Interrater reliability was found to be high in people with CP (Hidecker et al., 2011), but validation among adults with an intellectual disability is lacking.

An Individual plan is a planning document and structured collaborating process between the municipality services, the service user, their family, or guardian. The purpose is to give services according to the service user's identified goals. Participants were asked, 'Do you have an individual plan?' If they answered 'yes', they were asked 'When was the individual plan last evaluated?'

Some additional questions regarding living conditions were added (Molden et al., 2009) and categorized into the following: lives independently, lives with family, own apartment attached to the family house, and group home with care.

Table 1. Variables in the study.

Variable	Paper 1	Paper 2	Paper 3
Demographics			
Age	x	x	x
Gender	x	x	x
Living situation	x	x	x
Work status	x		
Diagnosis			
Level of intellectual disabilty	x	x	x
Downs syndrome	x	x	x
Autism, Cerebral palsy		x	x
Gross motor function	x	x	
Communication function	x		
Behaviour	x		
Blood pressure	x		
Lifestyle factors			
Body Mass Index (Height, Weight)	x	x	
Physical activity		x	
Smoking		x	
Physical capability tests			
Short Physical Performance Battery	x		
Timed-Up-and-Go	x		
One Leg Stance test	x		
Perceived general health		x	
Physical health conditions			
Nineteen physical health conditions, y/n		x	
Multimorbidity, y/n		x	x
Dental health			
Oral problems		x	x
Dental care services, last year			x
Access to dental care when needed			x
Perceived dental health			x
Use of healthcare services			
Health check, last year			x
General practitioner, last year			x
Hospital admission, last year			x
Hospital day care, last year			x
Mental health professional, last year			x
Physiotherapy, last year			x
Specialised habilitation services, last year			x
Breast examination, last year			x
Mammography, anytime			x
Cervical cancer screening, last 3 years			x
Individual plan (IP), y/n			x
When was the IP last evaluated?			x

3.7 Statistics

Data were directly transferred from REDCap to IBM SPSS Version 26.0 for all analyses.

Descriptive statistics were used to present participant characteristics and were reported as frequency, mean (*M*) with standard deviation (*SD*), 95% confidence interval (CI), or median and range.

In paper I, the completion rate of clinical measurements and physical capability tests were analysed by numbers and frequencies in relation to the total study population (*N* = 93*)*. The associations between variables and completion and non-completion of the SPPB tests were investigated with cross tabulations for nominal variables and with independent *t*-tests for continuous variables. For the analyses of ordinal scales (GMFCS, CFCS) and non-normally distributed scales (ABC-C subscales), non-parametric statistics (the Mann-Whitney *U*-test) were used. Confounder- adjusted logistic regression analysis was then performed to determine which variables were associated with the completion of the SPPB. A logistic regression analysis with the 'enter' method was performed with backward stepwise removal of non-significant variables. The independent variables entered in the regression analysis were age, gender and variables with *p* values less than .10 in the univariate analysis. The results are presented as adjusted odds ratios (OR). The Hosmer-Lemeshow test was used to investigate model fit and the amount of explained variance in the outcome was investigated using Nagelkerke's R^2.

Mean test scores were compared with published normative mean values for the SPPB, the TUG, and the OLS. To identify factors associated with physical capability test scores, analysis of variance (ANOVA) and, when appropriate, a post hoc least significant difference (LSD) test was used.

P-values below .05 were regarded as statistically significant; when the Bonferroni correction was applied, *p* values below .01 were considered significant.

In paper II, associations between levels of intellectual disability and physical health conditions as well as lifestyle factors were investigated by means of a one-way ANOVA for continuous variables and the chi-square test for categorical variables. When there were few cells in the crosstabs, the results were checked with Fisher's exact test.

Logistic regression analysis was used to investigate variables associated with dichotomized health ratings (good or poor) as the dependent variable. The predictors' effect sizes are given as OR with 95% CI.

Univariate (unadjusted) logistic regression analyses were performed, using the independent variables age (scale), gender (male/female), Down syndrome (yes/no), CP (yes/no), numbers of physical health conditions (scale), GMFCS (ordinal scale 1–5), level of ID (ordinal scale 1–4), BMI categories (underweight/normal/overweight/obese), BMI (scale), physical activity level (ordinal scale 4 levels), physical activity sweaty (yes/no) and physical activity at least 30 min per day (yes/no). Then multivariate logistic regression analyses were performed with the significant variables ($p < .05$) from the unadjusted analyses. The enter method and backward removal of insignificant variables were applied, always adjusting the multivariate models for age, gender, and intellectual disability level. The significance level was set at $p < .05$. In the exploratory studies of the impact of lifestyle factors on perceived health, when adjusting for other significant predictors, we decided to retain lifestyle factors with $p < .10$ in the final model.

Multicollinearity was checked between independent variables with 0.7 as the cut-off value. The degree of pseudo-explained variance was reported according to Nagelkerke R^2, while the Hosmer-Lemeshow test was used to investigate the model fit of the final model.

In paper III, frequency data were derived to determine prevalence rates regarding the use of healthcare services. Healthcare services such as health checks, GP visits, hospital admissions, hospital day care, visits to mental health professionals, physiotherapy, specialized habilitation services, and preventive procedures were registered either as service received during the preceding 12 months or a service not received.

Possible associations between the prevalence of the use of each healthcare service and three age groups were investigated with crosstabulation by means of the linear-by-linear association test.

As healthcare services use increased with age, possible associations between the use/no use of each care service as the dependent variable and intellectual disability level (mild/ moderate/ severe/profound) were examined, with several logistic regression analyses adjusted for age. Multicollinearity was checked between independent variables with .7 as the cut-off value.

The association between dental care services received in the preceding 12 months (yes/no) and the following variables were investigated by means of Fisher's exact test: dental care when needed (yes/no), pain in mouth/teeth (yes/no), and dental health (good/poor).

Variables associated with having/not having an intellectual disability as the dependent variable were investigated using univariate and multivariate logistic regression analysis. Independent variables were age, gender, and intellectual disability level.

The level of significance was set at $p < .05$. As we had varying levels of missing data, we only reported those who had registered use of services. Therefore, we reported on valid percentages for descriptive statistics.

4 Results

4.1 Summary of paper I: Substudy

Objectives: To investigate in a population of youths and adults with an intellectual disability: 1) the completion rates of physical capability measure; 2) possible associations between test completion and demographics and cognitive, gross motor, communicative and behavioural functioning; and 3) to identify predictors of physical capability test scores. A secondary objective was to compare physical capability tests result with existing reference values from the general population in the same area to document possible disparities in people with an intellectual disability and to make meaningful interpretations of physical capability scores.

Results: 93 out of 182 (51%) eligible adults with an intellectual disability in the municipality of Tromsø participated. The mean age of the participants was 34 years (*SD* = 14 years) and they were significantly younger than the non-participant who had a mean age of 42 (*SD* = 16 years). The gender distribution was 58% men and 42% women, and it was similar across the two groups. The distribution of intellectual disability levels in participants was mild (33%), moderate (24%), severe (28%), profound (14%) and unknown (1%).

The completion rate for one or more measurements or tests was 57% among the participants. Weight and height were the most frequently completed (57%) measurements. The SPPB had a completion rate of 46% for one or more subtests, the TUG had a completion rate of 42% and for the OLS with eyes open and closed, the completion rate was 35% and 20%, respectively. The completion rate of the SPPB for individuals with a mild to moderate intellectual disability was 70%, while 6 out of 26 participants (23%) with a severe intellectual disability completed the walking test of the SPPB. All participants with GMFCS levels 1 or 2

(the two highest levels of gross motor function) with one exception completed the physical capability tests. Four participants with the lowest communication function (CFCS levels 4–5) completed one or more physical capability tests. The OLS was not completed by 12 participants mainly because the instructor or the participants regarded it as unsafe.

Predictors of SPPB completion were having a higher cognitive function (a mild to moderate intellectual disability) and a higher BMI. Younger age (below 40 years) and a less severe intellectual disability predicted higher total SPPB scores. When participants with the two highest GMFCS levels were compared, there were significant better total SPPB score, walking speed, and sit-to-stand results in those with GMFCS level 1 compared to level 2. Participants with a normal BMI walked faster than obese people.

Compared to reference values in the general population, the mean test scores of participants with an intellectual disability were similar to people aged 80 years and older.

Conclusion: Around 50% of study participants completed one or more measures or physical capapility tests, more among those with a mild and a moderate intellectual disability, and less among participants with a severe intellectual disability. A low BMI predicted non-completion, whereas younger age and higher cognitive function were associated with better total SPPB scores. Regular use of physical capability tests in health surveys among adults with an intellectual disability should be used to monitor functional status and in health promotion strategies for this population.

4.2 Summary of paper II: Main study

Objectives: To investigate in a community-based setting: 1) the associations between perceived health in a population of adults with an intellectual disability and demographics, degree of intellectual disability, physical health conditions and weight and physical activity level: and 2) lifestyle factors and multimorbidity as predictors for perceived health adjusted for age, gender and intellectual disability level.

Results: The study sample comprised 214 participants with a mean age of 36.1 (*SD* = 13.8). The gender distribution was 56% men and 44% women. The distribution of intellectual disability levels was as follows: mild (38%), moderate (26%), severe (24%), profound (8%), and unknown (4%). The health rating for 211 of the participants was reported as very good (33%), good (40%), fair (19%), or poor (8%). No one rated their health as very poor. The mean number of physical health conditions was 2.1 with a reported frequency for

multimorbidity of 79%. The most frequent health conditions were weight disorders (underweight/overweight/obese) (68%), visual problems (43%), allergy (32%), epilepsy (26%), oral problems (25%) and constipation (23%). Obesity, hypertension and visual aids were more frequently observed among individuals with a mild intellectual disability than in those with a severe or profound intellectual disability. Only 3% of participants smoked. Autism, epilepsy, and constipation were significantly more prevalent in individuals with a severe or profound intellectual disability than in those with less severe forms of intellectual disability.

Regarding physical activity levels, 54% of the participants reported not exercising enough to get sweat once a week. Those with a mild intellectual disability (60%) were twice as likely to get sweat at least once a week as those with a severe or profound intellectual disability (31%) ($p = .002$). In total, 58% of the participants reported being physically active for at least 30 minutes per day. Normal BMI was more prevalent in the group with a severe or profound intellectual disability (43%) than in those with moderate (35%) or mild (20%) intellectual disability. Obesity was most common in the group with a mild intellectual disability (38%).

Perceived health was rated as 'good' by more than 70% of the participants, and more women rated their health as 'poor' than men (36% women vs. 20% men). Participants with a higher number of health conditions were more likely to score poor health ($p = .001$) and worse motor function was associated with poor perceived health. In the unadjusted analysis, poor perceived health was associated with lower physical activity level on the four-level scale ($p = .05$), not being sweaty at least once a week ($p = .01$), and not being physically active at least 30 min a day ($p = .001$).

In multivariate logistic regression analysis female gender (OR 2.4, $p \leq .05$), level of id (OR .65, $p \leq .05$) numbers of physical health conditions (OR 1.6, $p < .001$) and lower motor function (OR 1.5, $p < .05$) were significant explanatory variables for poor perceived health, with a tendency to independently impact failure to achieve 30 minutes of daily physical activity (OR 2.0, $p \leq .07$).

Conclusion: Multimorbidity was present in 79%, with weight disorders as the most frequent physical health condition. Obesity was more frequent in participants with a mild intellectual disability, whereas constipation and epilepsy was more frequent in those with a severe intellectual disability. Perceived health was rated as 'good' by more than 70% of the

participants. Women with an intellectual disability, adults with reduced motor function, and adults with more health conditions are at increased risk of lower perceived health and in need of attention in health-promoting strategies. Additionally, a low physical activity level tends to influence perceived health negatively.

4.3 Summary of paper III: Main study

Objectives: To investigate the use of health and dental care services in the preceding 12 months among adults with an intellectual disability according to national recommendations and in relation to age and intellectual disability level. A secondary aim was to explore the use of dental care services concerning experienced access to dental care, pain in the mouth and experienced good or poor dental health.

Results: The study sample was the same as in paper II (main study) (214 participants with a mean age of 36.1 years, of which 56% were men).

Annual health checks are recommended. Regarding the use of healthcare services, 57% had received a health check during the previous 12 months. As expected, more older participants than younger age groups had received a health check the preceding year. Similar results were observed in GP visits. Breast examination and mammographic investigations were more frequent in older women than younger women. However, cancer screening was performed in less than 20% of the women. No age differences were observed in hospital admission, hospital day care, use of mental health professionals, physiotherapy, specialized habilitation services, or cervical cancer examination for women.

Although individuals with severe or profound intellectual disability tended to be older than those with mild intellectual disability, fewer individuals with severe or profound intellectual disability (49%) had been for a health check in the previous 12 months than those with moderate intellectual disability (54%) or mild intellectual disability (65%) (age-adjusted model, OR 1.5, p =.029). A similar pattern was seen in GP visits; individuals with a severe or profound intellectual disability had consulted their GPs less (75%) than those with moderate intellectual disability (87%) or mild intellectual disability (89%) (age-adjusted model, OR .518, p = .007). Half of the participants had been in contact with the specialized habilitation services. No statistically significant associations between intellectual disability level and hospital treatments, services from specialized habilitation teams, physiotherapy, use of mental health professionals, or use of preventive procedures were found.

In terms of IPs, 40% of the participants reported having one, of whom 27% reported that it had been evaluated in the previous year and 38% that it had been evaluated in the previous two years. Participants with an IP were younger than those without (mean age 33.8 vs. 39.0 years) and more often had a more severe intellectual disability level. Of those with an IP, 40% had a severe or profound intellectual disability, and among those without an IP, 28% had a severe or profound intellectual disability. There were no gender differences in having or not having an IP.

Regarding dental health and dental care services, 94% of participants reported they had seen a dentist or dental nurse in the previous 12 months. No age and gender differences were observed. Individuals with a severe or profound intellectual disability tended to have a higher risk of not using dental services (10%) than those with milder intellectual disability levels (4%) (p = .093).

Lack of access to dental care when needed was reported by 32% of the participants; 25% reported pain in the mouth or teeth and 39% perceived their dental health as poor. Experience of poor dental health was more frequent among individuals who had received no dental care services in the previous 12 months (62%) than among those who had received dental care services (38%) (p = .085). There were no differences in dental care services use regarding intellectual disability level or age.

Conclusion: The use of health checks and cancer screening were in general lower than recommended. Enhancing access to adequate healthcare services is needed, even more so for individuals with a more severe intellectual disability levels with expected more concurrent complex health conditions. Also, the use of physiotherapy is low compared with results from other studies. The role of the specialized habilitation service in health follow-up should be clarified. Dental care quality should be improved since many individuals with an intellectual disability experienced poor dental health despite frequently reported dental service visits.

4.4 Additional results (unpublished)

Due to a small study sample, a thorough analysis of subgroups, such as individuals with an intellectual disability and autism, in relation to intellectual disability levels could not be done. However, some exploratory analyses were done and are presented in Table 2. The exploratory analyses showed that compared with the other participants fewer individuals with autism (44%) had received a health check and had visited a GP in the preceding 12 months.

Participants with CP more frequently received physiotherapy treatment than the other participants.

Table 2. An overview of exploratory analyses of healthcare services in subgroups with intellectual disability and concurrent diagnosis of Down syndrome, autism and cerebral palsy.

	Down syndrome N = 40	*P* value	Autism N = 48	*P* value	Cerebral palsy N = 24	*P* value
Health check, n (%)	26 (65%)	.258	21 (44%)	.031	15 (62%)	.564
General practitioner, n (%)	34 (85%)	.865	34 (71%)	.005	23 (96%)	.137
Hospital admittance, n (%)	3 (7%)	.103	9 (19%)	.622	6 (25%)	.224
Hospital day care, n (%)	12 (30%)	.009	22 (46%)	.691	15 (62%)	.148
Mental health professional, n (%)	4 (10%)	.247	5 (10%)	.197	2 (8%)	.384
Physiotherapy, n (%)	4 (10%)	.067	8 (17%)	.738	8 (33%)	.042
Specialized habilitation services, n (%)	15 (37%)	.105	23 (48%)	.828	11 (46%)	.737
Dental care services, n (%)	38 (95%)	1.000	43 (90%)	.174	23 (96%)	1.000

Statistical analyses are with Chi Square test, or when appropriate, Fishers exact test.

5 Discussion

The overall aim of the research project was to investigate physical performance and physical and perceived health, and to investigate the use of healthcare services in a population of Norwegian adults with an intellectual disability. A secondary aim was to explore oral health and the use of dental care services.

This study made use of an observational cross-sectional multicentre design. The main methods of data collection were structured interviews, standardized questionnaires and physical capability tests. In this section, a general discussion of the study's results is presented first, followed by methodological considerations. Finally, implications for practice and future research are discussed.

5.1 General discussion of results

5.1.1 Physical function in relation to physical activity and health

Approximately half of the participants in the current study who completed the questionnaires also performed one or more of the physical capability tests, a finding that was in accordance with the HA-ID study conducted in the Netherlands (Hilgenkamp et al., 2013). It is important to determine feasibility across intellectual disability levels, mobility levels, age categories and residential settings (Hilgenkamp, van Wijck, et al., 2012; Oppewal & Hilgenkamp, 2019a), but different inclusion criteria and test procedures make comparison across studies difficult. Many of the studies that included physical capability tests used convenience sampling of individuals with an intellectual disability, and mostly involved individuals with a mild to moderate degree of intellectual disability (Carmeli et al., 2005; Kovačič et al., 2020), while our study intended to include participants with more severe cognitive deficits. The good feasibility of the SPPB and the TUG physical capability tests that we found in participants with mild to moderate degree of intellectual disability was consistent with reports from other studies (Enkelaar et al., 2013; Torres-Unda et al., 2017). As only 6 (23%) participants with a severe intellectual disability in the current study completed the walking test in the SPPB, more research regarding the development of valid tests for individuals with a severe or profound intellectual disability is required. The development of tests with a more pedagogical approach (e.g., adapting communication and test-material to people with intellectual disability) may lead to enhanced participation by individuals with more severe intellectual disabilities (Dijkhuizen et al., 2018). Issues of importance in physical activity participation (Michalsen et al., 2020) may also play a role in test participation. For example, motivation for participating in physical performance tests could be improved by better preparation, use of pictures in communication and engagement with support persons. In general, reasons for not participating in research for individuals with an intellectual disability may include dependency on others, transport difficulties and skepticism towards new experiences (Brooker et al., 2014).

The association between non-completion of the SPPB and lower BMI suggests that individuals with an intellectual disability who fail to participate in or complete tests in health surveys may be at high risk for poor general health. In general, people with illnesses are less likely to participate in research (Fry et al., 2017) which could prejudice the generalizability of the study. An expected significant association was found between higher cognitive function and test-completion, which was also reported by Hilgenkamp et al. (2013).

Physical fitness is important to perform activities of daily living and low levels of strength and endurance limit independence (Oppewal et al., 2015). In the prevention of cardiovascular disease (CVD), training has been promoted as an economic strategy that improves cardiorespiratory fitness and muscular strength, both reported to be inversely associated with future CVD events in population-based studies (Tikkanen et al., 2018). Lower scores on physical capability tests may increase the risk of poorer everyday function and poorer health in older persons and probably in individuals with an intellectual disability (Bergland et al., 2017; Oppewal et al., 2015). Evenhuis et al. (2012) found age, Down syndrome, dementia, motor disability and a severe intellectual disability to be significantly associated with frailty in older adults with intellectual disabilities. Participants were defined as frail if they had at least three of the five criteria; weight loss, poor grip strength, slow walking speed, low physical activity, and poor endurance or exhaustion. The important relationship between falls, balance, and gait issues was reported in a previous review of the literature (Enkelaar et al., 2012) and physical activity is reported to have a significant impact on balance improvement among adults with an intellectual disability (Kovačič et al., 2020). More than half of the participants in our study reported being physically active for at least 30 minutes per day, although 54% did not exercise enough to get sweat once a week, which is lower than recommended. Other studies have reported that the frequency of falls significantly correlates with exercise, and falls may be greatly reduced by using balance-oriented and well-implemented physical activity programmes (Kovačič et al., 2020). People with an intellectual disability experience falls to the same degree as the general older population, but often at an earlier age. The consequences of falls can be profound and lead to loss of confidence, reduced mobility, injury, and even death (Axmon et al., 2019; Finlayson, 2018).

The low scores of the young group in the current study when compared with the general population are alarming and call for action. Furthermore, the findings reported in paper II where failing to achieve a minimum of 30 minutes of daily activity tended to influence perceived health negatively also highlight the importance of physical activity. Additionally, people with an intellectual disability and reduced motor function are at risk of low perceived health, even after adjusting for multimorbidity and cognitive functioning. This corresponds with reported deterioration in gross motor function and perceived health in young adults with CP (Usuba et al., 2014) and adults with CP in the long-term (Benner et al., 2017). ‘Older adults with CP are at greater risk of accelerated musculoskeletal system ageing often leading to loss of mobility, osteoporosis, chronic fatigue, and chronic pain’(Perkins & Moran, 2010).

Increased attention to physical activity support for individuals with an intellectual disability at all ages is recommended.

5.1.2 Multimorbidity, lifestyle factors and perceived health

Few epidemiological studies have been conducted among individuals with intellectual disability in the Nordic countries. A recent Swedish population-based cohort study reported that severe health challenges were associated with premature mortality in people with intellectual disabilities (Hirvikoski et al., 2021). Risk factors for cause-specific mortality in individuals with an intellectual disability that have been identified in the literature include obesity, hypertension and diabetes (Flygare Wallén et al., 2018). Research examining physical activity and its association with chronic disease and secondary conditions will always be relevant (Pitchford et al., 2018).

To our knowledge, no other recent studies have investigated perceived health with medical health conditions as one of the predictor variables. Although the multimorbidity rate was 79% in our study, the mean number of conditions was 2.1. This was lower than in other studies (Folch et al., 2018; Kinnear et al., 2018; McCarron et al., 2013) and could be caused by a young study population, the exclusion of mental health conditions, the list of diseases in the questionnaire or no physical examination to reveal potential new conditions. However, the result of 79% with at least one physical health condition in addition to an intellectual disability or a syndrome diagnosis was higher than the 61.5% reported by Cooper et al. (2015) in a Scottish representative study. The mean age was higher in other study populations and multimorbidity was defined in other ways (McCarron et al., 2013; Ng et al., 2017; Tyrer et al., 2019). To include mental health would possibly strengthen the association between higher frequency of health conditions and lower perceived health (Sigurdardottir et al., 2019).

The literature has reported that multimorbidity was independently associated with a severe or profound intellectual disability (Folch et al., 2018; Hermans & Evenhuis, 2014; Tyrer et al., 2019), a finding that was not observed in the present study. The different definitions of multimorbidity used in the literature complicate comparison. For example, Tyrer et al. (2019) included mental health disorders and two or more chronic conditions in addition to an intellectual disability, while Kinnear et al. (2018) required an intellectual disability plus at least two physical health conditions. However, this study found the preventable physical health condition constipation to be more frequent in the participants with a severe intellectual disability than those with mild intellectual disability (paper II).

Overall, participants with an intellectual disability in the current study reported their perceived health as good. Studies from Australia and Scotland reported perceived good health in individuals with an intellectual disability to be 78% and 48% respectively (Cocks et al., 2017; Kinnear et al., 2019). The better perceived health experienced by study participants in compared with the Scottish study population may be due to a younger and healthier study population with better economic conditions (Cocks et al., 2017; Emerson et al., 2016).

Predictors of poor perceived health in the final model of the present study were female gender, lower motor function, intellectual disability level, and having more physical health conditions. An American study reported the intellectual disability level was significantly associated with perceived health in unadjusted analyses (Jin et al., 2020). However, the intellectual disability level was a significant predictor but with a low effect size (OR.65, $p <$ .05) in the final model of the present study. The common adjustment for mobility in health studies of adults with an intellectual disability (Jin et al., 2020; Tyrer et al., 2019) is supported by the finding that motor function predicts poor health in the present study. A strong correlation between the degree of CP, intellectual disability level and prevalence of epilepsy has been confirmed in other studies (Andersen et al., 2008; Vukojević et al., 2017; Zafeiriou et al., 1999). As epilepsy is one cause of falls in individuals with intellectual disabilities (Pope et al., 2021), this combination could likely lead to poorer perceived health.

In unadjusted analyses several measures on physical activity levels were associated with better-perceived health, and the final model showed a tendency that 30 minutes of daily activity had an impact on perceived health. This finding is consistent with other reports of strong associations between physical activity levels and perceived health (Cocks et al., 2017; Jin et al., 2020). The positive impact that physical activity has on numerous health conditions has been confirmed in several studies (Bull et al., 2020; Tyrer et al., 2019). Recommendations from the WHO on how much physical activity is needed to improve and maintain good health are reported in guidelines (Bull et al., 2020). Physical capability tests may be used to follow up action for better physical health. Physical activity combined with healthy nutrition may prevent and treat overweight and obesity in people with intellectual disabilities (Bergström et al., 2013; Emerson, 2005).

Jin et al. (2020) reported lower perceived health in adults with intellectual disability and obesity than in those of normal weight. The present study did not confirm this, which could be a result of fewer participants with obesity or healthier participants despite the presence of

obesity in the present study. In the general population an association between obesity and lower perceived health has been found (Katya et al., 2013) and more research is needed on this topic in individuals with an intellectual disability.

Gender differences in perceived health favor men, found in the present study. This finding was also observed by Kinnear et al. (2019) but was not reported in other studies (Cocks et al., 2017; Jin et al., 2020). Studies in the general population regarding multimorbidity and gender differences have reported inconsistent findings (King et al., 2018; Rizza et al., 2012; Wister et al., 2016) while female gender has been associated with multimorbidity in people with an intellectual disability (Cooper et al., 2015; Tyrer et al., 2019).

In the literature, the most consistently reported factor that affected overall health, whether measured subjectively or objectively, is age (Cocks et al., 2017; Kinnear et al., 2019; Wister et al., 2016). Whereas increasing age was not a predictor for overall perceived health in the current study, the relatively young age of the study populations may have contributed to this finding.

The knowledge of strong associations between poor health ratings and female gender, intellectual disability severity, lower motor function and several physical health conditions can be used in the planning and organizing of healthcare services. Giving special attention to these subgroups may prevent poor perceived health.

5.1.3 Use of healthcare and dental care services

To the best of our knowledge, this is the first cross-sectional study on the use of healthcare services by adults with an intellectual disability in Nordic countries. Several countries, also Norway, include regular health checks as part of their best practice guidelines for primary care practice for individuals with an intellectual disability (Maltais et al., 2020; Norwegian Directorate of Health, 2021; Perera et al., 2019). The use of annual health checks for individuals with an intellectual disability is an effective way of identifying undetected comorbidities and increasing the use of preventative health-related activities, which could reduce avoidable deaths (Buszewicz et al., 2014; Robertson et al., 2014). In the present study, 57% of participants had been for a health check during the previous 12 months, although 79% of them had a known multimorbidity. The high level of multimorbidity could raise the risk of an increase in health problems if the individuals are not followed up properly. The reported use of annual health checks in the United Kingdom is between 50% and 64% (McConkey et

al., 2015; Perera et al., 2019), while studies in Spain and Canada have reported that 30% of the population with an intellectual disability had not had a health check during the previous year (Folch et al., 2018; Maltais et al., 2020). This means that according to the results of our study, Norway has poorer health follow-up than is found in comparable countries internationally.

The majority of individuals with an intellectual disability (84%) in the present study had visited their GP during the preceding year and increasing age was a significant factor, which is consistent with other studies (McCarron et al., 2017; McConkey et al., 2015). However, individuals with a severe or profound intellectual disability had been for a health check and seen their GP significantly less than those with milder forms of intellectual disability. This worrying finding was consistent with studies from Spain and Canada (Folch et al., 2018; Maltais et al., 2020). Previous studies have reported that multimorbidity was independently associated with a severe or profound intellectual disability (Folch et al., 2018; Hermans & Evenhuis, 2014; Tyrer et al., 2019), but the current study did not confirm this (paper II). Still, individuals with more severe forms of intellectual disability will likely have more severe concurrent health conditions than individuals with milder forms of intellectual disability. This may be due to the different distribution of health conditions, and because they may not be able to communicate their health problems. The use of physiotherapy was reportedly more common among individuals with a severe or profound intellectual disability than among those with milder forms of intellectual disability in a Spanish study (Folch et al., 2018), a finding we did not observe. Additionally, the use of physiotherapy treatment was overall lower in the present study than in the Spanish study, which may be due to the different organization of healthcare services between Norway and Spain.

Folch et al. (2018) reported more frequent hospitalization among those with a moderate or severe intellectual disability, which was not confirmed in the present study. This contradiction could be explained by the underuse of specialized health care services in individuals with a more severe intellectual disability in Norway, less use of health checks, communication issues, and difficulties with access to specialized medical care in hospitals. Hospital admittance did not increase with age in the present study, which contradicts the finding reported by Skorpen et al. (2016), probably because of the younger age in the current population.

However, Axmon et al. (2019) reported a different pattern of injuries in older people with an intellectual disability than in the general population. They were more likely to injure their head and legs but less likely to injure their arms. Older people with moderate and severe intellectual disabilities often live in group homes where staff are available around the clock. The decision to hospitalize a person with an intellectual disability who has fallen is often dependent on the staff rather than the person with an intellectual disability. Unless the fall results in a visible injury, such as an open wound, people with an intellectual disability might not understand the need for health care, nor is it always obvious to the caregiver that health care is required (Axmon et al., 2019). Especially people with a more severe form of intellectual disability could have problems with communicating symptoms requiring treatments. The lower level of health checks and GP visits among this group, as reported in paper III, could further lead to undiscovered health issues caused by a fall. Thus, staff working with people with intellectual disabilities must have knowledge not only of fall prevention and communication but also of fall-related injuries in this group (Axmon et al., 2019; Finlayson, 2018). This could suggest that different approaches to the planning of preventative measures to reduce falls and fall-related injuries are needed.

An annual health check is recommended for people with intellectual disabilities to improve their overall health and well-being, and thus lessen poor health factors that can contribute to or cause falls. An annual health check assessment tool that also considers fall and injury risk and occurrence would be most beneficial (Finlayson, 2018).

A qualitative Canadian study investigated the perspectives of individuals with intellectual and developmental disabilities on what they needed to access annual health examinations. Help from support persons in system navigation and person-centred care was reported as important to attend health examinations (Potvin et al., 2019).

Screening programmes for women with intellectual disabilities are reported to be used more frequently by women with a mild intellectual disability than by those with more severe forms of intellectual disability (Folch et al., 2018; Maltais et al., 2020). In the present study, there was limited use of cancer screenings in all groups.

The small study sample made it impossible to perform a thorough subgroup analysis, but we did some explorative analyses to investigate potential differences between individuals with autism, Down syndrome, CP and participants without these diagnoses. As Table II shows,

fewer individuals with autism (44%) had been for a health check or visited their GP compared with the other participants. The prevalence of autism spectrum disorders increased significantly as the intellectual disability severity level increased in the study by Folch et al. (2018). As almost all diseases were more prevalent in individuals with profound intellectual disability (Folch et al., 2018), the finding in the present study suggested that individuals with autism may face even greater health disparities. The increased contact with physiotherapists that individuals with CP had in the present study compared with the other groups may be due to CP guidelines and the prevalent motor disabilities.

An IP is a tool for better cooperation between different services for individuals with complex needs and is a statutory right for Norwegians in need of long-term and coordinated services (Norwegian Directorate of Health, 2021). Only 40% of the individuals with an intellectual disability reported having an IP, and in total only 13% had a functioning IP with regular evaluations. The new guidelines for Norwegians with intellectual disabilities state that the cooperation between service users, GP, and other service providers regarding healthcare follow-up must be documented in the service users' medical records and implemented in their IPs (Norwegian Directorate of Health, 2021).

After deinstitutionalization in Norway, many people with intellectual disabilities were moved into staffed group homes that accommodated 3 or 4 residents with each person having a private living area comprising a kitchen, a sitting area, a bedroom, and a bathroom (Tøssebro et al., 2012). However, while the typical group home had 3 or 4 residents in the mid-1990s, newer group homes have been built for two-three times as many people (Tøssebro et al., 2012). Ruud et al. (2020) reported on the experiences that next of kin, caregivers and leaders of group homes for individuals with intellectual disabilities had with healthcare for their patients in a part of Norway. This investigation included participants who had experience with both health follow-up through GPs and health follow-up through a primary health team. A primary health team was a pilot project that tried out new ways of distributing work tasks at the GPs' offices by employing nurses who were able to cooperate clinically with the GP with defined patient groups like individuals with intellectual disabilities. Several participants felt the GP provided a brief health follow-up and had little intellectual disability knowledge while the primary health team was seen as a more holistic form of health follow-up (Ruud et al., 2020).

5.1.4 Oral health

Regarding dental care, almost all participants had seen a dentist or dental nurse during the preceding year. This was a better result than that found in studies from Spain and Canada where only around 50% had visited a dentist during the previous year (Folch et al., 2018; Maltais et al., 2020). Despite the high frequency of dental care visits, 32% reported not having access to dental care when needed, and 39% experienced poor dental health. Several studies have reported poorer dental health among individuals with an intellectual disability than in the general population (Cabrita et al., 2017; Wilson et al., 2019). It is a well-known problem that even patients under routine maintenance still have oral health problems (Finkelman et al., 2013). Poor oral health was predicted by intellectual disability severity, older age, and independence in daily oral hygiene routine (Wilson et al., 2019). Problems with dental health continued even though recommendations for regular dental checks were being followed. Some reasons for this may be pain, or problems with communication or collaboration. The majority of studies worldwide have been cross-sectional screening studies that used convenience samples with a small number of retrospective case file reviews (Wilson et al., 2019). Oral health has been linked to BMI and physical activity level (Virtanen et al., 2018; Ward et al., 2019).

A study from the United Kingdom identified factors that affected access to daily oral and dental care among adults with an intellectual disability and divided them into two global themes: ‘Personal and lifestyle influences’ and ‘Social and environmental factors’. The first theme was more often mentioned as a barrier to oral care while the second theme was mentioned more as a facilitator of oral care (Chadwick et al., 2018). Barriers could be that the person with an intellectual disability does not understand the importance of brushing their teeth appropriately or forget to brush their teeth. The person with an intellectual disability could be very sensitive in the face or mouth area, making it difficult to brush their teeth. Lack of motivation for oral care and lifestyle factors including smoking, diet and use of medication were also seen as barriers. Examples of facilitators for oral care were caregiver support, the right kind of equipment and adaptations and having an individualized oral care routine (Chadwick et al., 2018). Chadwick et al. (2018) concluded that numerous individual, social and environmental factors influence oral care. A coordinated organizational response is advocated involving collaboration between dental and intellectual disability services and training for caregivers and people with intellectual disabilities.

5.2 Methodological considerations

There are several important issues to address regarding epidemiological research involving individuals with intellectual disabilities. First, people with intellectual disabilities are regarded as a vulnerable group and there are certain ethical procedures to follow when starting a research project involving them (The Norwegian National Research Ethics Committees, 2021). Secondly, study design and methods must be accommodated to people with intellectual disabilities in a way that does not jeopardize research integrity (Feldman et al., 2014; McCallion et al., 2019). For instance, physical capability tests and questionnaires must be standardized for the results to be valid, and some people with intellectual disabilities will need particular adaptations of tests and questions to enable participation.

The quality of a study depends on its internal and external validity, meaning the degree to which a study is free from error and is generalizable (Jager et al., 2020). Caution must be taken when interpreting the results of this study. Selection bias and the low response rate in one region will influence the external validity of the study. In the following section, methodological concerns regarding the current study's cross-sectional design and its internal and external validity will be discussed.

5.2.1 Study design.

The NOHID study had a cross-sectional design, meaning that data was collected at a single point in time. Cross-sectional designs are often used in epidemiological research when investigating the prevalence of diseases (or other health-related issues) and other variables of interest in a defined population. However, causal conclusions must be considered carefully as often the order of cause and effect is unknown. For instance, the association between physical activity level and perceived health in the present study might be bidirectional as poor perceived health could lead to less physical activity or less physical activity could lead to poor perceived health. On the other hand, the main impact factors that were investigated concerning an outcome (e.g., perceived health) were age, gender, and cognitive function, are less likely to be impacted by the outcome. The advantages of a cross-sectional design are that it can be done relatively quickly, is cheap to do and in general is quite simple to administer (Wang & Cheng, 2020). In the current study, the main outcomes were based on associations between specified variables, and not estimates of the prevalence of diseases, due to known problems with generalizability. The results may be useful for assessing the healthcare needs of a population and for planning and allocating health resources (Robertson et al., 2014).

5.2.2 Errors in the study

Internal validity is crucial in obtaining valid results from a study and may be affected by two types of errors: random errors and systematic errors. Random errors are associations between an exposure and an outcome that appear by chance. As no measurement system is perfect, all data will contain some random errors. Random errors may be reduced by enlarging the study sample and by using precision in measurements (Szklo & Nieto, 2014). The questionnaires used must be validated and reliable so that the research questions can be answered appropriately.

The measurements used in the present study were chosen because either they had been used and validated in the population with an intellectual disability (the P15; Perry et al., 2010) or they had at least been used previously in the target population (the GMFCS, the CFCS and the SPPB). The latter instruments have been validated in other populations with cognitive difficulties like CP or dementia. The TUG has been validated in individuals with Down syndrome and individuals with intellectual disabilities (Cabeza-Ruiz et al., 2019; Cabeza-Ruiz et al., 2020). Nevertheless, it was a weakness that not all the questionnaires and physical capability tests were validated for use in adults with intellectual disabilities. A detailed protocol was developed ahead of the study and adapted based on our experience with people with intellectual disabilities. As this was a multicentre study involving several research assistants, regular meetings between the research centres and research assistants were held online during the data collection period. The purpose of these meetings was to ensure that the procedures were equally followed across the study centres.

We chose to use the same battery of physical capability tests as in the Tromsø study using a comparison of the results with the general population from the same area. Also, the tests have been used in other studies in people with intellectual disabilities.

A strength of the study was the available information of participants' intellectual disability level, and the confirmation of the diagnosis in the participants' medical records.

However, the study had some limitations. The precision of the reported BMI values may have been affected as not all participants had their BMI measured on-site; for some participants, BMI was based on self-report.

Some of the tests (the SPPB) have not been validated for people with an intellectual disability or not for all intellectual disability levels, although we did not have any participants with a

profound intellectual disability and very few with a severe intellectual disability who performed those tests.

Regarding the most important outcomes, there was little missing data, and only participants with complete reported data were used in the analyses. Some scales (e.g., the ABC-C) that had missing data were treated according to proper procedures of replacing occasionally missing items.

5.2.3 Systematic error

Systematic error (also known as bias) in the design, in the conduct or the reporting of a study is problematic. A study may be biased by how the study participants were selected or how study variables were measured. Consequently, the true frequency of exposure and outcome may be either under- or overestimated leading to flawed study results. Since the error is systematic, bias cannot be reduced by increasing the sample size. Usually, bias cannot be adjusted only prevented (Jager et al., 2020).

There are many forms of bias, but two main categories are selection bias and information bias.

Selection bias stems from errors in the selection procedure of study participants, and factors affecting study participation. Selection bias implies that the relationship between exposure and outcome may differ between those who participate in the study and those who do not. As this relationship is typically unknown in non-participants, selection bias can usually not be observed, but only hypothesized (Szklo & Nieto, 2014). A low response rate is a frequently occurrence in surveys.

In the northern region, we included 140 participants, a participation rate of 53%. The total number of individuals with intellectual disabilities that we managed to include was 214. In the current study, selection bias resulted in the inclusion of younger participants than what could have been included if the total population with an intellectual disability participated.

All adult individuals with intellectual disabilities in these municipalities were invited to participate. To ensure that individuals with intellectual disabilities not receiving healthcare services also got the opportunity to participate, the study was promoted through different channels (regional television and radio stations, organizations, hospitals' internal newspaper, administrative leaders of the municipalities). The cooperation of the municipalities and access

to the hospitals' journal system enabled us to identify all individuals with intellectual disabilities who were receiving some sort of healthcare service. Yet, probably, we did not reach all individuals with an intellectual disability because there must be a subset of the population who were not receiving some sort of service, in particular individuals with a mild intellectual disability (Emerson et al., 2016). Therefore, we cannot claim to have had a representative study sample.

It is commonly known that people who are sick are less likely to participate in studies. Older people tend to be sicker than younger people. However, the age distribution of the participants was only somewhat lower than other population samples (Folch et al., 2018) and the distribution of cognitive functioning was quite similar to other studies (Cooper et al., 2017; Folch et al., 2018).

The need to include individuals with intellectual disabilities in research is acknowledged, however there remains a potential threat of exclusion for the least able through the over-protective gatekeeping roles of service providers (Doody, 2018). The complex process of gaining informed consent and the time-consuming logistic of transport and investigations may influence support persons to exclude some potential participants.

Information bias is caused by errors in the measurement, collection, or interpretation of the exposure, of the disease, or both (e.g., an exposed participant misclassified as non-exposed or vice-versa) (Szklo & Nieto, 2014). An example of the latter could be an individual registered as having GMFCS level 1 while level 4 is more accurate, or an individual registered as GMFCS level 4 while level 1 is more accurate.

As mentioned earlier, our study made extensive use of the P15, which has been tested and validated in a population of persons with intellectual disabilities (Perry et al., 2010). The GMFCS and the CFCS have not been validated in individuals with an intellectual disability but have been in a population with CP (many of whom have also been diagnosed with an intellectual disability). The physical capability tests used in the present study were used previously for individuals with an intellectual disability, but not all have been validated in a population of individuals with intellectual disability (e.g., the SPPB).

Recall bias is common in studies that use self-reporting and is caused by inaccurate or incomplete recall of past events or experiences. Recall bias may lead to the misclassification of exposure (Jager et al., 2020). The diagnosis of intellectual disability involves cognitive

impairments like memory difficulties, understanding, reasoning and language. 'Providing self-report involves four cognitive tasks: (1) accurate interpretation of the question, (2) retrieval of information, (3) judgement of retrieved information and (4) formatting a response. This cognitive process taps into comprehension, memory, ability to compare across time and people and verbalize correct responses' (Scott & Havercamp, 2018). People with intellectual disabilities are a heterogeneous group with significant individual differences. Some persons with a mild degree of intellectual disability will be able to answer many of the questions by themselves, while many who have a severe or profound intellectual disability will not be able to answer any questions due to cognitive impairment (Fujiura, 2012). In the latter cases, the only way to get answers is by asking a support person. This will, of course, affect the validity of the answers, particularly for the questions related to perceived health, dental health and pain as a proxy cannot know the internal physical and mental state of another person (Scott & Havercamp, 2018). Although it can be difficult to measure perceived health reliably in people with intellectual disabilities, we must learn from their experiences (Fujiura, 2012).

The answers to other questions asked during the interview may also be biased. Perceived health could be influenced by the simultaneous question about health disorders. Other biases could be the interviewer's (sub) conscious gathering of selective data, or they might influence the participant's responses. We have tried to minimalize this by having regular meetings with the research assistants during which we discussed the procedures to secure a common understanding of the questions asked.

Leading questions may lead to social desirability, that is the respondent's answer is what they think the interviewer wants to hear. Another possible form of bias is nay-saying or yea-saying, where questions are answered negatively or positively irrespective of their content (Fujiura, 2012). From clinical experience, some people with intellectual disabilities may answer no or yes to anything you ask them regardless of what you ask them about even though they sometimes mean the opposite.

In the present study, most of the participants had a support person with them, or the support person answered on their behalf. This increased the risk that observer bias (differences between a true value and the value observed) occurred. Subjective judgements have a much greater potential for variability between observers than is the case with objective data. For instance, two staff members asked to rate how physically active a person with an intellectual disability is would generally rate it differently. On the other hand, most of the questions asked

in the current study measured objective data as such as age, intellectual disability level, healthcare services, health conditions, etc.

The importance of including individuals with intellectual disabilities in research demands that researchers facilitate ways to gather as much valid information as possible. During the recruitment process we emphasized such facilitation so that the individuals with intellectual disabilities could participate by being flexible in where and how the data collection would take place. Obtaining both self -reports and proxy-reports when making medical, psychological, and service-related decisions regarding individuals with intellectual disability is seen as the best practice today (Scott & Havercamp, 2018).

5.2.4 Confounding

Confounding, in contrast to bias, can be accounted for. Confounding distorts the association between an exposure and an outcome due to the association of the exposure with one or more other factors that influence the outcome's occurrence. If these factors are known and measured, the real effect of the exposure on the outcome can be obtained by adjusting for these confounding factors (Szklo & Nieto, 2014; Wang & Cheng, 2020). When we analysed the data of how multimorbidity and lifestyle factors impacted perceived health, we adjusted for possible confounding factors such as age, gender, and intellectual disability level. In other analyses, for instance, health care services use in relation to cognitive functioning, age was adjusted for.

5.2.5 External validity

External validity: 'The extent to which the results of the research can be generalized beyond the sample that generated them' (American Psychological Association, n.d). Crucial to external validity is internal validity.

As discussed previously the participants in this study were generally younger than the identified non-participants. This means that we did not have a fully representative sample and therefore cannot generalize the findings to all adults with intellectual disabilities. We cannot know if the non-participants have more health conditions than the participants, if they would answer differently from the participants or if there are other differences between the two groups. In other words, we cannot know if the results from the current study will be generalizable to all adults with intellectual disabilities in the investigated regions or wider. In particular, figures for the prevalence of health conditions must be considered with caution.

However, as the internal validity is judged to be satisfactory, the analyses of associations between the health outcome indicators and other factors (Figure 1) are considered reliable and are often in concordance with other studies.

5.3 Clinical implications

First, the study reveals a need to implement annual health checks for all adults with intellectual disabilities in Norway as recommended in national guidelines (Norwegian Directorate of health, 2021). Regular health checks for individuals with intellectual disabilities have also been recommended in Canadian guidelines, but the implementation of health checks is challenging. However, performing health checks was associated with more preventive health actions and higher comfort levels of staff working with individuals with intellectual disabilities (Durbin et al., 2019). In developing better health care services for individuals with intellectual disabilities, a wider implementation and evaluation of health checks are needed, along with staff training (Durbin et al., 2019).

Second, we recommend that physical capability tests should be part of annual health checks whenever possible so that physical function can be monitored and action initiated if needed. Thereafter it can be evaluated by new measures of physical performance. Physiotherapists should mainly be responsible as part of the habilitation team for the implementation of physical capability testing in the clinical setting.

Health-promoting strategies involving the central lifestyle factors should be prioritized. Enhancing physical activity levels in people with intellectual disabilities may improve health and prevent diseases. Norway has a long winter and facilitating indoor activities is important, particularly for this group of people among whom poor balance and motor disabilities are common. Physiotherapists should be used more often as supervisors for staff working with individuals with intellectual disabilities. Health must be considered holistically and both physical activity and nutrition are important for an individual's well-being.

More specific guidelines for dental care services for individuals with intellectual disabilities should be prepared, as it is not enough with regular dental care visits to maintain good dental health.

Health promotion and disease prevention strategies should be tailored to the individual's health risks. In particular, attention should be paid to people with a more severe degree of intellectual disability. Better cooperation between GPs, specialized health care services, users

and dental care services is needed. Patient-centred interdisciplinary primary care teams offer a promising solution for adults with intellectual disabilities (Ruud et al., 2020).

5.4 Possible areas for future research

Health indicator studies with a focus on treatment of individuals with an intellectual disability and concurrent mental health conditions should be performed and are planned as an extension of the NOHID study. Additionally, the associations between health and use of healthcare services and living conditions, as well as day activities and work, need to be investigated in a Norwegian context.

The validation of tests such as the SPPB, the GMFCS, and the CFCS in individuals with an intellectual disability is relevant for future research. As part of this, the validation of physical capability tests against measures of daily living should be undertaken.

The low use of physiotherapy among individuals with a severe or profound intellectual disability is worrying and should be investigated since many of these individuals also have motor disabilities.

More focus on user involvement among people with intellectual disabilities in health research may help in the recruiting and facilitation for the participation of individuals with intellectual disabilities in health surveys. Furthermore, user involvement in health promotion may lead to better success in preventing diseases, improving health and getting more attention from policymakers.

An IP should be an effective tool, but it currently does not work as intended. More research on how to make it work, or preferably on new effective coordinating systems, is crucial.

Longitudinal studies on regular health screenings in follow-up programmes, and international collaboration would create new knowledge and enable more effective interventions.

Some interventions in promoting a healthy lifestyle for individuals with an intellectual disability based on educating the care providers have been tried out in Sweden and the Netherlands (Elinder et al., 2018; Overwijk et al., 2022). In the study by Elinder et al. (2018), an overarching theme for success was the need for a supportive structure and key persons with a mandate to act. The theory-based program used in the Netherlands was found to be feasible to implement and deliver positive changes in both persons with an intellectual

disability and their care providers (Overwijk et al., 2022). Similar interventions should be investigated on a larger scale.

An international study has looked at how to create inclusive health systems for people with intellectual disabilities. Several strategies were identified but demand a long time to implement due to the many different policies and health systems that exist. Nevertheless, the identified actions and indicators can form the basis for improved access to health and for advancing the human rights of persons with intellectual disabilities (McConkey et al., 2020). This could be further investigated in Norway taking into consideration how to make it work in all areas, including hospitals.

The lack of representative samples of people with and without intellectual disabilities continues to be one of the most important methodological limitations in intellectual disability research (McMahon & Hatton, 2020). Therefore, future research should address this problem.

6 Conclusion

The present study reports on several health challenges in Norwegian individuals with intellectual disabilities. Knowledge of the health of people with intellectual disabilities is important to reduce health challenges and improve quality of life. The current study showed that it is feasible to conduct community-based studies on health and healthcare services where individuals with an intellectual disability, also those with a severe or profound intellectual disability can be present at the examination or interview.

One of the most important findings in the present study was that people with intellectual disabilities have significantly poorer scores on physical capability tests than the general population. However, there is a need to develop physical capability tests that are feasible for individuals with severe to profound intellectual disabilities. Furthermore, being a woman, having a lower motor function, and having more physical health conditions increased the risk of poor perceived health. There was also a tendency that failing to achieve at least 30 minutes of daily activity impacted perceived health negatively. Therefore, more attention must be given to these individuals in terms of health promotion.

The results of the present study suggested that by enhancing physical activity levels, perceived health and physical performance for individuals with an intellectual disability in general, might improve. As weight disorders were the most frequent health disorder, nutrition must be emphasized to a greater extent. Systematic health assessments are important in

preventing poor health among this population and should be increased. Physical capability tests could be a part of the assessment. Many individuals with intellectual disabilities reported poor dental health despite frequently reported visits to dental care services. This suggested that the quality of dental care services for individuals with an intellectual disability needs improvement. Lastly, more research into effective measures in healthcare planning is needed as currently IPs do not work as intended.

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Paper I

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ORIGINAL ARTICLE

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Factors associated with non-completion of and scores on physical capability tests in health surveys: The North Health in Intellectual Disability Study

Monica Isabel Olsen[1,2] | Marianne Berg Halvorsen[3] | Erik Søndenaa[4,5] | Bjørn Heine Strand[6,7,8] | Ellen Melbye Langballe[6,7] | Anders Årnes[9] | Henriette Michalsen[1,2] | Frode Kibsgaard Larsen[6] | Wenche Gamst[10] | Erik Bautz-Holter[11] | Audny Anke[1,2,11]

[1]Department of Rehabilitation, University Hospital of North Norway, Tromsø, Norway

[2]Faculty of Health Sciences, Department of Clinical Medicine, UiT The Arctic University of Norway, Tromsø, Norway

[3]Department of Paediatric Rehabilitation, University Hospital of North Norway, Tromsø, Norway

[4]Faculty of Medicine, Institute of Mental Health, Norwegian University of Science and Technology, Trondheim, Norway

[5]Department of Brøset, St. Olavs University Hospital, Trondheim, Norway

[6]Norwegian National Advisory Unit on Ageing and Health, Vestfold County Hospital Trust, Tønsberg, Norway

[7]Department of Geriatric Medicine, Oslo University Hospital, Oslo, Norway

[8]Department of Chronic Diseases and Ageing, Norwegian Institute of Public Health, Oslo, Norway

[9]Department of Pain, University Hospital of North Norway, Tromsø, Norway

[10]Department of Clinical Research, University Hospital of North Norway, Tromsø, Norway

[11]Faculty of Medicine, Institute of Health and Society, Research Centre for Habilitation and Rehabilitation Model and Services (CHARM), University of Oslo, Oslo, Norway

Correspondence
Monica Isabel Olsen, Department of Rehabilitation, University Hospital of North Norway, Sykehusveien 38, P.O. Box 1, 9038 Tromsø, Norway.
Email: monica.isabel.olsen@unn.no

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Institute of Health and Society, Research Centre for Habilitation Model and Services (CHARM), University of Oslo, Norway; The Norwegian Dam Foundation

Abstract

Background: This study investigated the completion rates, scores and factors associated with non-completion and low scores on physical capability tests in a health survey administered to adults with intellectual disabilities.

Method: Assessment comprised body mass index (BMI), the Short Physical Performance Battery (SPPB), the timed up-and-go (TUG) test, the one-legged stance (OLS) test; and gross motor, communication and behavioural functioning tests.

Results: The completion rates among 93 participants (aged 17–78) were 46% for the SPPB, 42% for the TUG, and 31% for the OLS. More severe intellectual disability (OR = 3.12, $p < .001$) and lower BMI (OR = 0.859, $p = .001$) were related to test non-completion. The SPPB scores were below the reference values from the general population. Lower scores were associated with older age, motor disabilities and intellectual disability severity.

Conclusions: Including physical capability tests in health surveys among adults with intellectual disabilities is important to monitor functional status and guide prevention strategies.

KEYWORDS
body mass index, intellectual disability, physical capability, Short Physical Performance Battery, timed up-and-go

1 | INTRODUCTION

Several studies have reported higher prevalence rates of conditions such as epilepsy, obesity, asthma, diabetes and hypothyroidism (Cooper et al., 2015; Folch et al., 2019; Perera et al., 2019); less preventative screening (Havercamp & Scott, 2015; Maltais et al., 2020); and higher mortality rates among adults with intellectual disabilities than among the general population (Cooper et al., 2020; Heslop et al., 2014). Adults with intellectual disabilities often present below-average physical performance (Hilgenkamp et al., 2012, 2013; Lahtinen et al., 2007). The results of physical capability tests in health surveys are important to inform health services and policy makers about current health challenges.

In older adults, a low physical fitness level has been found to be predictive of a decline in the ability to perform activities of daily living (Oppewal et al., 2015), and physical fitness components have been shown to be predictive of 5-year survival (Oppewal & Hilgenkamp, 2019b). Individuals who do not complete physical capability tests in health surveys or who achieve markedly low scores on such tests may have health challenges (Oppewal & Hilgenkamp, 2019b) and therefore be at risk of developing serious illness (Bergland et al., 2017). Physical capability tests used in the general population rely on average cognitive and physical abilities, and even short physical performance batteries used for older adults (Guralnik et al., 1994) cannot be assumed to be suitable for the population with intellectual disabilities (Hilgenkamp et al., 2013). Recently, Oppewal and Hilgenkamp (2019a) recommended a physical fitness test battery for adults with intellectual disabilities (Oppewal & Hilgenkamp, 2019a). The present study contributes knowledge from a Norwegian investigation of adults with intellectual disabilities where physical capability tests identical to those in a health survey for the general population were administered (the Tromsø Study).

Data on the completion rates of short physical capability test batteries are limited for adults with intellectual disabilities. Hilgenkamp et al. (2013) reported the feasibility of eight physical fitness tests to be moderate to good in older Dutch adults with intellectual disabilities, except those with profound intellectual disabilities (all tests), with severe intellectual disabilities (response time and Berg Balance Scale), and who used a wheelchair (all tests that involve the legs). Others have reported that clinical tests of balance and gait are feasible in adults with mild to moderate intellectual disabilities (Enkelaar et al., 2013). Sufficient feasibility and test–retest reliability in lower extremity strength tests in 29 adults with severe or moderate intellectual and visual disabilities has been reported, but behaviour or communication problems may influence the examination results (Dijkhuizen et al., 2018).

Factors associated with scores on physical performance tests may explain the variance in test results (Oppewal & Hilgenkamp, 2019a). Lahtinen et al. (2007), in a Finnish longitudinal study, found a decline in balance and manual dexterity during adulthood, with a significant relationship between balance and intellectual disability severity. In the study by Enkelaar et al. (2013) on balance and gait performance in older persons, associations with age, body mass index (BMI), and number of co-morbidities were reported. In adults with visual and intellectual disabilities, the two significant explanatory variables for scores on a modified Berg Balance Scale were the Barthel Index and the Gross Motor Function Classification Scale (GMFCS) score (Dijkhuizen et al., 2018).

Factors associated with low scores on physical capability tests used in health surveys have rarely been investigated in adults with intellectual disabilities (Oppewal & Hilgenkamp, 2019a). The Short Physical Performance Battery (SPPB) (Guralnik et al., 1994) is a well-established tool for assessment of lower extremity physical capability. It has been used in general population studies in Norway (Bergland & Strand, 2019), for elderly people living in nursing homes (Sverdrup et al., 2018), and in intervention studies involving individuals with mild to moderate intellectual disabilities (Torres-Unda et al., 2017). The primary aims of this study were to (1) assess the completion rates of physical capability measurements; (2) assess whether test completion is associated with demographics and cognitive, gross motor, communicative and behavioural functioning; and (3) identify predictors of physical capability test scores. A secondary aim in the study was to compare physical capability test result with existing reference values from the general population in the same area to document possible disparities in people with intellectual disabilities and make meaningful interpretation of physical capability (Bergland & Strand, 2019).

2 | METHODS

2.1 | Study design and setting

The North Health in Intellectual Disability (NOHID) study was a population-based study including people with intellectual disabilities who lived in five different municipalities in northern and central Norway. Data were collected between October 2017 and December 2019. This study used NOHID data from the municipality of Tromsø, which is the largest municipality in northern Norway and has 60,868 inhabitants aged 18 years or older (Statistics Norway, 2019). The

prevalence of intellectual disability in adults is 0.5%–1%, and 0.45% of this population receives welfare support (Skorpen et al., 2016; Søndenaa et al., 2010); therefore, we expected that approximately 135–270 adults with intellectual disabilities received some sort of support from the municipality. The main data collection methods were questionnaires and interviews. The current study included additional clinical measurements, specified below. For data collection, the web-based instrument REDCap (Research Electronic Data Capture, Vanderbilt University, Nashville, TN) was used. The trial is registered in the Clinical Trials Registry under identification number NCT03889002.

2.2 | Participants

We included individuals with a verified diagnosis of intellectual disability according to International Classification of Diseases 10th revision (ICD-10) criteria (World Health Organization, 2019), who were aged 17 years and above, and who lived in Tromsø. According to official municipality information, a total of 170 inhabitants had a diagnosis of intellectual disability and received services from the municipality in 2017. Potential participants were identified through (1) the receipt of specialised intellectual disability services at the University Hospital of North Norway (UNN) or (2) information available from the municipality (receiving services). For the latter participant identification method, staff from the municipality contacted the individual with intellectual disability prior to researcher contact. There were no pre-defined exclusion criteria. In line with previous studies on physical fitness tests in adults with intellectual disabilities, both people with and without co-occurrence of genetic diagnoses were included (Hilgenkamp et al., 2013; Oppewal et al., 2018). Informed consent was obtained from each individual or his or her legal representative. The study was approved by the Committee for Medical Research Ethics, Health Region North (2017/811), and the data protection officer at the UNN.

2.3 | Demographics, level of intellectual disability and questionnaires

Information about age, gender and living conditions was collected from the participants. Living situation was classified as living independently in their own residence, living with family or living in a group home with care. In Tromsø municipality, group homes have individual apartments for those with intellectual disabilities in addition to shared areas. Information about intellectual disability degree and concurrent genetic syndromes or autism was confirmed in the participants' medical records. Intellectual disability degree was categorised as mild (IQ 50–69), moderate (IQ 35–49), severe (IQ 20–34) or profound (IQ <20) (World Health Organization, 2019). For eight individuals, the intellectual disability degree was unknown; it was determined considering information about adaptive functioning and consultation with specialised intellectual disability health service staff (Tassé et al., 2019).

The GMFCS classifies gross motor functioning into levels 1–5, with lower levels indicating better function. The GMFCS was developed for children with cerebral palsy (Palisano et al., 1997) and has high interrater reliability (McCormick et al., 2007). Individuals with level 1 motor function may have limitations in advanced motor skills (speed, balance) but generally walk unremarkably. Persons with level 2 motor function usually need to use railings on stairs and walk without aid but may occasionally use devices such as crutches or a wheelchair. Persons with level 3 motor function require walking aids inside and usually a wheelchair outside. Levels 4 and 5 generally indicate wheelchair use. The GMFCS has been used but not validated in studies of adults with intellectual disabilities (Dijkhuizen et al., 2018).

The Communication Function Classification System (CFCS) classifies communication function into five levels, with lower levels indicating better communication skills. Interrater reliability is high for people with cerebral palsy (Hidecker et al., 2011), but validation in adults with intellectual disabilities is lacking.

The Aberrant Behaviour Checklist-Community (ABC-C) is a rating scale with 58 items for the assessment of behavioural problems in people with intellectual disabilities (Aman & Singh, 1994, 2017). The items are grouped into five subscales: (I) Irritability (15 items), (II) Social Withdrawal (16 items), (III) Stereotypic Behaviour (7 items), (IV) Hyperactivity/Non-compliance (16 items) and (V) Inappropriate Speech (4 items). Each item is rated on a four-point scale from (0), not a problem, to (3), the problem is severe. The Norwegian version of the ABC-C was found to have satisfactory internal consistency, factor structure and divergent and convergent validity (Halvorsen et al., 2019).

2.4 | Clinical measurements and physical performance tests

BMI was calculated as weight in kilos divided by height in metres squared and was classified as follows: underweight (<18.5 kg/m^2), normal weight (18.5–24.9 kg/m^2), overweight (25–29.9 kg/m^2) and obese (≥30 kg/m^2) (Bailey & Ferro-Luzzi, 1995). Height and weight were measured on-site or, when that was not possible, were based on self-reports. Height without shoes was measured with a stadiometer (Seca 206, Hamburg, Germany). Weight without shoes and outdoor garments was measured with a mechanical floor scale (Seca 761, Hamburg, Germany). For participants who were in a wheelchair or had difficulty standing on a small plate, a wheelchair weight (Seca 675, Hamburg, Germany) was used.

The SPPB is a screening tool originally designed to assess physical performance and predict disability in the older population (Guralnik et al., 1994). The SPPB mainly measures lower extremity function and comprises three subtests. A score of 0 indicates inability to perform the subtest, while a score of 4 indicates the highest level of performance. The battery comprised the following tests: (1) static balance, tested with the feet in side-by-side, semi-tandem and tandem positions; (2) gait speed, assessed by two 4-m (13 ft) walking tests at the individual's habitual pace, with the best result of the two tests retained; and (3) lower limb

strength, assessed by the ability to rise from a chair with the arms folded across the chest. The total score was the sum of the three test scores and ranged from 0 to 12 points; 0–6 points was considered a low score, 7–9 points was a moderate score and 10–12 points was a high score (Guralnik et al., 1994). In addition, raw scores on the gait speed (m/s) and chair stand (seconds) tests are provided in this study.

The validity and reliability of the SPPB have been reported for older adult populations (Guralnik et al., 1994) and for Norwegian populations (Olsen & Bergland, 2017). Norwegian reference values for the general adult population were recently established (Bergland & Strand, 2019). The SPPB has been used in people with mild and moderate intellectual disabilities (Torres-Unda et al., 2017). According to Oppewal and Hilgenkamp (2019a), the SPPB may be calculated from tests included in the fitness tests battery recommended for adults with intellectual disabilities.

The timed up-and-go (TUG) test assesses basic mobility skills (Podsiadlo & Richardson, 1991) and has been applied in people with intellectual disabilities (Enkelaar et al., 2013). The subjects were seated and instructed to stand up, walk 3 m, turn around, return to the chair and sit down. The task was to be performed at an ordinary walking speed. The TUG time was measured in seconds (Podsiadlo & Richardson, 1991).

The one-legged stance (OLS) test is a simple tool to measure static aspects of balance (Springer et al., 2007). The subjects were instructed to choose one foot to stand on for as long as possible for a maximum of 30 s without moving the standing foot. They were allowed to move the upper body and the raised foot. Timing was stopped if the participants moved their standing foot or put their raised foot on the floor. If participants managed to keep their balance and felt safe, they were instructed to do the same with closed eyes. The OLS has been found to have excellent interrater reliability in the general population (Springer et al., 2007) and good reliability, with an intraclass correlation coefficient of 0.88, in individuals with mild and moderate intellectual disabilities (Blomqvist et al., 2012).

To complete the SPPB, TUG and OLS, the participants had to be able to follow a basic set of instructions and to stand and walk independently. Walking aids, such as walkers or canes, could be used if necessary.

We defined non-completers as participants who either did not attend the test appointment or failed to perform the tests but completed the questionnaires.

2.5 | Procedure

The tests were administered by an experienced intellectual disability nurse (first author) or study nurses at the research unit. 'Intellectual disability nurse' is the international title used for professionals with a Norwegian 3-year university education for care and services for individuals with intellectual disabilities. The test administrators received training in administering the tests from a research technician (physiotherapist) (author AÅ) who had carried out the same tests in the population-based Tromsø Study (Jacobsen et al., 2012). The following adjustments to the test procedures were made in advance based on experiences in previous studies in the general population and the researchers' clinical knowledge regarding individuals with intellectual disabilities: (1) the participant and next of kin were greeted in a friendly manner in the sitting area to help the participant relax and feel safe; (2) information about the study and the task to be performed was provided; (3) the instructions for each test were simplified and concretized; and (4) the researcher demonstrated the task. The clinical measurements and physical performance tests were carried out in a fixed order, in a calm atmosphere and with necessary breaks.

2.6 | Data analyses

Statistical analysis was performed using IBM SPSS Statistics for Windows version 26.0. The data set was checked for normal distribution. Descriptive statistics including the frequency, mean, standard deviation (SD), median and range were used to describe population characteristics.

To assess the rate of completion of measurements and physical capability tests, numbers and frequencies in relation to the total study population were used.

Relationships of the variables with the completion/non-completion of the SPPB test were investigated with cross tabulations for nominal variables and with independent *t*-tests for continuous variables. For ordinal scales (GMFCS, CFCS) and non-normally distributed scales with low sample sizes (ABC-C subscales), comparisons were made with non-parametric statistics (Mann–Whitney *U*-test). Then, confounder-adjusted logistic regression analysis was performed to determine which variables were associated with the completion of the SPPB. A logistic regression analysis with the 'enter' method was performed with backward, stepwise removal of non-significant variables. The independent variables entered in the regression analysis were age, gender and variables with *p*-values <.10 in the univariate analysis (intellectual disability degree, BMI, GMFCS and CFCS levels, and hyperactivity and inappropriate speech scores). The results are presented as adjusted odds ratios (ORs). Model fit was investigated using the Hosmer–Lemeshow test. The amount of explained variance in the outcome was investigated using Nagelkerke's R^2.

Mean test scores were later compared with published normative mean values for the SPPB, TUG and OLS. To identify factors associated with physical capability test scores, ANOVA, and when appropriate, a post hoc least significant difference (LSD) test, was used. *p*-values <.05 were regarded as statistically significant, and when Bonferroni correction was applied, *p*-values <.01 were considered significant.

3 | RESULTS

3.1 | Participant characteristics

In total, 93 of 182 eligible individuals with intellectual disabilities, representing 51% of the identified intellectual disability population in the municipality of Tromsø, participated. A flowchart of the recruitment

process is shown in Figure 1. Due to Norwegian ethical rules, only information on age and gender was available for the 89 individuals who did not participate in the current study. Non-participants, with a mean age of 42 years (SD = 16 years), were significantly older than participants, with a mean age of 34 years (SD = 14 years) ($p < .001$). The gender distribution was similar between the two groups.

Population characteristics are presented in Table 1; 58% were men, and 42% were women. There were 7 (8%) participants aged less than 20 years, 57 (61%) aged between 20 and 39 years, 23 (25%) aged between 40 and 60 and 6 (6%) aged more than 60years.

3.2 | Test completion

Table 2 shows the number of participants who completed each measurement and physical capability test. Fifty-three (57%) of the 93 participants completed one or more of the measurements or tests. Weight and height were the most frequently completed (57%) measurements. The completion rates were 46% for one or more subtests of the SPPB, 42% for the TUG, 35% for the OLS with eyes open and 20% for the OLS with eyes closed. Six of 26 participants (23%) with severe intellectual disability completed the walking test of the SPPB (23%). One of the participants could not follow the instructions for the balance tests in the SPPB, and another participant refused to continue after the walking test in

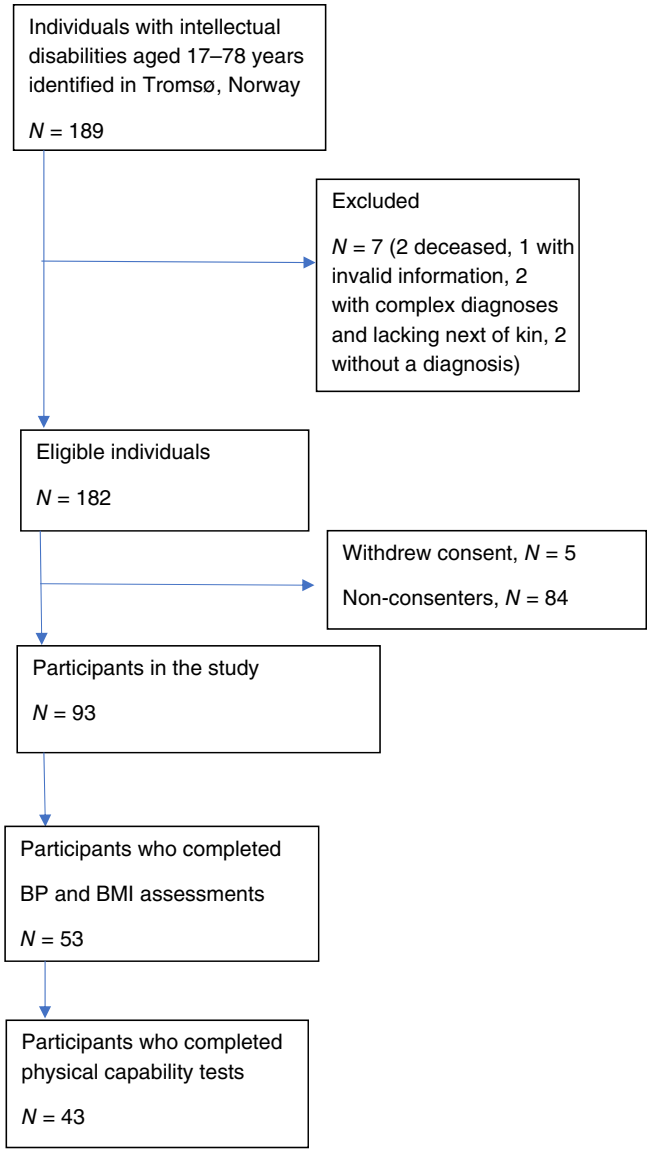

FIGURE 1 Flowchart of the study population selection

TABLE 1 Population characteristics ($N = 93$)

Characteristics	Total, $N = 93$
Gender, *n* (%)	
Men	54 (58)
Women	39 (42)
Age (year)	
Mean (SD)	34.2 (13.9)
Median (range)	30 (17–78)
Level of ID, *n* (%)	
Mild	31 (33)
Moderate	22 (24)
Severe	26 (28)
Profound	13 (14)
Unknown	1 (1)
Lives independently	14 (15)
Lives with family	25 (27)
Lives in a group home with care	53 (57)
Other	1 (2)
Work status, *n* (%)	
Regular paid work	1 (1)
Work with support	18 (26)
Day centre work	14 (19)
Day centre activity	17 (24)
Other	20 (28)
GMFCS[a], *n* (%)	
Level 1	45 (48)
Level 2	32 (34)
Level 3	5 (5)
Level 4–5	12 (12)
CFCS[b], *n* (%)	
Level 1	19 (20)
Level 2	15 (16)
Level 3	29 (31)
Level 4	23 (25)
Level 5	7 (7)

[a]Gross Motor Function Classification System, where level 1 is the highest level.
[b]Communication Function Classification System, where level 1 is the highest level.

TABLE 2 Participant completion rates for measurements and physical performance tests ($N = 93$)

	N	Height *N* (%)	Weight *N* (%)	Waist measurement *N* (%)	BP 1 *N* (%)	Balance SPPB *N* (%)	Walking SPPB *N* (%)	STS SPPB *N* (%)	Total SPPB *N* (%)	TUG *N* (%)	OLS1 *N* (%)	OLS2 *N* (%)
Total	93	50	51	51	49	41	43	39	43	39	29	19
Men	54 (58)	30 (60)	31 (61)	30 (59)	29 (59)	23 (56)	25 (58)	22 (56)	25 (58)	21 (54)	17 (59)	13 (68)
Women	39 (42)	20 (40)	20 (39)	21 (41)	20 (41)	18 (44)	18 (42)	17 (44)	18 (42)	18 (46)	12 (41)	6 (32)
Level of ID												
Mild	31 (33)	25 (50)	25 (49)	25 (49)	25 (51)	23 (56)	23 (53)	22 (56)	23 (53)	23 (59)	18 (62)	12 (63)
Moderate	22 (24)	14 (28)	14 (27)	14 (27)	14 (29)	13 (32)	14 (33)	13 (33)	14 (33)	12 (31)	11 (38)	7 (37)
Severe	26 (28)	10 (20)	10 (20)	10 (20)	7 (14)	5 (12)	6 (14)	4 (10)	6 (14)	4 (10)	0	0
Profound	13 (14)	1 (2)	2 (4)	2 (4)	3 (6)	0	0	0	0	0	0	0
GMFCS												
Level 1	45 (48)	27 (54)	27 (53)	27 (53)	26 (53)	26 (63)	26 (60)	26 (67)	26 (60)	25 (64)	21 (72)	15 (79)
Level 2	32 (34)	20 (40)	20 (39)	20 (39)	18 (37)	15 (37)	16 (37)	13 (33)	16 (37)	14 (36)	8 (28)	4 (21)
Level 3	5 (5)	1 (2)	1 (2)	1 (2)	1 (2)	0	1 (2)	0	1 (2)	0	0	0
Level 4–5	11 (12)	2 (4)	3 (6)	3 (6)	4 (8)	0	0	0	0	0	0	0
CFCS												
Level 1	19 (20)	14 (28)	13 (26)	14 (27)	14 (29)	13 (32)	13 (30)	12 (31)	13 (30)	13 (33)	10 (34)	7 (37)
Level 2	15 (16)	13 (26)	13 (26)	13 (25)	13 (26)	12 (29)	12 (28)	12 (31)	12 (28)	11 (28)	7 (24)	5 (26)
Level 3	29 (31)	15 (30)	16 (31)	15 (29)	14 (29)	12 (29)	14 (33)	12 (31)	14 (33)	12 (31)	9 (31)	6 (32)
Level 4–5	30 (32)	8 (16)	8 (16)	9 (18)	8 (16)	4 (10)	4 (9)	3 (8)	4 (9)	3 (8)	3 (10)	1 (5)

Note: In total 53 individuals completed one or more measurement or test. Numbers and percentages of participants in each subgroup with completed assessments are given.
Abbreviations: BP, blood pressure; CFCS, Communication Function Classification System; GMFCS, Gross Motor Function Classification Scale; ID, intellectual disability; OLS1, one-leg stance with eyes open; OLS2, one-leg stance with eyes closed; SPPB, Short Physical Performance Battery; STS, sit to stand; TUG, timed up-and-go.

the SPPB. The completion rate of the SPBB for people with mild to moderate intellectual disabilities was 70%. Except for one person, all participants with GMFCS levels 1 and 2 completed the physical capability tests. Four participants with the lowest communication function (CFCS levels 4–5) completed one or more physical capability tests. Twelve participants did not complete the OLS, mostly because the instructor or the participant regarded it as unsafe.

TABLE 3 Demographic and clinical characteristics of completers and non-completers of SPPB tests

Characteristics	Total, $N = 93$	SPPB completers, $n = 43$	SPPB non-completers, $n = 50$	p-Value
Gender, *n* (%)				
Men		25 (58)	29 (58)	.989
Women		18 (42)	21 (42)	
Age (year)				
Mean (SD)		34 (14.0)	34 (13.8)	.864
Level of ID, *n* (%)				
Mild*		23 (53)	8 (16)	.001
Moderate		14 (33)	8 (16)	
Severe		6 (14)	20 (40)	
Profound		0	13 (26)	
Unknown		0	1 (2)	
Down syndrome		14 (33)	9 (18)	.046
Weight*				
Mean (SD)	70.6 (21.6)	80.2 (21.7)	61.7 (17.4)	.001
Range	32.4–145.0	34.0–145.0	32.4–105.0	
Body mass index (BMI)*				
Mean (SD)	26.7 (6.7)	30.0 (6.6)	23.5 (5.1)	.001
Range	14.5–45.0	16.2–45.0	14.5–39.2	
≤18.5, underweight*, *n* (%)	9 (10)	1 (2)	8 (17)	.001
18.5–25, normal, *n* (%)	32 (36)	10 (23)	22 (48)	
26–29, overweight, *n* (%)	20 (23)	11 (26)	9 (20)	
≥30, obesity, *n* (%)	28 (31)	21 (49)	7 (15)	
GMFCS, *n* (%)				
Level 1	45 (48)	26 (60)	19 (38)	.01
Level 2	32 (34)	16 (37)	16 (32)	
Level 3	5 (5)	1 (2)	4 (8)	
Level 4–5	11 (13)	0	11 (22)	
CFCS, *n* (%)				
Level 1*	19 (20)	13 (30)	6 (12)	.001
Level 2	15 (16)	12 (28)	3 (6)	
Level 3	29 (31)	14 (33)	15 (30)	
Level 4	23 (25)	4 (9)	19 (38)	
Level 5	7 (7)	0	7 (14)	
ABC-C, mean (SD)	($n = 91$)	($n = 42$)	($n = 49$)	
Irritability	4.5 (6.0)	3.7 (5.7)	5.2 (6.3)	.149
Social withdrawal	3.0 (3.6)	2.6 (3.4)	3.3 (3.8)	.246
Stereotypic behaviour	1.0 (1.9)	0.9 (1.6)	1.1 (2.2)	.304
Hyperactivity/non-compliance	5.3 (6.7)	4.0 (5.8)	6.5 (7.3)	.090
Inappropriate speech	1.8 (2.5)	2.2 (2.7)	1.4 (2.2)	.048

Note: Level of ID: chi-square test with three categories, with severe and profound ID collapsed into one category. BMI categories: chi-square test with three categories, with underweight and normal weight collapsed into one category.

*p-Values < .01 after Bonferroni correction.

3.3 | Predictors of SPPB completion

As shown in Table 3, SPPB completers had a higher proportion of mild to moderate intellectual disability than non-completers ($p < .001$). SPPB completers had a higher BMI than non-completers, and 75% were overweight (26%) or obese (49%). In contrast, non-completers had a significantly higher proportion of underweight, at 17% compared to 2% ($\chi^2 = 15.92$, $p < .001$).

Multiple logistic regression analysis suggested a final model with two variables that predicted completion of the SPPB: higher cognitive function (level of intellectual disability) (OR 3.12, 95% CI 1.172–5.66, $p < .001$) and higher BMI (OR 0.86, 95% CI 0.78–0.94, $p = .001$). The Hosmer–Lemeshow test indicated a good model fit (χ^2: 3.09, df = 8 and $p = .929$). Nagelkerke's R^2 was 0.498.

3.4 | Physical capability test scores and score predictors among participants

The results of the SPPB and the three subtests are presented by gender and age in Table 4. The mean total SPPB score was 8.1 (range 0–12). The proportion of participants with a high score (11–12) was approximately 25%, indicating a ceiling effect. Younger participants performed better than older participants ($p = .040$). Higher total SPPB scores were predicted by younger age (<40 years) and less-severe intellectual disability. Regarding motor functioning, only participants with the two highest levels according to the GMFCS were compared, and there were significant differences in the SPPB total score (9.4 vs. 6.2, $p < .001$), walking speed (0.9 vs. 0.7 m/s, $p = .10$), and sit-to-stand results (12.8 vs. 18.7 s, $p < .01$). Participants with a normal BMI walked faster (1.0 m/s) than obese individuals (0.7 m/s, $p = .04$).

Fewer participants completed the TUG and OLS, and fewer significant associations were found, but the raw results yielded convergent findings.

3.5 | Physical capability test scores among participants compared to reference values in the general population

Considering the recently published normative mean values for the general Tromsø population (Bergland & Strand, 2019), the participants' scores were lower than those for both men and women aged more than 85 years (Table 4). Compared with the normative walking speed in the general population from the Tromsø Study, the participants had the same 4-m walking speed (m/s) as 85-year-old men in the general population (0.9 m/s), and women walked even more slowly (0.8 m/s).

As presented in Table 5, the total mean TUG score of the 39 participants was 12.1. There was a significant male bias in the study sample. Compared to the normative mean values for the general Norwegian population reported by Svinøy et al. (2020), the

TABLE 4 Means and confidence intervals of the SPPB ($n = 43$) scores for participants with ID and the normative mean values from a reference population

	Total SPPB score *M* (95% CI)	4 m walking speed (m/s) *M* (95% CI)	Sit to stand (s) *M* (95% CI)
Total	8.12 (7.26–8.98)	0.82 (0.74–0.91)	14.7 (12.8–16.7)
Gender			
Men	8.3 (6.97–9.59)	0.9 (0.74–0.97)	13.8 (11.95–15.72)
Women	7.9 (6.78–8.99)	0.8 (0.65–0.90)	15.9 (11.85–19.91)
Age			
<40 years	8.6 (7.71–9.54)*	0.9 (0.77–0.96)	13.7 (12.16–15.25)
≥40 years	6.6 (4.57–8.70)	0.7 (0.52–0.85)	18.1 (10.60–25.69)
Level of ID			
Mild	9.26 (8.22–10.30)**	0.91 (0.80–1.03)	12.6 (10.8–14.4)*
Moderate	7.29 (5.79–8.78)*	0.70 (0.56–0.85)	17.6 (12.6–22.5)*
Severe	5.67 (2.72–8.61)**	0.76 (0.50–1.02)	17.2 (11.8–22.7)
Normative mean values[a]			
Men age 40 years	11.99	1.32	7.4
Men age 80 years	10.41	0.99	11.4
Men age 85 years	9.80	0.90	12.4
Women age 40 years	11.88	1.31	7.9
Women age 80 years	9.75	0.96	12.3
Women age 85 years	9.06	0.89	12.9

Note: SPPB total score and 4 m walking speed: Higher scores indicate better functioning. Sit to stand in seconds: Fewer seconds indicate better functioning.

[a]Normative mean values from Bergland and Strand (2019).

*$p < .05$; **$p < .01$.

TABLE 5 Test results for participants in the TUG test and OLS test with eyes open (OLS1) and eyes closed (OLS2) and the normative mean values from a reference population

	TUG (s) Mean (95% CI), $n = 39$	OLS1 (s) Mean (95% CI), $n = 29$	OLS2 (s) Mean (95% CI), $n = 19$
Total	12.1 (11.05–13.07)	16.9 (12.52–21.22)	11.01 (6.39–15.63)
Gender			
Male	11.1 (9.76–12.37)*	18.5 (12.94–24.08)	9.6 (4.80–14.49)
Female	13.2 (11.69–14.75)	14.5 (6.72–22.37)	14.0 (0.65–27.29)
Age groups, years			
<40	11.7 (10.60–12.88)	17.7 (13.07–22.33)	11.5 (6.32–16.63)
≥40	13.1 (10.57–15.67)	11.7 (9.10–32.46)	7.0 (22.46–36.61)
Level of ID			
Mild	11.1 (9.77–12.53)	19.3 (13.71–24.97)	11.6 (5.66–17.48)
Moderate	13.2 (11.61–14.78)	12.8 (5.51–20.16)	10.0 (0.12–19.96)
Severe	13.9 (8.82–18.95)	–	–
Normative mean values[a]			
Men aged 40–49	–	40.1	7.3
Men aged 60/60–69	8.2	28.7	3.1
Men aged 80/80–99	10.4	5.6	1.3
Men aged 84 years	11.2	–	
Women aged 40–49	–	40.4	7.4
Women aged 60/60–69	7.8	25.1	2.5
Women aged 80/80–99	11.0	7.4	1.4
Women aged 84 years	12.0	–	–

[a]The normative values for TUG scores are from Svinøy et al. (2020), and those for the OLS scores are from Springer et al. (2007). The OLS scores used are for the age groups 40–49, 60–69 and 80–99 years.
*$p < .05$.

mean scores in the present study sample were lower than those for both men and women aged more than 80 years. The scores of women in the study sample were lower than the normative values for both men and women aged more than 84 years (Svinøy et al., 2020).

Additionally, scores on the OLS with eyes open, performed by 29 participants, and the OLS with eyes closed, performed by 19 participants, were lower than the reference values published by Springer et al. (2007).

4 | DISCUSSION

The completion rates for the SPPB, TUG and OLS were 46%, 42% and 31%, respectively. The SPPB had good feasibility for individuals with mild and moderate intellectual disability and low feasibility for individuals with severe intellectual disability, in accordance with a study by Oppewal and Hilgenkamp (2019a). The most important independent explanatory factors for non-completion were a more severe degree of intellectual disability and lower BMI. Compared to the normative reference values from the general Norwegian population, the participants' physical capability results were significantly worse than those of older adults.

4.1 | Test completion

Epidemiological studies on physical test performance in adults with intellectual disabilities are scarce (Oppewal & Hilgenkamp, 2019a). Half of the participants who completed questionnaires did not complete the physical capability tests, a result in line with the large Healthy Ageing and Intellectual Disability (HA-ID) study ($n = 10{,}150$, aged 50 years and above) in the Netherlands (Hilgenkamp et al., 2013). Inclusion criteria will be crucial for the degree of test completion. The HA-ID study had broader inclusion criteria than our study, as people with borderline intellectual disabilities were also included. In our study, the SPPB, for which participants obtained a score even if just one subtest was completed, had a higher completion rate than the TUG and OLS. No participants with severe intellectual disability completed the OLS, mainly because the instructor or the participant considered it to be unsafe. Therefore, it was not possible to conclude if the instructions were too complex or the participant was being asked for perform a skill they typically do not perform. However, one of the participants could not follow the instructions for the balance test in the SPPB, and another participant refused to continue with testing after the walking test in the SPPB.

The simple walking test, which is the first subtest in the SPPB, had the highest completion rate. The finding of good feasibility of the

walking test has also been reported by others (Enkelaar et al., 2013; Hilgenkamp et al., 2013). The good feasibility of the TUG is in accordance with the findings of Enkelaar et al. (2013). The sit-to-stand SPPB subtest has similarities to the 30-second chair stand test used by Dijkhuizen et al. (2018) in 29 individuals with moderate to severe intellectual and visual disabilities. They reported better feasibility than that in the present study. The divergent findings may emphasise the importance of detailed sample descriptions and the uniformity of tests.

In addition to disabilities, reasons for not completing tests may include difficulties with attending the examination due to lack of transport, support persons or desire to perform tests (Brooker et al., 2014). These proposed reasons are in line with our experiences. Research involving people with intellectual disabilities often meets practical challenges, such as recruiting participants by engaging caretakers and ensuring that the participants understand the assessment tasks and can follow instructions (Brooker et al., 2014; Feldman et al., 2014; Mulhall et al., 2018).

A more pedagogical approach to testing may lead to better success in testing, even for individuals with more severe intellectual disabilities (Dijkhuizen et al., 2018). Motivational issues of importance in physical activity participation could be of importance in test participation (Michalsen et al., 2020).

4.2 | Characteristics of the SPPB test completers

Increased occurrence of both overweight and underweight among adults with intellectual disabilities has been observed in several studies (Folch et al., 2019; Oppewal & Hilgenkamp, 2018; Torres-Unda et al., 2017). We found that completers had higher rates of overweight and obesity than non-completers, who had a higher rate of underweight. These findings call for special attention to adults with intellectual disabilities who do not attend or complete tests in health surveys, as they could be at high risk for poor general health. Consistent with other studies, the second main explanatory factor for SPPB completion was less-severe intellectual disability (Hilgenkamp et al., 2013). The other significantly associated factors in the univariate analysis, namely, gross motor and communication function and hyperactivity, were not significant in the final multiple logistic regression model.

4.3 | Physical capability test result compared to reference values from the general population

Physical capability results for the SPPB and the TUG were on average markedly poorer than recently published reference values for the Norwegian general population (Bergland & Strand, 2019; Svinøy et al., 2020). The participants had a mean age of 34 years but had, on average, poorer performance on the SPPB than 85-year-olds in the general population of the same city (Bergland & Strand, 2019), and TUG scores were lower than the reference values for 80-year-olds (Svinøy et al., 2020). The test results were comparable to those in a somewhat older population with intellectual disabilities (mean age 48.9) reported by Torres-Unda et al. (2017). Even poorer TUG test results than in the present study were found in other studies of individuals with intellectual disabilities (Enkelaar et al., 2013; Hakim et al., 2017). Fewer participants completed the OLS than the SPPB and TUG. The OLS with eyes open was also used in a study by Enkelaar et al. (2013) in older persons with mild to moderate intellectual disabilities, in which the mean scores were far lower than those in the present study. The finding of a ceiling effect on the SPPB indicates that the SPPB should not be used as the only physical capability test in a screening battery. The test battery proposed by Oppewal and Hilgenkamp (2019a) involves tests that were selected based on feasibility, reliability, validity and possibility for interpretation of the results. The OLS is included in this battery, but it requires holding the position for a maximum of 10 s, which is in contrast with our procedure that required holding the position for a maximum of 30 s. A ceiling effect was found for the OLS in young people with mild to moderate intellectual disabilities in the study by Blomqvist et al. (2012), but this result was not found in the present study. Correlation analysis was not performed between the physical capability tests used in this study. Validation analysis of tests could be relevant for future research, as well as validation of physical capability tests against measures of activities of daily living. Developing and exploring physical capability tests for individuals with more severe intellectual disability should be a research focus, as it is now a neglected research area.

A strength of this study is the municipality-based design as part of a health indicator study. As in a previous Norwegian prevalence study (Søndenaa et al., 2010), the study sample was mainly restricted to individuals with intellectual disabilities receiving some sort of municipality-based services. Recruitment of approximately 50% of the eligible individuals in the municipality is regarded as a satisfactory result compared to those in other studies in people with intellectual disabilities (Hilgenkamp et al., 2013) and in the Tromsø Study in the general population in the same city (The Tromsø Study, 2020). Standardised physical capability tests used in population-based studies allowed the comparison of the results with reference values from the general population in the same geographic area. Except in the Netherlands, little research has been conducted on this important topic in adults with intellectual disabilities.

The generalizability of the results is limited by the small sample size and the younger mean age in participants than in non-participants. In line with another study (Lahtinen et al., 2007), we found higher test scores in younger than older adult individuals with intellectual disabilities. Therefore, it is possible that if the participation rate had been higher, the physical capability test results would have been even poorer. Since not all participants' heights and weights were measured at the study site, we had to rely on self-reports for non-attenders. This could have affected the precision of the reported BMI values.

A lack of validation of the GMFCS and CFCS tools, as well as physical capability tests in adults with intellectual disabilities is another limitation in this study.

5 | CONCLUSIONS

The well-established SPPB and TUG tests had good feasibility for people with mild and moderate intellectual disability. Completion rates in those with severe intellectual disability were low. Participants' test scores were well below normative reference values, which calls for increased attention to physical activity support for individuals with intellectual disabilities of all ages and the identification of physical capability tests that can be applied in a wider population with intellectual disabilities. Last, individuals who fail to attend health surveys could be at risk of health conditions associated with underweight.

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DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author, (MIO). The data are not publicly available due to restrictions (their containing information that could compromise the privacy or research participants).

ORCID

Monica Isabel Olsen https://orcid.org/0000-0002-4955-2231

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Paper II

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How do multimorbidity and lifestyle factors impact the perceived health of adults with intellectual disabilities?

M. I. Olsen,[1,2] M. B. Halvorsen,[3] E. Søndenaa,[4,5] E. M. Langballe,[6,7] E. Bautz-Holter,[8] E. Stensland,[9] S. Tessem[1] & A. Anke[1,2,8]

1 *Department of Rehabilitation, University Hospital of North Norway, Tromsø, Norway*
2 *Faculty of Health Sciences, Department of Clinical Medicine, UiT - The Arctic University of Norway, Tromsø, Norway*
3 *Department of Pediatric Rehabilitation, University Hospital of North Norway, Tromsø, Norway*
4 *Faculty of Medicine and Health Sciences (MH), Department of Mental Health, Norwegian University of Science and Technology, Trondheim, Norway*
5 *Department of Brøset, St. Olavs University Hospital, Trondheim, Norway*
6 *Norwegian National Advisory Unit on Ageing and Health, Vestfold Hospital Trust, Tønsberg, Norway*
7 *Department of Geriatric Medicine, Oslo University Hospital, Oslo, Norway*
8 *Institute of Health and Society, Research Centre for Habilitation and Rehabilitation Model and Services CHARM), Faculty of Medicine, University of Oslo, Oslo, Norway*
9 *Department of Community, Medicine, UiT - The Artic University of Norway, Tromsø, Norway*

Abstract

Background Adults with intellectual disability (ID) have poorer physical and perceived health than the general population. Knowledge of perceived health predictors is both limited and important for guiding the development of preventive actions. The aims of this study were to investigate (1) the associations between perceived health and demographics, degree of ID, physical health conditions, and weight and physical activity level and (2) lifestyle factors and multimorbidity as predictors for perceived health adjusted for age, gender, and level of ID.

Method The North Health in Intellectual Disability study is a community based cross-sectional survey. The POMONA-15 health indicators were used. Univariate and multivariate logistic regression analyses with poor versus good health as the dependent variable were applied.

Results The sample included 214 adults with a mean age 36.1 (SD 13.8) years; 56% were men, and 27% reported perceiving their health as poor. In univariate analyses, there were significant associations between poor health ratings and female gender, lower motor function, number of physical health conditions and several indicators of levels of physical activity. In the final adjusted model, female gender [odds ratio (OR) 2.4, $P < 0.05$], level of ID (OR 0.65, $P < 0.05$), numbers of physical health conditions (OR 1.6, $P < 0.001$) and lower motor function (OR 1.5 $P < 0.05$) were significant explanatory variables for poor perceived health, with a tendency to independently impact failure to achieve 30 min of physical activity daily (OR 2.0, $P = 0.07$).

Conclusion Adults with ID with female gender, reduced motor function and more physical health conditions are at increased risk of lower perceived health and should be given attention in health promoting interventions. A lack of physical activity tends to negatively influence perceived health.

Correspondence: Ms Monica Isabel Olsen, Department of Rehabilitation, University Hospital of North Norway, Sykehusveien 38, 9038 Tromsø, Norway (e-mail: monica.isabel.olsen@unn.no)

Keywords intellectual disability, lifestyle, multimorbidity, perceived health, physical activity, physical health

Background

Population-based surveys have revealed that perceived health in adults with intellectual disability (ID) is below that of those without ID (Emerson *et al.* 2016; Kinnear *et al.* 2019). Furthermore, people with ID have poorer health status than the general population (van Schrojenstein Lantman-de Valk 2000; Haveman *et al.* 2011; Hermans and Evenhuis 2014). Multimorbidity, defined as having more than one simultaneous disease or medical condition [World Health Organization (WHO) 2016], is common in people with developmental disabilities including ID (Evenhuis *et al.* 2001; McMahon and Hatton 2020). Inadequate health promotion with higher prevalence of risk factors, such as obesity (Emerson *et al.* 2016; Kinnear *et al.* 2018) and lack of physical activity, has been associated with multimorbidity (Tyrer *et al.* 2019). However, knowledge of the associations between lifestyle factors and multimorbidity to general health ratings is limited.

In the general population, objective health status is consistent with self-rated health (Wu *et al.* 2013). Perceived health studies of those with ID are often reported by proxy responders (Emerson *et al.* 2016; Scott and Havercamp 2018; Kinnear *et al.* 2019; Jin *et al.* 2020). Scott and Havercamp (2018) concluded that self-health and caregiver-health reports were significantly related in individuals with ID, and both rating methods are in use (Kinnear *et al.* 2019; Jin *et al.* 2020).

The severity of ID is important for the occurrence of diseases and lifestyle. Individuals with severe or profound ID were found to have more comorbid diseases (Folch *et al.* 2018), and a higher risk of neurodevelopmental conditions than people with milder ID (van Schrojenstein Lantman-de Valk *et al.* 1997; Moreno-De-Luca *et al.* 2013). Van Timmeren *et al.* (2017) found a pattern of five prevalent physical health problems, which included visual impairment, constipation, epilepsy, spasticity and scoliosis, in individuals with severe or profound ID and motor disabilities (van Timmeren *et al.* 2017). Some diseases, including cardiovascular diseases, cancer, pulmonary diseases and allergies, occur less frequently in the ID population compared with the general population (Cooper *et al.* 2015; Folch *et al.* 2018; McMahon and Hatton 2020). Reviews indicate that lower intellectual capacity is perceived as a limiting factor for being physically active (Dairo *et al.* 2016; Bossink *et al.* 2017) with consequences for health and mortality rates (Oppewal and Hilgenkamp 2019). Several studies report that severe or profound ID is associated with being underweight (Emerson 2005; Bhaumik *et al.* 2008; Hsieh *et al.* 2014), while milder ID has been identified as a risk factor for being overweight and obesity (de Winter *et al.* 2012; Folch *et al.* 2018; Ranjan *et al.* 2018). Concordantly, the evidence regarding the association between the severity of ID and poorer perceived health is conflicting (Jin *et al.* 2020).

The reported prevalence of perceived poor health in adults with ID varies between 22% in an Australian study (Cocks *et al.* 2017), and 40.2% in the United States (Jin *et al.* 2020), and 52% in the United Kingdom (Kinnear *et al.* 2019). The Australian study found increasing age, financial hardship and being physically inactive to be associated with 'not good' health (Cocks *et al.* 2017). Recently, Jin *et al.* (2020) found that obese adults had worse perceived health than those with normal weight and found significant negative impacts on perceived health from smoking and lack of moderate physical activity. However, medical health conditions or multimorbidity were not adjusted for in the multivariate analyses in previous publications on perceived health in adults with ID (Cocks *et al.* 2017; Bond *et al.* 2019; Kinnear *et al.* 2019; Jin *et al.* 2020). Accordingly, the objectives of the current study are to investigate in a community-based setting (1) the associations between perceived health and demographics, degree of ID, physical health conditions, and weight and physical activity level and (2) lifestyle factors and multimorbidity as predictors for perceived health adjusted for age, gender and level of ID.

Methods

Study design

The North Health in Intellectual Disability study is a cross-sectional multicentre study.

Setting and procedure

This study was led from the University Hospital of North Norway (UNN) in Tromsø in cooperation with the St. Olavs Hospital in Trondheim. Data were collected between October 2017 and December 2019 in the municipalities of Tromsø, Balsfjord, Narvik, Malvik and parts of Trondheim, which are situated in the north and middle of Norway. The recruitment and data collection in each municipality were performed by research assistants with a health professional background (research nurses, ID nurses and one physiotherapist). Regular meetings on Skype between all collaborators were held to clarify questions and secure quality in the data collection. A pilot study was done in 2016 to test out the feasibility of the study.

Potential participants were identified through (1) information available from the municipality (receiving services) (Søndenaa *et al.* 2010) or (2) specialised ID services. An invitation letter to the study was sent out to each eligible person registered in the specialised ID services records at the UNN and St. Olavs Hospital. The eligible person's next of kin or guardian was then contacted by telephone. After approximately 4 weeks, a reminder letter was sent out to those who did not respond. Eligible individuals who were not registered at the hospitals specialised ID services were directly contacted by employees of the municipalities by invitation letters and/or telephone. Administrative leaders of the services in the municipalities and the user organisations were informed, and the study was promoted through the services and through regional tv and radio news and use of the hospital's internal newspaper.

Information was collected via structured interviews and questionnaires from the participants and/or their next of kin, caregivers or support person. The questionnaires were filled out either at the hospitals research unit, in the participants' home, at another preferred location or by telephone. Information regarding the level of ID and other health conditions was confirmed by the participant's medical record (hospital or general practitioner).

Comprehensive information sheets were provided to all potential participants, including an easy-read version. Informed consent was obtained from each individual or his or her legal representative. The study was approved by the Committee for Medical Research Ethics, Health Region North (2017/811) and the data protection officer at UNN and St. Olavs Hospital. The trial is registered in Clinical Trials with identification number NCT03889002.

Participants

Potential participants had a verified diagnosis of ID according to the International Statistical Classification of Diseases and Related Health Problems-10 criteria (WHO 2019), were age 16 years or older and living in the defined areas.

There were no predefined exclusion criteria, but some individuals were excluded because circumstances made it hard to obtain valid information or the ID diagnosis was withdrawn. Information about eligible nonparticipants was available only in the northern region, which included 266 eligible individuals and 140 participants, for a participation rate of 53%. The 140 participants were younger with mean age 35.3 (SD 14.1) versus mean age 42.3 (SD 15.9) in the 126 eligible nonparticipants ($P < 0.001$), while gender was similar across the two groups. In the middle part of Norway, there were lower participation rates, resulting in a sample of 74 participants with similar distribution of age and gender as in the north.

The degree of ID was categorised as mild (IQ 50–69), moderate (IQ 35–49), severe (IQ 20–34) or profound (IQ < 20) (WHO 2019). For eight individuals, the degree of ID was determined from information about adaptive functioning in cooperation with specialised ID health staff (Tassé *et al.* 2019).

Participants' living conditions were categorised as living alone, living with family or living in apartments attached to services (Molden *et al.* 2009). In Norway, adults with ID mainly reside in individual apartments where they receive services from the municipalities as needed. Some lives independently, while others live in clustered apartments with shared housing areas.

Multimorbidity

This study defined multimorbidity as one or more physical health conditions in addition to the ID-diagnosis (WHO 2016). Diagnoses of Down's syndrome, autism and cerebral palsy were not defined as physical health conditions. Mental health

conditions were not included in this operationalization.

The internationally developed POMONA-15 (P15) health indicators (Perry *et al.* 2010) were used for the assessment. The P15 is an assessment battery that was developed by a partnership of 13 EU member states to assess health inequity for adults with ID. Through an extensive literature search, a set of health indicators were derived and tested in the field. Indicators were selected if they were appraised as important, useful, measurable and if resulting data would enable comparisons between the health of people with ID and that of the general population (van Schrojenstein Lantman-de Valk *et al.* 2007; Perry *et al.* 2010). The health questions asked were 'Did you ever have this disease, and do you have it now?' A physical health condition was registered if the participants had the condition during the last year or as a chronic condition. The list of diseases in the P15 questionnaire were asthma, allergy, diabetes, cataract, hypertension, heart attack, stroke, chronic obstructive pulmonary disease/emphysema, arthritis (osteoarthritis/ rheumatoid arthritis), osteoporosis, peptic ulcer, cancer including leukaemia, migraine or frequent headaches, constipation, thyroid disease, epilepsy and other diseases. Other frequent conditions registered were skin conditions and musculoskeletal disorders. Oral problems were registered when participants indicated pain in either the mouth or teeth.

Perceived health

Perceived health was rated by either the participant with ID, in collaboration with a family member or staff support person, or by a close representative alone. The question, 'How is your health in general?' had five response options: (1) very good, (2) good, (3) fair, (4) poor and (5) very poor. This same question has been used in general population studies (Wu *et al.* 2013; Bennie *et al.* 2017) and other studies of people with ID (Cocks *et al.* 2017; Kinnear *et al.* 2019). As previously reported (Cocks *et al.* 2017; Kinnear *et al.* 2019), the variable was dichotomized into good health (very good or good health) or poor health (fair, poor or very poor health).

Motor function

The Gross Motor Function Classification System (GMFCS) classifies gross motor functioning into levels 1–5, with lower scores indicating better function. The GMFCS was developed for children with cerebral palsy (Palisano *et al.* 1997), has high interrater reliability (McCormick *et al.* 2007) and has been used in studies of adults with ID (Dijkhuizen *et al.* 2018). Individuals with motor function level 1 may have limitations in advanced motor skills; level 2 usually require stair railings, walk unassisted, but may occasionally use assist devices; level 3 require walking assist devices inside and usually outside and levels 4 and 5 usually require a wheelchair for mobility.

Lifestyle factors

The lifestyle factors included physical activity, weight and smoking. Smoking was measured with the question 'Do you smoke?' and dichotomized into yes or no. The amount of physical activity was measured with the question; 'In how much of your leisure time have you been physically active in the last year?' The four response categories are (1) 'Participating in hard training or sports competitions regularly more than once a week,' (2) 'jogging and other moderate sport or heavy gardening for at least 4 hour each week,' (3) 'walking, cycling or other forms of light exercise at least 4 hour a week,' or (4) 'reading, tv or other sedentary activities.' The question has been used in the general population (Grimby *et al.* 2015) and in European health indicator studies of individuals with ID (Haveman *et al.* 2011). In addition, the two questions 'Do you work out enough to get sweaty at least once a week?' (Perry *et al.* 2010) and 'Are you physically active for at least 30 minutes each day? (e.g., walking with faster heart rate),' were used based on national recommendations from the Norwegian Directorate of Health in 2019. Both questions have the following response categories: no, yes and cannot answer. Body mass index (BMI) (Bailey and Ferro-Luzzi 1995) was categorised as underweight (BMI $<$ 18.5), normal weight (BMI $\geq$ 18.5–24.9), overweight (BMI $\geq$ 25.0–29.9) or obese (BMI $\geq$ 30.0).

Data analysis

All analyses were conducted using IBM SPSS Statistics for Windows Version 26.0.

To investigate associations between levels of ID and physical health conditions as well as lifestyle factors a one-way analysis of variance was used for continuous variables and the χ^2 test for categorical variables. When there were few cells in the crosstabs, the results were checked with Fishers' exact test.

Variables associated with dichotomised good or poor health ratings as the dependent variable were investigated by logistic regression analyses. The effect sizes of the predictors are given as odds ratio (OR) with 95% confidence interval.

A series of univariate (unadjusted) logistic regression analyses were performed, using the independent variables age (scale), gender (male/female), Down syndrome (yes/no), autism (yes/no), cerebral palsy (yes/no), numbers of physical health conditions (scale), GMFCS (ordinal scale 1–5), level of ID (ordinal scale 1–4), BMI categories (underweight/normal/overweight/obese), BMI (scale), physical activity level (ordinal scale 4 levels), physical activity sweaty (yes/no) and physical activity at least 30 min per day (yes/no). Multivariate logistic regression analyses were then performed. Only variables that were significant ($P < 0.05$) in unadjusted logistic regression analyses were included, and the enter method and backward removal of insignificant variables were applied, always adjusting the multivariate models for age, gender and level of ID. The level of significance was set at $P < 0.05$. In the exploratory studies of the impact of lifestyle factors on perceived health, when adjusting for other significant predictors, we decided to retain lifestyle factors with $P < 0.10$ in the final model. Multicollinearity was checked between independent variables with 0.7 as cut-off value. The degree of pseudo-explained variance was reported according to Nagelkerke R^2, while the Hosmer and Lemeshow test was used to investigate model fit of the final model.

Results

Participant characteristics

A total of 214 participants [56% men, mean age 36.1 (SD 13.8) years] were included. The level of ID was mild (38%), moderate (26%), severe (24%) profound (8%) and unknown (4%). The 211 participants rating their health, reported it as either very good (33%), good (40%), fair (19%) or poor (8%). No one rated their health as very poor. Characteristics of the participants are presented in Table 1.

The registered physical health conditions within the whole sample and in relation to level of ID are

Table 1 Population characteristics ($N = 214$)

Characteristic	Total ($N = 214$)
Gender, *n* (%)	
Men	119 (56)
Women	95 (44)
Age (year), mean (SD)	36.1 (13.8)
median (range)	32.5 (16–78)
Level of ID*, *n* (%)	
Mild	82 (39)
Moderate	56 (26)
Severe	50 (24)
Profound	17 (8)
Unknown	9 (3)
Down syndrome, *n* (%)	40 (19)
Autism diagnosis, *n* (%)	48 (23)
Cerebral palsy, *n* (%)	24 (11)
Living condition, *n* (%)	
Lives independently	25 (12)
Lives with family	41 (19)
Own apartment attached to family house	2 (1)
Group home with care	146 (68)
Life style factors, *n* (%)	
Physical activity level	
Sedentary	95 (44)
Low level	92 (43)
Moderate level	15 (7)
High level	8 (4)
Weight, *n* (%)	
Underweight	18 (9)
Normal	62 (32)
Overweight	60 (31)
Obese	55 (28)
Smoking, *n*%	6 (3)
Respondents	
Adult with ID alone	(3)
Adult with ID and support person	(46)
Support person only	(51)
Support persons	
Family member	(64)
Healthcare professional	(34)
Other	(2)

*ID, intellectual disability.

presented in Table 2, as well as data for comparison with Folch *et al.* (2018). The mean number of physical health conditions was 2.1 (SD 1.5), and the frequency for multimorbidity was 79%. The most frequent health conditions were weight disorders (underweight/overweight/obese) (68%), visual problems (43%), allergy (32%), epilepsy (26%), oral problems (25%) and constipation (23%). Obesity, hypertension and visual aids were more frequently observed among individuals with mild ID than in those with severe/profound ID. Very few participants smoked (3%). Autism, epilepsy and constipation were significantly more prevalent in individuals with severe and profound ID than in those with less severe ID levels.

Lifestyle factors

As seen in Table 2, the levels of physical activity were consistent across the three groups of ID. Over half of

Table 2 Physical health conditions and lifestyle factors in relation to level of intellectual disability in 205 participants

Characteristic	Level of ID, *N* = 205				Whole cohort	
	Mild ID *N* = 82	Moderate ID *N* = 56	Severe/Profound ID *N* = 67	*P* value	*N* = 214, %	Folch *et al.* (2018)
Age years, mean (SD)	34.1 (12.5)	34.9 (14.0)	38.5 (14.8)	0.126	36.1 (13.8)	42.6 (15.3)
Autism (%)	14%	21%	35%	0.007	23%	18%
Downs syndrome (%)	6%	37%	18%	<0.001	19%	
Physical health condition, numbers of physical conditions, mean (SD)	2.0 (1.8)	1.9 (1.8)	2.1 (1.5)	0.718	2.1 (1.5)	
Frequence multimorbidity, one physical health cond.	78%	79%	84%	0.652	79%	
Allergy (%)	34%	29%	34%	0.800	32%	10%
Epilepsy (%)	20%	18%	40%	0.004	26%	31%
Constipation (%)	15%	20%	38%	0.004	23%	31%
Thyroid disorders (%)	8%	18%	8%	0.128	10%	10%
Migraine/headaches (%)	24%	9%	20%	0.111	15%	11%
Asthma (%)	11%	4%	4%	0.155	7%	3%
Diabetes (%)	7%	9%	1%	0.172	6%	7%
Cataracts (%)	4%	12%	2%	0.021	6%	9%
Hypertension (%)	13%	2%	2%	0.004	6%	12%
Skin conditions (%)	10%	11%	15%	0.598	12%	17%
Oral problems (%)	17%	24%	40%	0.011	25%	57%
Musculoskeletal disorders (%)	28%	16%	30%	0.167	25%	
Visual aids (%)	60%	46%	21%	<0.001	43%	
Hearing aids (%)	6%	4%	10%	0.308	7%	
Physical activity level (%)						
Sedentary	48%	45%	44%	0.899	44%	
Low level	38%	42%	50%	0.331	43%	
Moderate/high	15%	13%	6%	0.270	11%	
Sweaty at least once a week (%)	60%	45%	31%	0.002	45%	
30-min activity each day (%)	59%	63%	52%	0.632	58%	
Body mass index (BMI) (%)						
Underweight	7%	8%	11%	0.621	9%	
Normal	20%	35%	43%	0.002	32%	
Overweight	35%	31%	26%	0.483	31%	
Obese	38%	27%	19%	0.026	28%	

BMI, body mass index; ID, intellectual disability.

Prevalence of physical health conditions is given for the whole cohort (n = 214), in comparison with the study of Folch *et al.* (2018). Physical health conditions with prevalence above 5% are presented.

the participants (54%) reported, they did not exercise enough to get sweaty once a week. The group with mild ID (60%) were twice as likely to get sweaty at least once a week as the group of severe/profound ID (31%) ($P = 0.002$). In total, 58% of the participants reported being physically active for at least 30 min per day.

Normal BMI was more common among the group with severe/profound ID (43%) than in those with moderate (35%) or mild (20%) ID. Obesity was most common in the group with mild ID (38%) (Table 2).

Variables associated with perceived health in univariate logistic regression analysis

More than 70% of the participants rated their perceived health as good. As shown in Table 3, women rated their perceived health worse than men

Table 3 Factors associated with perceived health in univariate and multivariate regression analyses ($n = 211$)

	Univariate					Multivariate		
Characteristic	**Good health *N* = 154**	**Poor health *N* = 57**	**Unadjusted OR**	**95% CI**	***P***	**Adjusted OR**	**95% CI**	***P***
Age, mean (95% CI)	35.1 (32.9–37.2)	38.5 (34.8–42.2)	1.02	1.00–1.04	0.107	0.99	.96–1.02	.538
Gender, *n* (%)								
Men (*n* = 117)	94 (61)	23 (40)						
Women (*n* = 94)	60 (39)	34 (60)	2.32	1.25–4.31	0.008	2.40	1.13–5.09	.023
Syndromes and comorbidity, *n* (%)								
Downs syndrome	27 (17)	13 (23)	1.40	0.660–2.93	0.387			
Autism	39 (26)	9 (16)	1.82	0.82–4.0	0.140			
Cerebral palsy	16 (10)	8 (14)	1.41	0.57–3.95	0.461			
Numbers of physical health Conditions, mean (95% CI)	1.6 (1.4–1.8)	3.0 (2.4–3.5)	1.62	1.33–2.0	<0.001	1.55	1.22–1.97	<.001
Motor function, GMFCS, *n* (%)								
Level 1	101 (66)	20 (35)						
Level 2	29 (19)	26 (46)						
Level 3–5	24 (16)	11 (19)	1.37	1.05–1.80	0.020	1.52	1.04–2.22	.030
Level of intellectual disability, *n* (%)								
Mild	56 (38)	24 (44)						
Moderate	40 (27)	15 (28)						
Severe/profound	52 (36)	15 (28)	0.83	0.60–1.14	0.258	.65	.42–.99	.047
BMI categories								
Underweight	14 (10)	4 (8)	1.30	0.40–4.10	0.672			
Normal	50 (35)	11 (22)	2.1	0.93–4.18	0.075			
Overweight	39 (27)	20 (39)	0.59	0.30–1.15	0.120			
Obese	39 (27)	16 (31)	0.83	0.41–1.73	0.60			
BMI scale, mean (95% CI)	26.6 (25.6–27.7)	27.5 (25.7–29.2)	1.0	0.97–1.10	0.436			
Physical activity level								
Sedentary	59 (38)	34 (60)						
Light	71 (46)	20 (35)						
Moderate/high	20 (13)	3 (6)	1.76	1.10–2.81	0.017			
Physical activity, sweaty, *n (%)*	79 (52)	17 (31)	2.45	1.27–4.72	0.007			
Physical activity 30 min/day, *n* (%)	92 (66)	22 (40)	2.88	1.51–5.47	0.001	2.02	0.935–4.37	0.073

BMI, body mass index; CI, confidence interval; GMFCS, Gross Motor Function Classification System; OR, odds ratio.

(Poor health: 36% women vs. 20% men). Participants with a higher number of physical health conditions were more likely to score poor health ($P < 0.001$). Worse motor function was associated with poor perceived health. In the unadjusted analysis, poor perceived health was associated with lower physical activity level on the four-level scale ($P < 0.05$), not being sweaty at least once a week ($P < 0.01$), and not being physically active at least 30 min a day ($P < 0.001$).

Variables associated with perceived health in multivariate logistic regression analyses

In the final model of the binary logistic regression analysis (Table 3), female gender (OR 2.4, $P \leq 0.05$), level of ID (OR.65, $P \leq 0.05$), numbers of physical health conditions (OR 1.6, $P < 0.001$) and lower motor function (OR 1.5, $P < 0.05$) were significant explanatory variables for poor perceived health, with a tendency to independently impact failure to achieve 30 min of daily physical activity (OR 2.0, $P \leq 0.07$). The Hosmer and Lemeshow test indicated a good model fit (χ^2 9.34, $df = 8$, and $P = 0.314$). The Nagelkerke R^2 was 0.285.

Discussion

This study explored lifestyle factors and multimorbidity as predictors for perceived health in a community-based sample of adults with ID. More than 70% of the participants reported their perceived health as very good or good, somewhat lower than the 88% found in the general population in Ireland (Darker *et al.* 2016) and the 78% reported in an Australian sample (Cocks *et al.* 2017) but higher than the 48% in individuals with ID in Scotland (Kinnear *et al.* 2019). The participants in our study reported better perceived health than those in the study by Kinnear *et al.* (2019), which may be due to a somewhat younger and healthier study population, unidentified health conditions or better financial circumstances (Emerson *et al.* 2016; Cocks *et al.* 2017).

As expected, in unadjusted analyses, significant associations were found between poor perceived health ratings and the number of physical health conditions, in addition to several indicators of physical activity levels. No relationship between obesity and perceived health was observed. In multivariate logistic regression analyses, predictors were female gender, lower motor function, level of ID, and greater number of physical health conditions, while there was a tendency for physical inactivity to predict poor perceived health.

Multimorbidity and perceived health

The finding that a higher number of physical health conditions predict poor perceived health is consistent with that of previous research in the general population (Darker *et al.* 2016; Hetlevik *et al.* 2020). Although we did not find recent studies of perceived health in people with ID that included medical health conditions as a predictor variable (Cocks *et al.* 2017; Kinnear *et al.* 2019; Jin *et al.* 2020), our finding was not unexpected, as adults with ID have markedly poorer health than nondisabled peers on self-rated health (Kinnear *et al.* 2019) as well as multimorbidity (Kinnear *et al.* 2018).

The reported mean of two health conditions in this cohort was lower than that reported in existing research literature (McCarron *et al.* 2013; Folch *et al.* 2018; Kinnear *et al.* 2018). This could be due to a younger study population, that mental health conditions were not included, the use of a fixed list of diseases and no physical examination to reveal unidentified conditions. The selection of a young study population was probably the result of easier recruitment because of more support from family members than in older individuals, which were more dependent on assistance from staff. On the other hand, the occurrence of 79% with at least one physical condition is higher than the 61.5% found in the representative study by Cooper *et al.* (2015). To include mental health would possibly strengthen the association between higher level of health conditions and lower perceived health (Sigurdardottir *et al.* 2019).

Multimorbidity has been reported to be independently associated with severe/profound ID (Hermans and Evenhuis 2014; Folch *et al.* 2018; Tyrer *et al.* 2019), a finding that was not confirmed in the present study. This discrepancy could be due to the fact that Tyrer *et al.* (2019) used a definition that included mental health disorders and required two or more chronic conditions in addition to ID. Epilepsy and constipation are significantly more prevalent in

adults with severe/profound IDs in this study, which is in line with the findings of Kinnear *et al.* (2018) and Tyrer *et al.* (2019). Autism was also more prevalent in the group of severe/profound ID, which differs from a Canadian study by Bryson *et al.* (2008) but is consistent with the findings of Folch *et al.* (2018).

Jin *et al.* (2020) investigated the association between levels of ID and perceived health and found a significant association in unadjusted analyses, in accordance with our study. In the present study, the level of ID was a significant predictor of perceived health in the multivariate analyses but with a low effect size (OR.65, $P < .05$). The fact that mobility is often adjusted for in health studies of adults with ID (Tyrer *et al.* 2019; Jin *et al.* 2020) is supported by our finding of motor function as a predictor of perceived health. Studies including participants with cerebral palsy report perceived health and functional level decrease with age (Usuba *et al.* 2014; Benner *et al.* 2017).

Lifestyle factors and perceived health

Several indicators of physical activity were associated with better perceived health in unadjusted models, and in the adjusted model, 30 min of daily physical activity tended to impact perceived health ($P = 0.07$). Similarly, a moderate physical activity level was found to significantly predict perceived health in the studies by Jin *et al.* (2020) and Cocks *et al.* (2017). Although the questions used differ, the findings that more active participants were more likely to rate their health as good is consistent.

A previous study reported that adults with ID and obesity had lower perceived health than those with normal weight (Jin *et al.* 2020), which was not confirmed in the present study. These conflicting results could be due to the somewhat lower proportion of obese individuals in our sample than in the American sample or due to healthier individuals in the Norwegian study, despite the presence of obesity. An association between obesity and lower perceived health has been observed in the general population (Katya *et al.* 2013) and should be investigated further in adults with ID.

Demographics and perceived health

Men rated health better than women in the present study, which is consistent with the research of Kinnear *et al.* (2019) but not confirmed in other studies (Cocks *et al.* 2017; Jin *et al.* 2020). Multimorbidity is associated with female gender in people with ID (Cooper *et al.* 2015; Tyrer *et al.* 2019), while in the general population, gender differences in multimorbidity and perceived health are not consistent (Rizza *et al.* 2012; Wister *et al.* 2016; King *et al.* 2018).

The most consistent factor affecting overall health, whether measured subjectively or objectively, is reported to be age (Wister *et al.* 2016; Cocks *et al.* 2017; Kinnear *et al.* 2019). Increasing age showed borderline significance to multimorbidity in the study by Tyrer *et al.* (2019). In the current study, age was not a significant factor for overall perceived health, but this may be due to a relatively young study population.

Health promotion

In the investigated regions, regular health assessments of adults with ID are mainly implemented for people with specific syndrome diagnoses or health conditions. However, regular checks by GPs are recommended (Norwegian Directorate of Health 2018). People with ID require focused services from an early age (Cooper *et al.* 2015), with health promotion programmes that include physical activity and a healthy diet. This study indicates female gender as an independent risk factor for poor perceived health. In addition, the study implies the importance of physical activity programmes and possibilities for a healthy lifestyle for people with mobility problems. Health promotion with regular health checks and facilitating participation in physical activity should be prioritised for all adults with ID.

Strengths and limitations

First, a cross-sectional design precludes interpretation of causal direction. Secondly, selection bias must be taken into consideration when interpreting the results. Individuals included were identified because they received health or care services and results may not reflect the findings in other individuals with ID. Representativity analyses showed that participants had a significantly lower age than that of eligible nonparticipants. This selection could reduce the occurrence of physical health conditions and increase the level of perceived health.

However, the prevalence of specific health conditions was quite comparable with the findings by Folch *et al.* (2018). A possible limitation was that ratings of perceived health were performed by both individuals with ID and proxies (family members or staff), although there are satisfying correlations between self-and caregiver-health reports for subjective health in individuals with ID (Scott and Havercamp 2018). The rating of perceived health may be affected by the simultaneous interview about health status.

One strength of the study was the collection of information of ID level from the participants' medical records. A further strength of the study was the inclusion of actual physical health conditions in addition to the ratings of perceived health, thereby enabling the adjustment for multimorbidity in the multivariate analyses.

Conclusions

Adults with ID with female gender, reduced motor function and more physical health conditions are at increased risk of lower perceived health and should be a focus of health promoting interventions. A lack of physical activity tends to negatively influence perceived health.

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Conflict of Interest

No conflicts of interest have been declared.

Data Availability Statement

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available to privacy or ethical restrictions.

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Paper III

Monica Isabel Olsen, Eric Søndenaa, Ellen Melbye Langballe, Marianne Berg Halvorsen, Per Wilhelmsen, Erik Bautz-Holter, Audny Anke. Use of health and dental care services in adults with intellectual disability in relation to age and intellectual disability levels. *In review*.

Use of health and dental care services in adults with intellectual disability in relation to age and intellectual disability levels.

Monica Isabel Olsen[1,2], Erik Søndenaa[3,4], Ellen Melbye Langballe[5,6], Marianne Berg Halvorsen[7], Per Wilhelmsen[1], Erik Bautz-Holter[8], Audny Anke[1, 2, 8]

[1]*Department of Rehabilitation, University Hospital of North Norway, P.O. Box 1, 9038 Tromsø, Norway.*

[2] *Faculty of Health Sciences, Department of Clinical Medicine, UiT- The Arctic University of Norway, Tromsø, Norway.*

[3]*Norwegian University of Science and Technology, Faculty of Medicine, Institute of Mental Health, Trondheim, Norway.*

[4]*St. Olavs University Hospital, Department Brøset, Trondheim, Norway.*

[5]*Norwegian National Advisory Unit on Ageing and Health, Vestfold County Hospital Trust, Tønsberg, Norway.*

[6]*Department of Geriatric Medicine, Oslo University Hospital, Oslo, Norway.*

[7]*Department of Pediatric Rehabilitation, University Hospital of North Norway, Tromsø, Norway.*

[8]*Institute of Health and Society, Research Centre for Habilitation and Rehabilitation Model and Services CHARM), Faculty of Medicine, University of Oslo, Oslo, Norway.*

Correspondence concerning this article should be addressed to:

MSc. Monica Isabel Olsen, University Hospital of North Norway, Sykehusveien 38, 9038 Tromsø, Norway

Email: monica.isabel.olsen@unn.no

Tel.: +47 41206791

Conflict of Interest

None.

Data availability statement

The data that support the findings of this study are available on request from the corresponding author.

The data are not publicly available to privacy or ethical restrictions.

Abstract

Background: This study investigates the use of health and dental care services in adults with intellectual disability (ID) in the last 12 months according to Norwegian recommendations and in relation to age and ID levels.

Method: A cross-sectional survey including 214 participants.

Results: Use of health checks and contacts with general practitioners in the last year increased with age but were, in age-adjusted analyses, less frequent in those with more severe ID levels. Hospital admissions were age independent. Less than one-fifth of women had undergone cancer screening with small variations according to ID severity levels. Few had an individual plan (IP). More than one-third experienced poor dental health despite frequent controls.

Conclusions: The use of health checks was lower than recommended, especially in individuals with more severe ID. Access to services and the use of IP need to be enhanced. The quality of dental health care should be improved.

Keywords: intellectual disability, health care services, individual plan, dental health care

Introduction

UK-based population studies on people with intellectual disabilities (ID) confirm high rates of physical health disorders (Kinnear et al., 2018), increased mortality rates (McCarron et al., 2015), and poor general health (Dunham et al., 2018). Moreover, higher frequencies of several health conditions are found in individuals with severe ID compared to those with milder ID (Cooper et al., 2018; Kinnear et al., 2018; Olsen et al., 2021; Perera et al., 2020).

Health checks are effective in identifying unrecognized health care needs (Durbin et al., 2019; Robertson et al., 2014) and are recommended in several national guidelines (Byrne et al., 2016; Maltais et al., 2020; McConkey et al., 2015).

Despite adults with ID having poorer health than the general population, they have less access to health care services and health-promoting activities (Cooper et al., 2018; Reppermund et al., 2019). A national health surveillance in the US found that people with ID have primary care at a similar rate as people without ID but were significantly less likely to receive a mammogram (Havercamp & Scott, 2015). In general practice in the UK (Carey et al., 2016) and Ireland (McCarron et al., 2017), adults with ID had more consultations in primary care than those without ID but were less likely to have longer durations of doctor consultations and had lower continuity of care with the same doctor (Carey et al., 2016). Approximately one-third of participants in a Canadian study reported not having had a comprehensive medical examination performed in the last year, which was non-consistent with best practice guidelines (Maltais et al., 2020). Rates of hospitalization, physiotherapy, and dental care increased with age (McCarron et al., 2017), while Skorpen et al. (2016) found that adults with ID were more frequently hospitalized at a younger age than at an older age compared to the general population.

Few studies–none in the Nordic countries–have investigated how the use of health care services varies with levels of ID. McConkey et al. (2015) found in a region of the UK

that adults with ID who had a health check were significantly older than those who did not, but there were no differences in the use of health checks in terms of the levels of ID Contrastingly, others have reported more prominent inequities, such as fewer psychiatry services and cancer screenings of women, for individuals who had more severe levels of ID (Folch et al., 2019; Maltais et al., 2020).

Good oral health is important for an individual's wellbeing and influences their general health (Hsieh et al., 2018; Wilson et al., 2019). Contrastingly, although poor oral health is preventable through proactive oral care support, it is common in individuals with ID (Ward et al., 2019). Even among patients under routine maintenance, significant oral health problems remain (Finkelman et al., 2013). Moreover, Wilson et al. (2019) found that participants with ID have significantly poorer oral health, less preventative dentistry, and poorer access to services than those without ID. Consequently, preventative oral actions are recommended in Norway (Norwegian Directorate of Health, 2021).

Co-occurring physical health disorders and ID raises challenges for staff working in municipality and specialised health care services because of the additional complexity in assessments, diagnoses, and interventions (Dunn et al., 2020). In some countries, this area has received little attention (Dunn et al., 2020), and hence GPs may feel that they are left alone (Bakker-van Gijssel et al., 2017; Fredheim et al., 2013). The organization of health care services for people with ID in Norway is a shared responsibility between GPs, standard medical specialties, and specialised multidisciplinary hospital-based rehabilitation services with outpatient clinics and ambulatory functions. On the municipality level, individual plans (IP) are a statutory right for individuals with disabilities who need coordination of multiple services (Norwegian Directorate of Health, 2015); however, the degree of implementation for adults with ID is unknown. According to the supervision of the Norwegian county governors in 2016, there were challenges attached to sound health care services at home and access to

assessment at the GP's (Norwegian Board of Health Supervision, 2017). Recently, the Norwegian health authorities have formally recommended that the GPs should offer annual health checks to people with ID (Norwegian Directorate of Health, 2021). More information about the use of regular health assessments, other treatments, and preventive actions for this population is needed to develop better health care services (Durbin et al., 2019).

Therefore, this study aims to investigate the use of health and dental care services in the last 12 months among adults with ID according to national recommendations and in relation to age and level of ID. A secondary aim is to explore the use of dental care services in relation to experienced access to dental care, pain in the mouth, and experienced good or poor dental health.

Methods

Study design and setting

This cross-sectional multicentric study included five municipalities in the northern and central regions of Norway (e.g., Tromsø, Balsfjord, Narvik, Malvik, and parts of Trondheim). The study was led from the University Hospital of North Norway (UNN) in Tromsø in close cooperation with the St. Olavs Hospital in Trondheim.

Procedure

Potential participants were identified through specialised ID care services or the information regarding individuals with ID receiving these services available from the municipality. An invitation letter to the study was sent to each eligible person registered in the specialised ID services records at the UNN and St. Olavs Hospital. Moreover, eligible individuals who were not registered at the hospitals' specialised ID services were directly contacted by the municipality employees through invitation letters and/or over the telephone. The user

organisations and administrative leaders of the services in the municipalities were informed about the study.

Comprehensive information sheets were provided to all potential participants, including an easy-read version. Written informed consent was obtained from each individual or their legal representative.

Data were collected between October 2017 and December 2019 by research assistants with a health professional background (research nurses, intellectual disability nurses, and one physiotherapist). Regular meetings on Skype were held to clarify questions and to ensure the collection of quality data. The internationally developed POMONA-15 (P15) health indicators (Perry et al., 2010) were used to assess health care services, dental health, and physical health conditions. Information was collected via structured interviews and questionnaires from the participants and/or their next of kin, caregivers, or support person. Information regarding the level of ID and other health conditions was confirmed by the participant's medical record. The study was approved by the Committee for Medical Research Ethics, Health Region North (2017/811) and the data protection officer at UNN and St. Olavs Hospital. The trial is registered in Clinical Trials with identification number NCT03889002.

Participants

All persons with a verified diagnosis of ID according to the International Statistical Classification of Diseases and Related Health Problems (ICD)-10 criteria (WHO, 2019), aged 16 years or older and living in the defined areas were invited to participate in this study.

As also described in Olsen et al. (2021), some individuals were excluded because circumstances made it hard to obtain valid information, or the ID diagnosis was withdrawn. Information about eligible non-participants was available only in the northern region; there were 266 eligible individuals (140 participants and 126 non-participants; participation rate=53%). The participants were younger (mean age = 35.3; SD = 14.1) compared to the

non-participants (mean age = 42.3 years; SD =15.9) (p <.001), while gender was similar across the two groups. In the central region of Norway, there were lower participation rates, resulting in a sample of 74 participants with a similar distribution of age and gender as in the north.

Information about the levels of ID and concurrent conditions of autism spectrum disorder and Downs syndrome was confirmed in the participants' medical records. The levels of ID were categorized as mild (IQ= 50-69), moderate (IQ= 35-49), severe (IQ= 20-34), or profound (IQ= <20) (WHO, 2019). For eight individuals without registered levels of ID, the level of ID was determined from information about adaptive functioning in cooperation with specialised ID health staff (Tassé et al., 2019).

A physical health condition was registered if the participants had the condition during the last year or if it was chronic (Olsen et al. 2021). Multimorbidity was defined as having one or more physical health conditions in addition to the ID diagnosis (WHO, 2016).

Participants' living conditions were categorised as living alone, with family, or in apartments with closely available care services (Molden et al., 2009).

Use of health care services

The P-15 was developed by a partnership of 13 EU member states to assess health inequity for adults with ID (Perry et al., 2010). The use of health care services was identified by the question, 'Did you get this service during the last 12 months?' The services included were annual health checks, GP visits, hospital admission, hospital day visit, contact with mental health professionals, physiotherapy, specialised habilitation service, flu vaccine, and breast and cervix examination for women. The questions with code response options are presented in Table 1.

Dental care

Use of dental care service was examined with the questions, 'How many times did you visit a dentist/dental nurse during the last 12 months?' and 'Do you have access to a dentist/dental nurse when you need it?'

Dental health was examined with the questions, 'Do you have pain in your mouth or teeth?' and 'How is your dental health?' Information about the variables with coded response options is presented in Table 1.

Individual plan

In Norway, an IP is a planning document and a structured collaborating process. It is a written document between the municipality services and the service user, their family, or guardian about the disability services to be delivered to meet the service user's identified goals. According to the Norwegian Directorate of Health (2015), the plan should be updated continuously and be a dynamic tool in the coordination and targeting of the service offered. Persons in need of long-term and coordinated services in several areas of life have a statutory right to an IP (Norwegian Directorate of Health, 2015). The questions asked were, "Do you have an IP?" (Yes/No) "If yes, when was the IP last evaluated?" (during the last year/during the last two years/more than two years ago).

Data Analysis

All analyses were conducted using IBM SPSS Statistics for Windows version 26.0. Summaries of the characteristics of the participants are provided using numbers and percentages, mean and standard deviations, or median and range. Frequency data were derived to determine prevalence rates of the use of health care services.

The health care services, health check, GP visits, hospital admission, hospital day-care, mental health professional, physiotherapy, specialised habilitation services, and the

preventive procedures were registered either as received service during the last 12 months or not.

Possible associations between the prevalence of the use of each health care service and three age groups were investigated with crosstabulation with the Linear-by-Linear Association test.

Age, a continuous variable, and its association with the levels of ID was examined with ANOVA and the post-hoc Least Significant Difference (LSD) test. As the use of health care services increased with age, possible associations between the use/no use of each health care service as the dependent variable and levels of ID (mild/moderate and severe/profound) were examined, with several logistic regression analyses adjusted for age. Multicollinearity was checked between independent variables with .7 as the cut-off value.

The association between dental care services received in the last 12 months (yes/no) and the variables, such as dental care when needed (yes/no), pain in mouth/teeth (yes/no), and dental health (good/poor) were investigated by Fisher's exact test.

Variables associated with having/not having an IP were investigated as the dependent variable with univariate and multivariate logistic regression analysis. Independent variables were age, gender, and levels of ID.

The level of significance was set at $p < .05$. As we had varying levels of missing data, we only reported those who have registered use of services. Therefore, we reported on valid percentages for descriptive statistics.

Results

Participants' characteristics

The sample comprised 214 individuals with ID, of whom 56% were men. The age range was 16-78 years (mean= 36.1 years; SD= 13.8). Additionally, 22% were diagnosed with autism, 19% with Down syndrome, and 11% with cerebral palsy. The distribution ID levels were mild (38%), moderate (26%), severe (24%), profound (8%), and unknown (4%). A total of 79% had multimorbidity (Table 2). In the study by Olsen et al. (2021) with the same sample, an overview of physical health conditions (Table 2) shows that autism, epilepsy, and constipation were significantly more prevalent in individuals with severe and profound ID than in those with less severe ID levels.

Use of health care services in the last 12 months related to age

Table 3 shows that 57% of the participants had a health check during the last 12 months. More of the older participants (age ≥45;73%) had been to a health check than the younger age groups (age ≤29; 48% and age 30-44; 53%) (p=.002). Moreover, 84% of all the participants had consulted their GPs in the last 12 months. Similarly, more of the older individuals (age ≥45; 94%) had consulted their GPs compared to the younger age groups (age ≤29; 76% and age 30-44; 85%) (p=.002). Additionally, there were more frequent breast examinations (p= .023) and mammographic investigations (p<.001) in older women than younger women. No age differences were observed in hospital admission, hospital day care, use of mental health professionals, physiotherapy, specialised habilitation services, or cervical cancer examination for women.

Table 3 also shows the use of health care services in the Canadian study by Maltais et al. (2020) that has a comparable age distribution with our study. Compared to the Canadian study, fewer Norwegian participants reported having comprehensive medical examinations

performed last year, and screening for cancer in women was less frequently performed in Norway.

Use of health care services in the last 12 months related to ID level

Table 4 shows that individuals with severe/profound ID tended to be older than those with mild ID (ANOVA with posthoc LSD test $p = .050$). Fewer individuals with severe/profound ID (49%) had been to a health check in the last 12 months than those with moderate (54%) or mild ID (65%) (Age-adjusted model, OR 1.5, $p = .029$).

Additionally, fewer individuals with severe/profound ID (75%) had consulted their GPs than those with moderate ID (87%) or mild ID (89%) (Age-adjusted model, OR .518, $p = .007$).

There were no statistically significant associations between levels of ID and hospital treatments, services from specialised habilitation teams, physiotherapy, use of mental health professionals, or preventive procedures (Table 4).

Access to individual plan and evaluation of individual plan

Forty percent of the participants reported having an IP (Figure 1). Of those with an IP among the participants, 27 individuals had it evaluated in the last year and 38 in the last two years. Participants who reported having an IP were younger than those without (33.8 vs. 39.0 years) and had a more severe level of ID more frequently (Table 6). Of those with an IP, 40% had severe/profound ID, and among those without an IP, 28% had severe/profound ID. There was no gender difference in having/not having an IP.

Dental care services during the last 12 months in relation to age, gender, level of intellectual disability, perceived pain in mouth/teeth and experience of poor dental health.

The frequency of use of dental care services defined as seeing either a dentist or a dental nurse was 94% in the last 12 months; there were no age and gender differences. Individuals with severe/profound ID tended to have a higher risk of not using dental services (10%) than those with milder levels of ID (4%) (p= .093). Of the participants, 32% had no access to dental care when needed, 25% had pain in the mouth/teeth, and 39% perceived their dental health as poor (Table 5). More among those not receiving dental care reported not having access to dental care when needed. Experience of poor dental health tended to be more frequent among individuals with no dental care service in the last 12 months (62%) than among those receiving dental care service (38%) (p= .085). There were no differences in use of dental care services regarding level of ID and age.

Discussion

In this first Nordic study on the use of health care services in adults with ID, about half of the participants (57%) had been to a health check during the last 12 months. Notably, individuals with more severe ID levels had been to a health check and seen a GP significantly less in the last 12 months than those with milder ID levels. The use of health care services, in general, increased with increasing age, but contradictory to our expectations, hospital admittance did not. Few women had received cancer screening of the breast or cervix. Even though 94% of the participants had been to a dentist or dental nurse in the last 12 months, 32% reported they did not have access to dental care services when needed, and 39% experienced poor dental health. There tended to be a significant association between experience of poor dental health and not receiving a dental check. In a previous study of the same sample, oral problems increased with a more severe level of ID (Olsen et al., 2021).

UK-based studies involving adults with ID have found a reported use of annual health checks to be between 50%- 64% (Perera et al., 2020; McConkey et al., 2015), while approximately 30% of the study population in a Spanish and Canadian study reported not having had a health check in the previous year (Folch et al., 2019; Maltais et al., 2020). These findings are not consistent with the current consensus on best practice guidelines for primary care practice with ID in the UK, Canada, or Norway (Perera et al., 2020; Maltais et al., 2020; Norwegian Directorate on Health, 2020). Annual health checks for people with ID are associated with an increase in health-related activities and the identification of important comorbidities, which may reduce avoidable deaths if managed effectively (Buszewich et al., 2014). As 79 % of the participants in our study had known multimorbidity, they may be at risk of developing further complications and remaining undetected if not followed up regularly. However, GP visits were used more frequently (84% in the last year) and are consistent with the findings in other studies (Folch et al., 2019; McCarron et al., 2017).

The increasing use of health checks and GP consultations with age was not unexpected and is consistent with the findings from Northern Ireland and Ireland-based studies (McCarron et al., 2017; McConkey et al., 2015). In the study by Skorpen et al. (2016), hospital admissions of people with ID did not increase with age, which contradicts the findings in the general population. This could indicate the underuse of specialised health care services among older individuals with ID in Norway, associated with limited organised health checks by GPs, the ability to express health problems compared to the general population, and problems with access to specialised medical care in hospitals.

The use of health checks and GP visits were more common among those with milder ID levels, which is in line with findings from Spain and Canada (Folch et al., 2019; Maltais et al., 2020). Contradictory to our study, screenings have been found to be more frequent in individuals with mild ID than those with more severe levels (Folch et al., 2019; Maltais et al.,

2020) and hospitalisation among those with moderate and severe IDs (Folch et al., 2019). While Folch et al. (2019) found the use of physiotherapy to be more common among those with severe and profound IDs, we did not find such differences.

Due to a small study sample, we could not properly analyse subgroups, such as individuals with autism in relation to ID levels, but in explorative analyses, fewer individuals with autism (44%) had received a health check and visited their GP compared to the other participants. Moreover, individuals with autism face additional barriers to health care services. Folch et al. (2019) found that the prevalence of autism spectrum disorders increases markedly as the ID severity level increases, and almost all illnesses are much more prevalent in the populations with profound ID. These observations underline the importance of regular comprehensive health assessments in individuals with severe and profound levels of ID.

Health checks for individuals with ID are clinically efficient and cost-effective (Cooper et al., 2014), reveal health disorders, and initiate treatments (Durbin et al., 2019; Hanlon et al., 2018). GP-led health checks are the most effective intervention and lead to significantly more clinical activities, such as vision testing (Byrne et al., 2016). Generally, people with ID often receive more services than the general population (McCarron et al., 2017; Maltais et al., 2020; Folch et al., 2019), but not in the management of long-term conditions (Cooper et al., 2018). Therefore, people with ID need more access to services regarding their health profiles (Maltais et al., 2020).

Dental care services

Most of the participants in the present study had visited a dentist or dental nurse in the last 12 months. This differs from the Spanish study by Folch et al. (2019), and the Canadian study by Maltais et al. (2020) where only approximately 50% had visited a dentist the previous year. Several studies report that individuals with ID are more likely to have seen a dentist compared to those without ID (Finkelman et al., 2013; Havercamp & Scott, 2015; McCarron et al.,

2017). Nevertheless, 32% in our study reported not having access to dental care services when needed, and 39% experienced poor dental health. Additionally, Folch et al. (2019) reported that of those who did not visit a dentist, 25% reported oral pain; in our study, the proportion was 38%. In the literature, there is increasing evidence of people with ID having poorer dental health than the general population (Cabrita et al., 2017; Wilson et al., 2019). Even among patients under routine maintenance, significant oral health problems remain (Finkelman et al., 2013). A greater degree of ID, being older, and independence with daily oral hygiene routine predicted poorer oral health (Wilson et al., 2019). Despite recommendations of regular dental checks and municipality-based oral care, difficulties may arise due to pain, communication or collaboration problems.

Individual plan

In the present study, only 40% of the participants reported having an IP, and 13% a functioning IP with regular evaluations. An IP has been a statutory right for Norwegian individuals in need of long-term and coordinated services since 2001. However, not everyone in need of rehabilitation or habilitation gets this right fulfilled for various reasons (Norwegian Directorate of Health, 2021). The new guidelines for services for Norwegian people with ID state that the cooperation of health follow-up between service users, GPs, and other service providers shall be documented in the service users' medical records and implemented in their IP (Norwegian Directorate of Health, 2021).

Strengths and limitations

This study has some limitations regarding representativeness. The sample is limited, and there may be selection bias as the included individuals were identified because they received health or care services; therefore, the results may not reflect the findings of other individuals with ID. Furthermore, representative analyses showed that the participants were significantly

younger than the eligible non-participants, which may lead to underestimations of the use of services. However, our opinion is that a health check with a comprehensive clinical assessment would not be more frequent among non-participants. Ratings of health care services and dental health were reported both by participants and proxies (family members or staff) at a single point in time but not verified in medical journals or service registries; this may be done in future studies. A strength of this study is that level of ID was confirmed in the participants' medical records.

Conclusions

Individuals with severe/profound ID had less health checks and visited their GPs less frequently than those with milder ID levels despite having, more often, physical health conditions that need follow-ups (Folch et al., 2019). Access to adequate health care services for adults with ID needs to be enhanced, particularly cancer screening for women and annual comprehensive health assessments for individuals with more severe ID levels. The quality of dental health care should be improved with concrete and evidence-based actions for individuals who have oral problems, as a significant proportion experience poor dental health despite frequent visits. As IP to organise and coordinate services do not work as intended, this statutory right should be reconsidered.

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Table 1. Health and dental care ser services. Questions asked and coded responses.

Variables	Question asked	Coded responses	
Health check	When did you last have a full medical assessment?	No health check last year/ cannot answer 9%	Yes, health check during last year
General practitioner visits	During the last 12 months, approximately how many times have you been to or had on-to-one visit by your GP (or other doctor)?	No GP visits last year/ cannot answer (3%)	Yes, GP visit last year
Hospital admission	During the last year did you stay one or more nights at the hospital?	No hospital admission/ cannot answer (<1%)	Yes
Hospital day visit	During the last year did you receive treatment at the hospital without spending the night?	No hospital day visit /cannot answer (<1%)	Yes
Mental health	During the last 12 months, approximately how many times did you been to a psycholgists, psychiatrist or other similar?	No visits/ cannot answer (2%)	Yes, one or more visits
Physiotherapy	During the last 12 months, approximately how many times did you see a physical therapist?	No visits/ cannot answer (<1%)	Yes, one or more visits
Specialized habilitation services	During the last 12 months did you receive any follow-up by the specialised habilitation unit?	No/ cannot answer (included refuse (1%)	Yes
Flu vaccine	During the last 10 years did you get vaccinated against the flu?	No/ cannot answer (5%)	Yes
Individual plan (n= 203)	Does the person have an individual plan?	No/ cannot answer (3%)	Yes
Women (n= 95)			
Breast examination (n=95)	Did you get a breast examination during the last year?	No/ cannot answer (4%)	Yes
Mammography (n=95)	When did you last get a mammography?	Never/ cannot answer (6%)	Ever
Cervical cancer (n=95)	Have you been screened for cervical cancer during the last 3 years?	No/ cannot answer (6%)	Yes
Dental Care services	How many times did you visit a dentist or dental nurse during the last 12 months?	No visits/ cannot answer (<1%)	One or more times last year
	Can you visit a dentist or dental nurse when you need it?	No/ cannot answer (2%)	Yes

Dental health	Do you have pain in your mouth or teeth?	No/ cannot answer (6%)	Yes
	How is your dental health?	Poor: Fair/ poor / very poor	Good: Very good/ good

Table 2. *Population Characteristics (N=214)*

	Total *N* = 214
Gender, *n* (%)	
Men	119 (56)
Women	95 (44)
Age (year), mean (SD)	36.1 (13.8)
median (range)	32.5 (16-78)
Level of ID*, *n* (%)	
Mild	82 (38)
Moderate	56 (26)
Severe	50 (24)
Profound	17 (8)
Unknown	9 (4)
Numbers of physical health conditions, mean (SD)	2.1 (1.5)
Multimorbidity, *n* (%)	169 (79%)
Living condition, *n* (%)	
Lives independently	25 (12)
Lives with family	41 (19)
Own appartment attached to family house	2 (1)
Group home with care	146 (68)

ID:Intellectual disability

Table 3. Use of health care services the last 12 months related to age (N=214). Proportions in the current study are compared to utilization in the last year in a Canadian study (Maltais et al., 2020).

	Total n=214	Age ≤29 N= 86	Age 30-44 N= 62	Age ≥45 N= 66	*P*-value[1]	Maltais et al. (2020)
Health check, *n* (%)	122 (57%)	41 (48%)	33 (53%)	48 (73%)	.002	70%
GP, *n* (%)	180 (84%)	65 (76%)	53 (85.5%)	62 (94%)	.002	
Hospital admission, *n* (%)	35 (16%)	15 (17%)	10 (16%)	10 (15%)	.703	
Hospital day care, *n* (%)	104 (49%)	44 (51%)	29 (47%)	31 (47%)	.593	
Mental health professional, *n* (%)	36 (17%)	18 (21%)	9 (14.5%)	9 (14%)	.220	15%[2]
Physiotherapy, *n* (%)	39 (18%)	15 (17%)	16 (26%)	8 (12%)	.479	4%
Specialised habilitation services, *n* (%)	105 (49%)	40 (46.5%)	29 (47%)	36 (54.5%)	.344	
Dental care services	201 (94%)	80 (93%)	60 (97%)	61 (92%)	.430	56%
Flu-vaccine last 10 years	102 (48%)	32 (37%)	34 (55%)	36 (54.%)	.027	
Women	*Total n=95*	*N*= 36	N= 28	N= 31		
Breast examination last year	15 (16%)	3 (8%)	3 (11%)	9 (29%)	.023	
Mammography anytime	15 (16%)	1 (3%)	1 (4%)	13 (42%)	<.001	61%[3]
Cervical cancer examination last 3 years	17 (18%)	3 (8%)	6 (21%)	8 (26%)	.061	47%

[1] Crosstabulation with Linear-by-Linear Association (Exact Sig. 2-sided)
[2] Percent of consultation within psychiatry
[3] Mammogram in the last 2 years, women aged 50-69

Table 4. Use of health care services the last 12 months related to level of ID in 205 participants. *P* values are adjusted for age in logistic regression analyses.

	Total N= 205	Mild ID N= 82	Moderate ID N= 56	Severe/ Profound ID N= 67	*P*-value Adj. Age
Age, mean (SD)	35.8 (13.7)	34.1 (12.5)	34.9 (14.0)	38.5 (14.8)	
Health check, *n* (%)	116 (57%)	53 (65%)	30 (54%)	33 (49%)	.029
GP, *n* (%)	172 (84%)	73 (89%)	49 (87.5%)	50 (75%)	.007
Hospital admission, *n* (%)	34 (17%)	14 (17%)	8 (14.3%)	12 (18%)	.850
Hospital day care, *n* (%)	100 (49%)	39 (48%)	24 (43%)	37 (55%)	.328
Mental health professional, *n* (%)	35 (17%)	20 (24%)	6 (11%)	9 (13%)	.098
Physiotherapy, *n* (%)	37 (18%)	18 (22%)	9 (16%)	10 (15%)	.339
Specialised habilitation services, *n* (%)	101 (49%)	41 (50%)	24 (43%)	36 (54%)	.699
Flu vaccine last 10 years, *n* (%)	94 (46%)	38 (46%)	22 (39%)	34 (51%)	.864
Women	*Total n=92*	*N*= 44	*N*= 22	*N*= 26	
Breast Examination last year, *n* (%)	15 (16%)	6 (14%)	2 (9%)	6 (23%)	.728
Mammography anytime, *n* (%)	15 (16%)	4 (9%)	3 (14%)	8 (31%)	.287
Cervical cancer examination last 3 years, *n* (%)	17 (18%)	9 (20.5%)	3 (14%)	5 (19%)	.489

Table 5. Dental care services during the last 12 months in relation to age, gender, level of intellectual disability, subgroups and perceived pain in mouth/teeth.

	Total N= 214	Dental care service last 12 months N= 201	No dental care service last 12 months N= 13	*P-value*
Gender				
Men	119 (56%)	111 (55%)	8 (62%)	
Women	95 (44%)	90 (45%)	5 (38%)	.657[2]
Age <= 29	86 (40%)	80 (40%)	6 (46%)	
>=30	128 (60%)	121 (60%)	7 (54%)	.651[2]
Access to dental care when needed	145 (68%)	140 (70%)	5 (38%)	.030[1]
Pain in Mouth/teeth	53 (25%)	48 (24%)	5 (38%)	.332[1]
Level of ID	*Total n=205*	*n= 192*	*n= 13*	
Mild/moderate	138 (67%)	132 (69%)	6 (46%)	
Severe/profound	67 (33%)	60 (31%)	7 (54%)	.093[2]
Dental health	*Total n=213*	*N= 200*	N= 13	
Good	130 (61%)	125 (62%)	5 (38%)	
Poor	83 (39%)	75 (38%)	8 (62%)	.085[2]

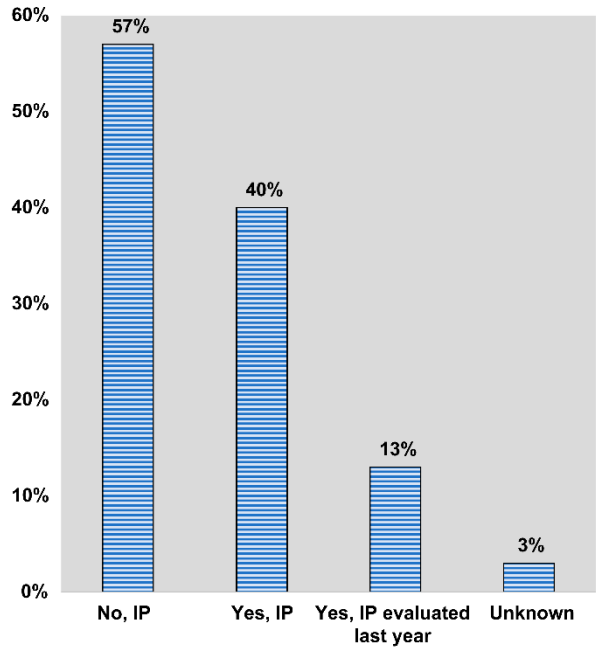
[1] Crosstabulation with Fisher´s Exact Test (Exact Sig. 2-sided)

[2] Chi-Square tests

Table 6. Age and level of intellectual disability in association to having an individual plan in multivariate binary logistic regression analyses.

Variable	Adjusted Odds Ratio	95% CI for OR	*P- value*
Age	.97	0.94 - .99	.003
Level of ID	1.37	1.01 – 1.85	.044

Figure 1. Use and evaluation of individual plan (IP) in 203 adults with intellectual disability.



Appendix

Appendix 1 - Decision Regional Committee for Health Research Ethics

Appendix 2 - Flyer

Appendix 3 – Information and consent form

Appendix 4 – POMONA Health Indicators 1, 2 and 3

Appendix 5 – Gross Motor Function Classification System

Appendix 6 – Physical capability tests

Appendix 1

Decision Regional Committee for Health Research Ethics

REK
REGIONALE KOMITEER FOR MEDISINSK OG HELSEFAGLIG FORSKNINGSETIKK

Region:	Saksbehandler:	Telefon:	Vår dato:	Vår referanse:
REK nord	Lill Martinsen	77646140	19.05.2017	2017/811/REK nord
			Deres dato:	Deres referanse:
			10.05.2017	

Vår referanse må oppgis ved alle henvendelser

Audny Anke
Rehabiliteringsavdelinga

2017/811 Helseindikatorer hos mennesker med utviklingshemning

Forskningsansvarlig: Universitetssykehuset Nord-Norge HF, Norges teknisk-naturvitenskapelige universitet
Prosjektleder: Audny Anke

Vi viser til søknad om forhåndsgodkjenning av ovennevnte forskningsprosjekt. Søknaden ble behandlet av Regional komité for medisinsk og helsefaglig forskningsetikk (REK nord) i møtet 01.06.2017. Vurderingen er gjort med hjemmel i helseforskningsloven (hfl.) § 10, jf. forskningsetikkloven § 4.

Prosjektomtale
Dette er en søknad om en kartleggingsstudie av helseindikatorer, funksjon og bruk av helsetjenester hos mennesker med psykisk utviklingshemning. Vi vil påvise hvilke personer som har økt risiko for fysisk og psykisk sykdom, og avdekke udekkede behov for tjenester. Målgruppen er mennesker 16 år og eldre med psykisk utviklingshemning. Alle mennesker med utviklingshemning i Tromsø kommune og to andre kommuner i Nord inviteres. I Midt-Norge rekrutteres på tilsvarende vis kommuner som tilsvarer en befolkning på 100 000 innbyggere. Potensielle deltaker er brukere av habiliteringstjenestene ved UNN/St.Olavs, tjenestebrukere kommunalt eller de melder seg til studien. Antall deltakere stipuleres til 500. Det benyttes POMONA helseindikatorer og andre mål for helse og funksjon. Datainnsamling er fra personer med utviklingshemning og informanter med spørreskjema/ intervju og sikring av intern validitet med journal-data, samt noen enkle kliniske målinger og tester for fysisk funksjon.

Vurdering

Vi har mottatt tilbakemelding av 8.5.17.

Tilbakemeldingen er stort sett iht. de merknader komiteen hadde.

Når det gjelder tilbakemelding som framkommer som punkt 3 i prosjektleders tilbakemelding, anmerkes det at som hovedregel aksepterer ikke REK telefonisk oppfølging av forespørsel og kan ikke se at det er spesielle forhold som tilsier at dette skal gjøres i denne studien. I de samtykkeskrivene som er vedlagt som en del av prosjektet, framkommer kontaktinformasjon og telefonnummer, slik at eventuelle deltakere kan ta kontakt dersom de har behov for det.

Når det gjelder tilbakemelding under punkt 5, legges det til grunn at prosjektet ikke har annonsert studien, da REK ikke har mottatt noen annonse til vurdering. Dersom det er plan om at studien skal annonseres, bes det om at annonsen innsendes da REK skal forhåndsgodkjenne den før annonsering.

Etter fullmakt er det fattet slikt

Vedtak
Med hjemmel i helseforskningsloven § 10 og forskningsetikkloven § 4 godkjennes prosjektet.

Generelle vilkår
Godkjennelsen er gitt under forutsetning av at prosjektet gjennomføres slik det er beskrevet i søknaden og protokollen med de eventuelle endringer som fremkommer etter komiteens merknader og tilbakemeldingen på disse. For øvrig gjelder bestemmelsene som følger av helseforskningsloven med forskrifter.

Sluttmelding og søknad om prosjektendring
Prosjektleder skal sende sluttmelding på eget skjema senest et halvt år etter prosjektslutt, jf. helseforskningslovens § 12. Dersom det skal gjøres vesentlige endringer i forhold til de opplysninger som er gitt i søknaden må prosjektleder sende søknad om prosjektendring til REK, jf. helseforskningslovens § 11.

Klageadgang
Du kan klage på komiteens vedtak, jf. helseforskningslovens § 10 tredje ledd og forvaltningslovens § 28 flg. Klagen sendes til REK nord. Klagefristen er tre uker fra du mottar dette e-brevet. Dersom vedtaket opprettholdes av REK nord, sender REK nord klagen videre til Den nasjonale forskningsetiske komité for medisin og helsefag for endelig vurdering

Med vennlig hilsen

May Britt Rossvoll
Sekretariatsleder

Lill Martinsen
rådgiver

Kopi til:bjorn.yngvar.nordvag@unn.no; erik.sondenaa@ntnu.no

Appendix 2

Flyer

Hvordan har du det?

Har du en utviklingshemming? Vil du bidra til forskning?

Forskere gjør nå en kartlegging av hvordan personer med utviklingshemming har det i hverdagen sin. De vil vite om din helse, helsetilbudet, aktiviteter og andre tilbud du benytter. Målet er å gjøre tilbudene til mennesker med utviklingshemming bedre! Vi ønsker å intervjue deg og en av dine nærpersoner, enten hjemme hos deg eller på Forskningsposten UNN.
Alle personer i Tromsø over 16 år, som har en utviklingshemming, kan delta.

KONTAKT:
Monica Olsen, vernepleier/stipendiat, tlf: 412 06 791
Wenche Gamst/Brita Lena Hansen, studiesykepleiere, tlf: 77626909
eller
Audny Anke, professor/prosjektleder, tlf: 959 36 333

Du gjør en innsats for forskning,
og får samtidig en liten helsesjekk!

Deltakere får 3 Flax-lodd

EXTRA STIFTELSEN

UNIVERSITETSSYKEHUSET NORD-NORGE
UNIVERSITY HOSPITAL OF NORTH NORWAY

nfu
Norsk Forbund for Utviklingshemmede

Invitasjon

Du og en av dine nærpersoner inviteres til å delta i et forskningsprosjekt om helse, aktiviteter og helsetilbud for personer med utviklingshemming.

Målsettingen med prosjektet er å forbedre tjenestetilbudet.

INTERVJU
Du og/eller din nærperson får spørreskjema om helse, daglige aktiviteter og om kontakt med helsepersonell. Skjemaet fylles ut ved at medarbeider i prosjektet gjør intervju. Noe kan også fylles ut elektronisk eller på papir på forhånd.
Du selv må gjerne delta i litt av eller hele intervjuet, men det er ikke nødvendig. Et familiemedlem, en verge eller en ansatt bør alltid være med, og kan være den som svarer på spørsmål sammen med deg eller på vegne av deg.

MÅLINGER
Hvis du vil kan du delta i målinger, men du kan også delta i studien uten å være med på dette. Med målinger mener vi å måle blodtrykk, høyde og vekt. Vi tester også for gangfunksjon og balanse hos de som kan eller vil delta på det. De fleste målingene våre er også laget for deg som bruker rullestol.
Selve undersøkelsen vil foregå på Forskningsposten ved Universitetssykehuset Nord-Norge. Der har vi blant annet rullestolvekt. Den kan også foregå ved Habiliteringsenheten på UNN eller intervjueren kan reise ut til deg, om det gjør det enklere for deg å delta.
Det er frivillig å være med på forskningsprosjektet. Samtykkeskjemaet er siste arket i skjemaet med full informasjon om studien. Samtykket sendes oss i svarkonvolutten som ligger i brevet. Vi tar kontakt for avtale.

Hvis du har spørsmål kan du gjerne kontakte
Monica Olsen, vernepleier/stipendiat, tlf: 412 06 791, e-post: monica.isabel.olsen@unn.no eller
Audny Anke, professor/prosjektleder, tlf/sms: 959 36 333, e-post: audny.anke@uit.no

Hvis du bestemmer deg for å delta får du får en liten helsesjekk, og gjør samtidig en stor innsats for viktig forskning!

Deltakere får 3 Flax-lodd.

Forskningen foregår i byene Tromsø, Narvik og Trondheim. Den utføres av Universitetssykehuset Nord-Norge i Tromsø og Narvik, og av St. Olavs hospital i Trondheim.

EXTRA STIFTELSEN

UNIVERSITETSSYKEHUSET NORD-NORGE
UNIVERSITY HOSPITAL OF NORTH NORWAY

nfu
Norsk Forbund for Utviklingshemmede

Appendix 3

Information and consent form

Universitetssykehuset Nord-Norge HF
HABILITERINGSSEKSJONEN

FORESPØRSEL OM DELTAKELSE I FORSKNINGSPROSJEKTET

HELSE OG FUNKSJON HOS PERSONER MED UTVIKLINGSHEMMING

Dette er et spørsmål til deg som har en funksjonshemming og en nærperson om å delta i et forskningsprosjekt. Din helse og fungering i dagliglivet kartlegges med intervju, spørreskjema og enkle tester for fysisk funksjon. Vi registrerer hvilken behandling du har fått og får, og om det er behov som ikke dekkes. Overordnet hensikt med studien er å forbedre tjenestetilbudet.

HVA INNEBÆRER PROSJEKTET?

Studien innebærer at det fylles ut spørreskjema i forbindelse med intervju med stipendiat eller prosjektmedarbeider. I prosjektet vil vi registrere opplysninger om deg. En nærstående person (familiemedlem eller personale) vil fylle ut spørreskjema om din helsetilstand, fungering i dagliglivet og hvilke helsetjenester du får. Du kan gjerne delta i utfyllingen selv dersom du ønsker det. Det er også ønskelig å registrere opplysninger fra din pasientjournal om diagnoser og behandling. Utfylling av spørreskjema ved intervju tar ca. 1 time.

Det kan gjøres målinger. Vi ønsker at du deltar selv om du ikke gjør målingene. Målingene er av blodtrykk, midjemål, høyde, vekt, og vi tester også for gange og balanse. Målingene tar 10-15 minutter. Dersom du ikke ønsker å delta i studien vil det ikke få noen konsekvenser for tjenestetilbudet du mottar.

MULIGE FORDELER OG ULEMPER

Det er ikke noe ubehag eller noen ulempe forbundet med å delta i studien bortsett fra den tiden en må bruke. Noen opplever at det er ubehagelig hvis spørsmål handler om ting en ikke ønsker å svare på. Da trenger en ikke gi opplysninger. En fordel er at du som deltar får en vurdering av din helse og daglige aktivitet. Hvis det er noe det bør gjøres noe med, henviser vi deg videre til riktig instans.

FRIVILLIG DELTAKELSE OG MULIGHET FOR Å TREKKE SITT SAMTYKKE

Det er frivillig å delta i prosjektet. **Dersom du ønsker å delta, undertegner du samtykkeerklæringen på siste side. Send inn arket i vedlagte frankerte svarkonvolutt.** Så kontakter vi deg for avtale. Du kan når som helst og uten å oppgi noen grunn trekke ditt samtykke. Dette vil ikke få konsekvenser for din videre behandling. Dersom du trekker deg fra prosjektet, kan du kreve å få slettet opplysninger, med mindre opplysningene allerede er inngått i analyser eller brukt i vitenskapelige publikasjoner. Dersom du senere ønsker å trekke deg eller har spørsmål til prosjektet, kan du kontakte prosjektleder overlege, professor Audny Anke tlf. 95936333, e-post: audny.anke@uit.no; eller stipendiat vernepleier Monica Olsen tlf. 41206791, e-post: monica.isabel.olsen@unn.no

HVA SKJER MED OPPLYSNINGENE OM DEG?

Opplysningene som registreres om deg skal kun brukes slik som beskrevet i hensikten med prosjektet. Du har rett til innsyn i hvilke opplysninger som er registrert om deg og rett til å få korrigert eventuelle feil i de opplysningene som er registrert. Du har også rett til å få innsyn i sikkerhetstiltakene ved behandling av opplysningene.

Alle opplysningene vil bli behandlet uten navn og fødselsnummer eller andre direkte gjenkjennende opplysninger. En kode knytter deg til dine opplysninger gjennom en navneliste. Det er kun prosjektleder Audny Anke, stipendiat Monica Isabel Olsen og forskningssykepleier fra Forskningsposten ved UNN som har tilgang til denne listen.

Opplysningene om deg vil bli anonymisert eller slettet senest fem år etter prosjektslutt.

FORSIKRING

Det er ingen egen forsikring for deltakerne. Pasientskadeloven vil gjelde.

OPPFØLGINGSPROSJEKT

Du kan senere bli kontaktet med spørsmål om å delta i oppfølgingsprosjekter eller andre studier.

GODKJENNING

Regional komité for medisinsk og helsefaglig forskningsetikk har vurdert prosjektet, og har gitt forhåndsgodkjenning (2017/811/ REK nord).

Etter ny personopplysningslov har behandlingsansvarlig Universitetssykehuset Nord Norge ved administrerende direktør og prosjektleder Audny Anke et selvstendig ansvar for å sikre at behandlingen av dine opplysninger har et lovlig grunnlag. Dette prosjektet har rettslig grunnlag i EUs personvernforordning artikkel 6a og artikkel 9 nr. 2 og ditt samtykke.

Du har rett til å klage på behandlingen av dine opplysninger til Datatilsynet.

KONTAKTOPPLYSNINGER

Dersom du har spørsmål til prosjektet kan du ta kontakt med prosjektleder overlege, professor Audny Anke tlf. 95936333, e-post: audny.anke@uit.no

Personvernombud ved institusjonen er personvernombudet@unn.no

JEG SAMTYKKER TIL Å DELTA I PROSJEKTET OG TIL AT MINE PERSONOPPLYSNINGER BRUKES SLIK DET ER BESKREVET

Sted og dato

Deltakers signatur

Deltakers navn med trykte bokstaver

Stedfortredende samtykke

Som nærmeste pårørende/verge til _ (Fullt navn) samtykker jeg til at hun/han kan delta i prosjektet.

Sted og dato

Pårørendes signatur

Pårørendes navn med trykte bokstaver

Appendix 4

POMONA Health Indicators 1, 2, and 3, relevant questions used in the PhD project

Pomona Seksjon 1

Record ID _____

Denne seksjonen fylles ut av forsker ved starten av intervjuet med personen med utviklingshemming (og andre hvis aktuelt). Sett bare ett kryss på hvert spørsmål om ikke annet er oppgitt. NB: Personen med utviklingshemming benevnes i dette skjemaet "Person med ID".

Navn/initialer til den som fyller ut: _____

A3. Vennligst oppgi regionen der deltaker bor _____
(Bruk den vedlagte kodelisten)

A6. Vennligst oppgi metoden som dataene ble samlet inn etter.
- ☐ Postundersøkelse
- ☐ Telefonundersøkelse
- ☐ Intervju ansikt til ansikt
- ☐ Annet

(Ett eller flere kryss)

A7. Hvem har gitt skriftlig samtykke til deltakelse i undersøkelsen?
- ☐ Person med ID
- ☐ Familiemedlem
- ☐ Annet

(Ett eller flere kryss)

A7. Angi hvem: _____
(Mor, far, bror, offentlig verge, annet)

A8. Hvem er til stede under intervjuet?
- ◯ Kun person med ID
- ◯ Kun annen person (nærperson)
- ◯ Person med ID med bistand fra nærperson

A9. Hvis en nærperson eller en annen bistår under gjennomføringen av dette intervjuet, vær vennlig å oppgi deres forhold til personen med utviklingshemming:

- ◯ Ikke aktuell, person med ID var alene til stede under intervjuet
- ◯ Forelder (mor) til personen med ID
- ◯ Forelder (far) til personen med ID
- ◯ Annet familiemedlem (ikke forelder) til personen med ID
- ◯ Verge som ikke er forelder
- ◯ Talsperson/ frivillig i forhold til person med ID
- ◯ Ansatt/betalt omsorgsyter (BPA)
- ◯ Helsepersonell inkludert miljøterapeut
- ◯ Annen person

A9. Hvilken relasjon _____
(Fyll ut)

A10. Hvor lenge har personen som bistår under _____ gjennomføringen av intervjuet, kjent personen med utviklingshemming?

POMONA Seksjon 2

Record ID _____

Denne delen av skjemaet skal besvares av personen med utviklingshemming (og andre hvis det anmodes om det) under intervju med forsker. Hvis personens funksjonsnivå er slik at han eller hun anses å ikke kunne svare på spørsmålene, må intervjuet gjennomføres med en som kjenner personen godt (nærperson). Spørsmål bør omformes for å være tilpasset bruk av en annen intervjuperson - f. eks spørsmålet "hvem bor du sammen med" må omformes til "hvem bor(navnet på personen med utviklingshemming) sammen med?".

Sett bare ett kryss på hvert spørsmål om ikke annet er oppgitt.

B1. Hvilket år ble du født?
Skriv 4-sifret årstall, f. eks. 1978, 1989, 2001.
998 = Kan ikke svare/ uklart svar
_____

BX1. Sivilstatus

◯ Gift eller samboer
◯ Enke eller enkemann
◯ Ikke gift

BX2. Utdanning

☐ Grunnskole
☐ Videregående/ yrkesutdanning
☐ Folkehøgskole
☐ Høgskole eller universitet
☐ Annet

Annen utdanning, spesifiser: _____

Kommentar til utdanning: _____

C1. Hvem bor du sammen med?
NB: I de tilfellene hvor en person bor i mer enn en bolig (f.eks. med familie i helga og i annen bolig i uka) skal alle spørsmål relatert til bolig referere til den boligen hvor personen tilbringer størstedelen av tiden i løpet av uka.
(Ett eller flere kryss)

☐ Alene
☐ Med partner/ ektefelle
☐ Med barn (inkludert stebarn/ adoptivbarn/ fosterbarn)
☐ Med foreldre (inkludert steforeldre/ adoptivforeldre/ fosterforeldre)
☐ Med søsken (inkludert stesøsken/ adoptivsøsken/ fostersøsken)

CX1. Hva slags bolig bor du i?

◯ Frittstående selvstendig eller delvis selvstendig bolig/ leilighet (evt. med samboer eller venn)
◯ Bor sammen med familien
◯ Egen bolig i umiddelbar tilknytning til foreldrehjemmet/annen slekt (samme hus eller tomt)
◯ Bokollektiv (eget rom i bolig der andre rom er felles med andre med hjelpebehov)
◯ Bofellesskap/ samlokalisert bolig (egen leilighet i tilknytning til andre leiligheter for personer med hjelpebehov, med eller uten fellesareal)
◯ Kommunal eller fylkeskommunal institusjon (sykehjem, psykiatrisk sykehus)
◯ Sammensatt omsorgsbolig (kompleks med mange enheter)
◯ Omflakkende eller uten bolig
◯ Kan ikke svare/ uklart svar/ vet ikke

EX1. Går du på skole?

- ◯ Nei
- ◯ Ja
- ◯ Kan ikke svare/ uklart svar/ vet ikke

EX2. Hvis du går på skole:

- ◯ Grunnskole
- ◯ Videregående skole
- ◯ Annet

Hvis annet, beskriv: _____

E1. Har du jobb?
(Som jobb regnes sysselsetting i vanlig eller vernet arbeid, kommunal dagvirksomhet/dagsenter, enten abeidet er betalt eller ikke

- ◯ Nei
- ◯ Ja
- ◯ Kan ikke svare/ uklart svar/ vet ikke

Hvis du ikke går på skole, hvilken dagaktivitet har du?

- ◯ Vanlig arbeid (med vanlig lønn)
- ◯ Varig tilrettelagt arbeid (VTA) i regi av NAV
- ◯ VTA i ordinær bedrift
- ◯ Arbeid med bistand
- ◯ Arbeid organisert av kommunen: Dagsenter/ arbeidssenter eller annet der aktivitetene i hovedsak er arbeidslignende MED lønn
- ◯ Arbeid organisert av kommunen; Dagsenter/ arbeidssenter eller annet der aktivitetene i hovedsak er arbeidslignende UTEN lønn
- ◯ Dagsenter eller aktivitetsgruppe, i hovedsak preget av aktivisering
- ◯ Dagsenter der aktiviteten er en kombinasjon mellom aktivisering og arbeidspregede aktiviteter
- ◯ Arbeidsplass laget spesielt for en person
- ◯ Annet/ kombinasjoner

Beskriv _____

Nå skal jeg liste opp noen sykdommer. Kan du fortelle meg om du noen gang har hatt sykdommen og også om du har den nå (dvs. i løpet av de siste 12 månedene)?

	Har aldri hatt det	Har hatt det før (mer enn 1 år siden)	Har hatt det siste 12 mnd	Kronisk tilstand	Kan ikke svare/ uklart svar
I1. Astma	◯	◯	◯	◯	◯
I2. Allegi (utenom allergisk astm	◯	◯	◯	◯	◯
I3. Diabetes/ sukkersyke	◯	◯	◯	◯	◯

	Har aldri hatt det	Har hatt det før (mer enn 1 år siden)	Har hatt det siste 12 mnd	Kronisk tilstand	Kan ikke svare/ uklart svar
I4. Grå stær	◯	◯	◯	◯	◯
I5. Høyt blodtrykk (hypertensjon)	◯	◯	◯	◯	◯
I6. Hjerteinfarkt	◯	◯	◯	◯	◯

	Har aldri hatt det	Har hatt det før (mer enn 1 år siden)	Har hatt det siste 12 mnd	Kronisk tilstand	Kan ikke svare/ uklart svar
I7. Slag, hjerneblødning	◯	◯	◯	◯	◯
I8. Kronisk bronkitt, emfysem	◯	◯	◯	◯	◯
I9. Gikt (slitasjegikt/ artritt/ reumatisme)	◯	◯	◯	◯	◯

	Har aldri hatt det	Har hatt det før (mer enn 1 år siden)	Har hatt det siste 12 mnd	Kronisk tilstand	Kan ikke svare/ uklart svar
I10. Benskjørhet	◯	◯	◯	◯	◯
I11. Magesår	◯	◯	◯	◯	◯
I12. Ondartet svulst/ kreft inkl. leukemi (blod/ lymfekreft)	◯	◯	◯	◯	◯

	Har aldri hatt det	Har hatt det før (mer enn 1 år siden)	Har hatt det siste 12 mnd	Kronisk tilstand	Kan ikke svare/ uklart svar
I13. Migrene eller hyppig hodepine	◯	◯	◯	◯	◯
I14. Forstoppelse	◯	◯	◯	◯	◯
I15. For høyt eller for lavt stoffskifte	◯	◯	◯	◯	◯

I16. Annet (eks. sure oppstøt/ reflux, søvnvansker, hudsykdommer, brudd) _____

	Svært god	God	Rimelig bra	Dårlig	Svært dårlig
J1. Hvordan er helsen din generelt sett?	◯	◯	◯	◯	◯

J1. ☐ Kan ikke svare, uklart svar

K1

	Nei	Ja, av og til	Ja, daglig	Kan ikke svare/ uklart svar
Røyker du?	◯	◯	◯	◯
Snuser du	◯	◯	◯	◯

K2. Hvor mange sigaretter røyker du gjennomsnittlig pr. dag?

◯ Røyker ikke
◯ Færre enn 20 sigaretter pr. dag
◯ 20 sigaretter eller mer pr. dag
◯ Kan ikke svare/ uklart svar

L1. Hvor ofte har du drukket alkohol (f. eks. øl, vin, brennevin) de siste 12 månedene?

◯ Aldri
◯ Hver dag
◯ 5 - 6 dager i uka
◯ 3 - 4 dager i uka
◯ 1 - 2 dager i uka
◯ 1 - 3 dager i mnd
◯ 5 - 6 dager i året
◯ 1 - 2 dager i året
◯ Kan ikke svare/ uklart svar/ vet ikke

M1. Har du diagnosen epilepsi?

◯ Nei
◯ Ja
◯ Kan ikke svare/ uklart svar/ vet ikke

N1. Har du smerter i munnen?

◯ Nei
◯ Ja
◯ Noen ganger
◯ Kan ikke svare/ uklart svar/ vet ikke

N2. Hvis du har smerter i munnen, er det i tennene eller andre steder?

◯ Har ikke smerter i munnen
◯ I tennene
◯ Andre steder
◯ Kan ikke svare/ uklart svar/ vet ikke

N3. Hvordan er din tannhelse?

◯ Svært god
◯ God
◯ Rimelig bra
◯ Dårlig
◯ Svært dårlig
◯ Kan ikke svare/ uklart svar/ vet ikke

N4. Hvor mange ganger har du vært hos tannlege/ tannpleier de siste 12 månedene?
0 = Ingen; 998 = Kan ikke svare/ uklart svar

_____

N5. Kan du oppsøke en tannlege / tannpleier hvis du har behov for det (med bistand hvis behov)?

◯ Nei
◯ Ja
◯ Kan ikke svare/ uklart svar/ vet ikke

O1. Bruker du briller, linser eller andre hjelpemidler for å se godt?

◯ Nei
◯ Ja
◯ Kan ikke svare/ uklart svar/ vet ikke

P1. Bruker du høreapparat (eller andre hjelpemidler for å høre)?

◯ Nei
◯ Ja
◯ Kan ikke svare/ uklart svar/ vet ikke

Fysisk aktivitet

R1. Hva av følgende stemmer best med dine fritidsaktiviteter siste år?
(Responsen skal relateres til det mest typiske aktivitetsnivå i løpet av foregående år.)

◯ Hard trening og konkurransesport mer enn én gang i uken
◯ Jogging, annen moderat sport eller tungt hagearbeid, minst fire timer i uken
◯ Spasering, sykling eller andre lette aktiviteter minst fire timer i uken
◯ Lesing, TV-titting eller andre stillesittende aktiviteter
◯ Kan ikke svare/ uklart svar/ vet ikke

R2. Trener du nok til å bli svett minst en gang i uken
(f. eks. ved å jogge, sykle eller annet)?

◯ Nei
◯ Ja
◯

RX2. Er du i minst 30 minutters fysisk aktivitet daglig
(f. eks. gange som gir raskere puls)?

◯ Nei
◯ Ja
◯ Kan ikke svare/ uklart svar/ vet ikke

Kan ikke svare/ uklart svar/ vet ikke

S1. Har du vært på sykehus én natt eller flere i løpet av det siste året?
(dvs. de siste 12 månedene)?

◯ Nei
◯ Ja
◯ Kan ikke svare/ uklart svar/ vet ikke

S1A. Hvis ja, hvor mange ganger?

_____

S2. Har du i løpet av det siste året vært på sykehus for behandling, men uten å være lagt inn over natten?

◯ Nei
◯ Ja
◯ Kan ikke svare/ uklart svar/ vet ikke

S2A. Hvis ja, hvor mange ganger?
998 = Kan ikke svare/ uklart svar

_____
(ganger)

T1. Omtrent hvor mange ganger har du vært hos eller hatt en-til-en-besøk av fastlegen (eller annen lege) i løpet av de siste 12 månedene?
0 = Ingen kontakt/ besøk; 998 = Kan ikke svare/ uklart svar

☐

_____
(ganger)

T2. Omtrent hvor mange ganger har du vært hos psykolog, psykiater el. l. i løpet av de siste 12 månedene?
0 = Ingen besøk; 998 = Kan ikke svare/ uklart svar

_____
(ganger)

T3. Omtrent hvor mange ganger har du vært hos fysioterapeut i løpet av de siste 12 månedene?
0 = Ingen besøk; 998 = Kan ikke svare/ uklart svar

_____ (ganger)

T4. Omtrent hvor mange ganger har du vært hos ergoterapeut i løpet av de siste 12 månedene?
0 = Ingen besøk; 998 = Kan ikke svare/ uklart svar

_____ (ganger)

T5. Omtrent hvor mange ganger har du vært hos logoped i løpet av de siste 12 månedene?
0 = Ingen besøk; 998 = Kan ikke svare/ uklart svar

_____ (ganger)

TX2. Har du hatt oppfølging fra den spesialiserte habiliteringstjenesten de siste 12 månedene?

- ◯ Nei
- ◯ Ja
- ◯ Nekter
- ◯ Kan ikke svare/ uklart svar/ vet ikke

T6. Når hadde du sist en full medisinsk undersøkelse?

- ◯ I løpet av siste 6 mnd
- ◯ 6 mnd til 1 år siden
- ◯ 1 - 5 år siden
- ◯ Over 5 år siden
- ◯ Aldri
- ◯ Kan ikke svare/ uklart svar/ vet ikke

T12. Kun for kvinner: Har du fått undersøkt brystene (bortsett fra mammografi) hos en lege eller sykepleier i løpet av det siste året?

- ◯ Nei
- ◯ Ja
- ◯ Kan ikke svare/ uklart svar/ vet ikke

T13. Kun for kvinner: Når fikk du utført mammografi sist?

- ◯ Aldri
- ◯ Siste året
- ◯ Siste 1 - 2 år
- ◯ Over 2 år siden
- ◯ Kan ikke svare/ uklart svar/ vet ikke

T14. Kun for kvinner: Har du vært undersøkt for livmorhalskreft i løpet av de siste 3 årene (kreftprøve)?

- ◯ Nei
- ◯ Ja
- ◯ Kan ikke svare/ uklart svar/ vet ikke

POMONA Seksjon 3

Record ID _____

Må fylles ut før intervjuet med en som kjenner personen med utviklingshemming.
I noen tilfelle hvor spørreskjemaet blir fylt ut av personen med utviklingshemming assistert av en nærperson, kan de ha ulike oppfatninger om spesielle spørsmål. I slike tilfelle er det viktig som et utgangspunkt å prøve å få til enighet om svaret. Hvor dette ikke er mulig og siden de fleste spørsmålene er utformet for å kunne besvares av en nærperson, er det hensiktsmessig å benytte nærpersonens svar med unntak av tilfelle hvor det finnes belegg for det motsatte.

Sett bare ett kryss på hvert spørsmål om ikke annet er oppgitt.

ID1. Er personens ferdighetsnivå målt? ◯ Nei ◯ Ja ◯ Vet ikke

ID2. Hvis personens ferdighetsnivå er målt, vennligst oppgi dette i en av de følgende kategoriene?
◯ Mild utviklingshemming
◯ Moderat utviklingshemming
◯ Alvorlig utviklingshemming
◯ Dyp utviklingshemming
◯ Vet ikke

DS1. Hva er den primære årsaken til personens funksjonsnedsettelse? Down's syndrom ◯ Annet
◯ Vet ikke
◯

DSX1. Har personen en autisme-spekter diagnose? ◯ Nei ◯ Ja ◯ Vet ikke

DSX2. Har personen andre diagnoser? ◯ Nei ◯ Ja ◯ Vet ikke

Hvis ja, hvilke: _____

BMI1. Hvor mye veier personen uten klær og sko? Oppgi vekt i hele kg uten desimaler. 998 = Vet ikke. _____ (kg)

BMI2. Hvor høy er personen uten sko? Oppgi høyde i hele cm uten desimaler. 998 = Vet ikke. _____ (cm)

Veiledning

KX4. Har personen en Individuell Plan (IP)?
◯ Nei
◯ Ja
◯ Kan ikke svare/ uklart svar/ vet ikke

KX5. Hvis ja, når ble IP evaluert sist?
◯ I løpet av siste 6 mnd
◯ 6 mnd til 1 år siden
◯ 1 - 2 år siden
◯ Over 2 år siden
◯ Aldri
◯ Kan ikke svare/ uklart svar/ vet ikke

Appendix 5

The Gross Motor Function Classification System

GMFCS

Record ID _____

GMFCS 12-18 beskrivelse og illustrasjoner

[Attachment: "GMFCS12-18-norsk.pdf"]

GMFCS spørreskjema for ungdom

[Attachment: "GMFCSfamilie_sporreskjema12-18.pdf"]

Gross Motor Function Classification Scale (GMFCS) spørreskjema
Vennligst les det følgende og kryss av i én rute ved siden av beskrivelsen som best tilsvarer din grovmotoriske funksjon.

Jeg ...
1.
Har vansker med å sitte selv og kontrollere hodet og bolens stilling i de fleste stillinger
og har vansker med å oppnå viljestyrt kontroll av bevegelse
og trenger spesialtilpasset stol med støtte for å sitte komfortabelt og bli kjørt noe sted
og må bli løftet eller bruke spesialhjelpemiddel ved forflytning

2.
Kan sitte selv, men verken står eller går uten betydelig støtte
og bruker alltid rullestol utendørs
og kan oppnå selvstendig forflytning ved bruk av elektrisk rullestol
og kan krype eller rulle i begrenset utstrekning for å forflytte meg innendørs

3.
Kan stå selv og går bare med ganghjelpemiddel (som forover- eller bakovervendt rullator, krykker, stokker, etc)
og har vansker med å gå i trapp eller på ujevnt underlag uten støtte
og benytter forskjellige måter å forflytte meg på avhengig av omstendighetene
og foretrekker å bruke rullestol for å forflytte meg raskt eller over lengre avstander

4.
Kan gå selv uten ganghjelpemiddel, men trenger å holde meg i rekkverk opp og ned trapp
og går derfor i de fleste omgivelser
og har ofte vansker med å gå på ujevnt underlag, i skråninger eller i folkemengder
og kan av og til foretrekke å bruke et ganghjelpemiddel (som en stokk eller krykke) eller rullestol for å forflytte med raskt eller over lengre avstander

5.
Kan gå selv uten ganghjelpemiddel, og kan gå opp og ned trapp uten å holde meg i rekkverk
og kan gå hvor som helst (medregnet på ujevnt underlag, i skråninger eller i folkemengder)
og kan løpe og hoppe selv om farten, balansen og koordinasjonen kan være lett nedsatt

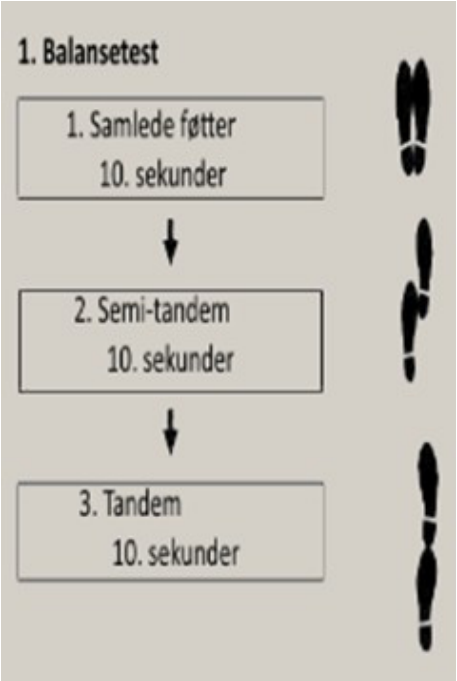
Appendix 6

Physical capability tests

Fysisk Funksjonsevne

Record ID _____

Balansetest



Balansetest, samlede føtter _____
(SS, MS)

Balansetest, semi-tandem _____
(SS, MS)

Balansetest, tandem _____
(SS, MS)

Hvis deltaker ikke har forsøkt eller mislyktes, velg hvorfor i listen

- ◯ Forsøkte, men ikke i stand til
- ◯ Deltakeren kunne ikke holde stillingen uten hjelp
- ◯ Ikke forsøkt, tester følte det utrygt
- ◯ Ikke forsøkt, deltaker følte seg utrygg
- ◯ Deltaker tar ikke instruksjon
- ◯ Annet (spesifiser)
- ◯ Deltaker nekter

Annet _____

Gang test X2

Ganghjelpemidler ved test
(kryss av, ved flere hjelpemidler bruk Annet feltet)

- ☐ Uten
- ☐ Krykke/ stokk (er)
- ☐ Rollator
- ☐ Annet

Annet spesifiser: _____

Gangtest 1 _____
(SS, MS)

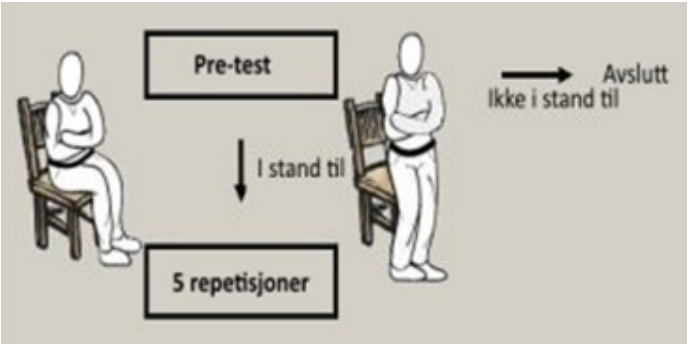
Gangtest 2 _____
(SS, MS)

Hvis deltaker ikke har forsøkt eller mislyktes, velg hvorfor i listen

- ◯ Forsøkte, men ikke i stand til
- ◯ Deltakeren kunne ikke gå uten hjelp
- ◯ Ikke forsøkt, tester følte det utrygt
- ◯ Ikke forsøkt, deltaker følte seg utrygg
- ◯ Deltaker tar ikke instruksjon
- ◯ Annet (spesifiser)
- ◯ Deltaker nekter

Annet _____

Reise/ sette seg test 5 repetisjoner



Setehøyde i centimeter: _____
(cm)

Pre test, reise/ sette seg x1
Klarer deltager å reise seg med armene i kryss over brystet?

◯ Ja ◯ Nei

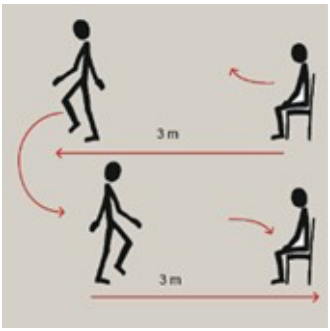
Tid 5 repetisjoner uten armbruk _____
(SS, MS)

Hvis deltaker ikke har forsøkt eller mislyktes, velg hvorfor i listen

- ◯ Forsøkte, men ikke i stand til
- ◯ Deltakeren kunne ikke reise seg uten hjelp
- ◯ Ikke forsøkt, tester følte det utrygt
- ◯ Ikke forsøkt, deltaker følte seg utrygg
- ◯ Deltaker tar ikke instruksjon
- ◯ Annet (spesifiser)
- ◯ Deltaker nekter

Annet _____

TUG



Tid for TUG: _____ (sekunder)

Usikker tid for opp og gå test: ◯ Ja ◯ Nei

Flamingo, balansere på ett ben med åpne øyne

Tid balansert på ett ben med åpne øyne: _____ (SS, MS)

Årsak til at deltager ikke forsøkte testen (marker alle som passer):

- ☐ Deltager følte seg utrygg.
- ☐ Proxy følte seg utrygg for deltakeren.
- ☐ Intervjuer følte seg ikke trygg for deltageren. Deltager var ustødig med støtte.
- ☐ Deltakeren hadde vanskeligheter med å forstå instruksjonene.
- ☐ Annet

Annet, spesifiser: _____

Flamingo, balansere på ett ben med lukkede øyne

Tid balansert på ett ben med lukkede øyne (SS, MS)