UiT The Arctic University of Norway

Faculty of Health Sciences

Encouraging participation in physical activity for individuals with intellectual disability: Motivational factors, barriers, and mHealth applications

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A dissertation for the degree of Philosophiae Doctor February 2024

Encouraging participation in physical activity for individuals with intellectual disability: motivational factors, barriers, and mHealth applications

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HELSE NORD

Acknowledgements

This research project, funded by the Regional Health authorities, involved a collaboration between the project researchers and the Clinical Research Unit at the University Hospital of North Norway. I extend my gratitude to research nurses Britt-Ann, Brita, and Annika for their excellent collaboration and commitment to maintaining high data quality in the pilot study.

I am deeply grateful to my supervisor, Audny Anke, for her invaluable guidance, support, and inspiration from the onset of my Ph.D. journey. Her meticulous review and constructive feedback on my drafts have transformed my writing process from a strenuous task to an enjoyable daily routine. Her assistance has been instrumental in the completion of this thesis.

My co-supervisor, Gunnar Hartvigsen, and co-author, André Henriksen, deserve special mention for their enthusiasm, support, and advice on the technological aspects of this thesis. Their involvement in the technical development, physical activity measurement, and article writing has enriched our meetings and trips.

I appreciate my co-supervisor, Cathrine Arntzen, for her significant contribution to the qualitative analysis and co-authorship of my first article. I also thank co-author Gunn Pettersen for her assistance with the qualitative analysis in the mixed-methods article and her support as the leader of the “Public Health and Rehabilitation” research group. My co-supervisor, Silje Wangberg, provided insightful comments and ideas on the article, for which I am thankful. I also extend my gratitude to all co-authors, including Reidun Jahnsen, Gyrd Thrane, Letizia Jaccheri, Eirik Søndenaa, and Erlend Refseth Pedersen, for their help in producing high-quality articles.

I thank Magnus, Vebjørn, Marius, Valter, Asgeir, Ida, Thomas E., Thomas L., and Dorthe for their work on developing and improving the applications as part of their master's theses. Mirek's technical assistance during the first three years of this project was invaluable.

Special thanks go to my colleagues Synne and Monica for their enriching discussions about research and life. I am grateful to my colleagues Silje, Christel, and Anne for their social support. The support of the Habilitation unit for adults at the University Hospital was crucial to this research project. I also thank my colleagues at the Child Habilitation unit for their support during my tenure as a 50% clinical psychologist from 2017 to 2023.

Lastly, I express my deepest gratitude to my partner, Tom, and daughter, Astrid, for making every day of this thesis journey possible and enjoyable. I am thankful to my parents, Anita and Kjetil, for their wise advice, and to my sister, Kamilla, and brother, Fredrik, for their unwavering support and engaging conversations.

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List of papers

Paper I

Michalsen, H., Wangberg, S. C., Anke, A., Hartvigsen, G., Jaccheri, L., & Arntzen, C. (2020). Family members and health care workers' perspectives on motivational factors of participation in physical activity for people with intellectual disability: A qualitative study. *Journal of Intellectual Disability Research, 64*, 259–270. https://doi.org/10.1111/jir.12716

Paper II

Michalsen, H., Henriksen, A., Pettersen, G., Hartvigsen, G., Wangberg, S., Thrane, G., Jahnsen, R., & Anke, A. (2023). Using mobile health to encourage physical activity in individuals with intellectual disability: A pilot mixed methods feasibility study. *Frontiers in Rehabilitation Sciences, 4*, 1225641. https://doi.org/10.3389/fresc.2023.1225641

Paper III

Michalsen, H., Henriksen, A., Hartvigsen, G., Pedersen, E. R., Søndenaa, E., Jahnsen, R., & Anke, A. (2024). Barriers to physical activity participation for adults with intellectual disability: A cross-sectional study. *In review.*

During my Ph.D., I wrote and contributed to the following publications:

Michalsen, H., Wangberg, S. C., Hartvigsen, G., Jaccheri, L., Muzny, M., Henriksen, A., Olsen, M. I., Thrane, G., Jahnsen, R. B., Pettersen, G., Arntzen, C., & Anke, A. (2020). Physical activity with tailored mHealth support for individuals with intellectual disabilities: Protocol for a randomized controlled trial. *JMIR Research Protocols, 9*(6), e19213. https://doi.org/10.2196/19213

Berg, V., Haugland, V., Wiik, M. F., Michalsen, H., Anke, A., Muzny, M., et al. (2020). E-health approach for motivating the physical activities of people with intellectual disabilities. *Digital Transformation for a Sustainable Society in the 21st Century IFIP WG 6.11 International Workshops: i3e*. Trondheim, Norway, 18 September–20, 2019, Revised selected papers 18, p. 2019

Torrado, J. C., Wold, I., Jaccheri, L., Pelagatti, S., Chessa, S., Gomez, J., Hartvigsen, G., Michalsen, H. (2020). Developing software to motivate individuals with intellectual disabilities to perform outdoor physical activities. *2020 IEEE/ACM 42nd International Conference on Software Engineering: Software Engineering in Society (ICSE-SEIS)*.

Michalsen, H., Wangberg, S. C., Hartvigsen, G., Henriksen, A., Pettersen, G., Jaccheri, L., Jahnsen, R. B., Thrane, G., Arntzen, C., & Anke, A. (2022). mHealth support to stimulate physical activity in individuals with intellectual disability: Protocol for a mixed methods pilot study. *JMIR Research Protocols, 11*(9), e37849. https://doi.org/10.2196/37849

Stellander, M., Henriksen, A., Michalsen, H., Anke, A., Ursin, D., Martinez, S., et al. (2022). Sorterius – an augmented reality app for encouraging outdoor physical activity for people with intellectual disabilities. *Linköping Electronic Conference Proceedings. Proceedings of*

the 18th Scandinavian Conference on Health Informatics, p. 88–91. https://doi.org/10.3384/ecp187015

Martinez-Millana, A., Michalsen, H., Berg, V., Anke, A., Gil Martinez, S., Muzny, M., et al. (2022). Motivating physical activity in individuals with intellectual disabilities through indoor bike cycling and exergaming. *International Journal of Environmental Research and Public Health, 19,* 2914. https://doi.org/10.3390/ijerph19052914

Summary

Objective: The overall objective of this thesis was to explore the participation in physical activity for adults with intellectual disabilities in physical activities. The study focused on understanding motivation, utilising mobile health (mHealth) applications, and identifying barriers to participation. The specific objectives were to understand the motivation for physical activity among this group through insights from family members and staff and develop, test, and evaluate a mHealth intervention. The study also sought to enhance understanding of the relationship between physical activity and barriers to participation, considering factors such as age, gender, living situation, and health conditions. Additionally, to examine barriers significantly associated with a sedentary activity level, adjusting for identified correlates of physical activity.

Methods: Paper I utilised an abductive qualitative design, conducting focus group interviews with healthcare professionals and family members, supplemented by individual interviews. A thematic analysis was performed with the social cognitive and self-determination theory as theoretical framework. Paper II employed a mixed-method design in an innovate pilot feasibility trial, involving nine participants aged 16–36 years with low physical activity levels. Data were collected at baseline, 4-weeks, and 12-weeks, using questionnaires and physical activity measurements from two activity trackers. Two mHealth applications were developed, tested, and goals for physical activity was set through goal attainment scaling. A qualitative interview was conducted post-follow-ups to assess the acceptability of procedures, activity measurement tools, and the mHealth applications. Paper III was a cross-sectional study that utilised the POMONA-15 health indicator questionnaire to evaluate physical activity levels and barriers to participation. A logistic regression analysis was performed to identify significant barriers.

Results: Paper I categorised motivation for physical activity into three primary themes: individual, contextual, and interactional. Individual motivation is driven by enjoyment, social rewards, and health consciousness. Contextual motivation involves support factors such as caregiver engagement, resource availability, and activity presentation. Interactional motivation, crucial for maintaining motivation, involves predictability and positive reinforcement during activities. In Paper II, the trial had a response rate of 16% and a retention rate of 100%. The data quality was high, with the exception of approximately 30% missing data from Fitbit activity trackers at the 4- and 12-week follow-up stages. Challenges with the feasibility of activity trackers included device-induced rashes, size, non-acceptance, and loss of motivation. All participants, except one, achieved one or more of their physical activity goals. The applications were well-received, although regular use necessitated support from staff and family members. Two participants demonstrated a significant increase in physical activity, and social support from family members significantly increased from baseline to follow-up. Paper III involved 213 participants, with 35% leading sedentary lifestyles. Barriers significantly associated with sedentary behaviour included the severity of intellectual disability, lack of activities at day centres, wheelchair dependence, health issues, and inability to use public transport.

Conclusions: Study I propose that fostering motivation for physical activity among individuals with intellectual disabilities relies on supportive interactions with their caregivers. Future research should probe the influence of predictability, social rewards and technology on motivating physical activity. Paper II, one of the pioneering studies to assess the impact of mHealth applications and activity trackers on the physical activity of adults with intellectual disabilities, suggests that goal attainment and customised applications are promising tools. However, subsequent studies should incorporate a larger sample size and more extensive staff engagement. Paper III pinpointed significant barriers to physical activity among individuals

with intellectual disabilities. To develop effective health interventions, it is imperative to address these barriers, such as enhancing activity opportunities at day centres, tailoring physical activity interventions for wheelchair users, and improving access to public facilities.

Sammendrag

Hensikt: Det overordnede målet med denne avhandlingen var å utforske deltakelse i fysisk aktivitet for voksne med utviklingshemming, gjennom kartlegging av motivasjon, bruk av mobile apper og identifisering av barrierer for deltakelse i fysisk aktivitet. Spesifikke mål var å utforske motivasjonen for deltakelse i fysisk aktivitet blant personer med utviklingshemming gjennom familiemedlemmer og ansatte, utvikle, teste og evaluere gjennomførbarheten og tilfredshet av en mobil helseintervensjon på fysisk aktivitet, aktivitetsmålere og studieprosedyrer. I tillegg bidra til økt kunnskap om hvordan fysisk aktivitet henger sammen med barrierer for deltakelse i fysisk aktivitet, samt alder, kjønn, bosituasjon og helseforhold. Videre å undersøke barrierer som er signifikant assosiert med et stillesittende aktivitetsnivå justert for identifiserte fysiske aktivitetskorrelater.

Metode: Artikkel I benyttet et abduktivt kvalitativt design, med fokusgruppeintervjuer med helsepersonell og familiemedlemmer, og individuelle intervjuer. Tematisk analyse ble utført innenfor rammen av sosial kognitiv teori og selvbestemmelsesteori. I artikkel II ble et blandet metodedesign brukt i en innovativ pilot- og gjennomførbarhetsstudie med ni deltakere i alderen 16–36 år med lavt fysisk aktivitetsnivå. Data ble samlet inn ved baseline, 4 uker og 12 uker, gjennom spørreskjemaer og måling av fysisk aktivitet ved hjelp av to aktivitetsmålere. To mHelse-apper ble utviklet og testet, og måloppnåelse ble brukt for å sette mål for fysisk aktivitet. Kvalitative intervjuer for vurdering av tilfredshet av prosedyrer, aktivitetsmåling og mHelse-appene ble gjennomført etter endt oppfølging. Artikkel III var en tverrsnittsstudie som brukte spørreskjemaet POMONA-15 Health Indicators for å vurdere fysisk aktivitetsnivå og barrierer for deltakelse. Logistiske regresjonsanalyser ble utført for å identifisere signifikante barrierer.

Resultat: I artikkel I ble motivasjon for fysisk aktivitet kategorisert i tre hovedtemaer: individuell, kontekstuell og interaksjon mellom individ og kontekst. Individuell motivasjon er drevet av glede, sosiale belønninger og helsebevissthet. Kontekstuell motivasjon innebærer støtte, inkludert engasjement av omsorgspersoner, ressurstilgjengelighet og presentasjon av aktiviteten. Interaksjonsmotivasjonen innebærer forutsigbarhet og positiv forsterkning under aktiviteter og er avgjørende for å opprettholde motivasjonen. I artikkel II var responsraten og gjennomføringen av studien henholdsvis 16 % og 100 %. Datakvaliteten var høy, bortsett fra manglende data fra Fitbit-aktivitetsmålere på omtrent 30% fra 4- og 12-ukers oppfølging. Gjennomførbarhetsutfordringene med aktivitetsmålere inkluderer tilfeller av utslett fra armbånd, størrelse, ikke-aksept og tap av motivasjon. Alle unntatt én deltaker oppnådde ett eller flere av sine fysiske aktivitetsmål, og appene ble godt mottatt, selv om regelmessig bruk krevde støtte fra ansatte og familiemedlemmer. To deltakere økte sin fysiske aktivitet signifikant, og sosial støtte fra familiemedlem økte signifikant fra baseline til oppfølging. Artikkel III inkluderte 213 deltakere, med 35% stillesittende livsstil. Barrierer som var signifikant forbundet med stillesittende livsstil inkluderte alvorlighetsgraden av utviklingshemming, mangel på aktiviteter på dagsentre, bruk av rullestol, helseproblemer og manglende evne til å bruke offentlig transport.

Konklusjoner: Artikkel I foreslår at støttende samspill mellom personer med utviklingshemming og deres omsorgspersoner er nøkkelen til å fremme motivasjon for fysisk aktivitetsdeltakelse. Fremtidig forskning bør videre undersøke hvilken rolle forutsigbarhet, sosiale belønninger og teknologi spiller for å motivere til fysisk aktivitet. Artikkel II er blant de første som undersøker effekten av mHelse-apper og aktivitetsmålere på fysisk aktivitet hos voksne med utviklingshemming. Funnene tyder på at måloppnåelse og skreddersydde apper er lovende verktøy, men fremtidige studier bør involvere et større utvalg og sikre større engasjement fra personalet. Artikkel III identifiserte viktige barrierer for fysisk aktivitet for

personer med utviklingshemming. Å adressere disse barrierene er avgjørende for å utvikle effektive helseintervensjoner, for eksempel å styrke aktivitetsmulighetene på dagsentre, tilpassede fysiske aktivitetsintervensjoner for rullestolbrukere og forbedre tilgangen til offentlige fasiliteter.

Abbreviations

ASD: Austism Spectrum Disorder

BMI: Body Mass Index

CFCS: Communication Function Classification System

CIQ: Community Integration Questionnaire

CRPD: Convention on the Rights of Persons with Disabilities

GAS: Goal Attainment Scale

ICD-10: International Classification of Diseases, 10th edition

IPAQ: International Physical Activity Questionnaire

IQ: Intelligence quotient

IQR: Interquartile Range

MET: Metabolic Equivalents

MVPA: modeate to vigorous physical activity

mHealth: Mobile health

RCT: Randomized Controlled Trial

SE/SS-AID: Self-efficacy/Social support for Activity for Persons with Intellectual Disability Scale

UNN: University Hospital of North Norway

WHO: World Health Organization

1 Introduction

This thesis aimed to investigate the motivation for physical activity among individuals with intellectual disabilities, providing a foundation for exploring mobile health application (mHealth apps). The study sought to enhance understanding of physical activity behaviours and barriers to participation. To our knowledge, this is the first study to utilise mobile applications and activity trackers to promote and objectively measure physical activity levels in adults with intellectual disabilities. It is also among the pioneering studies to identify barriers to physical activity participation in relation to known physical activity correlates in this population.

Improving the evidence base on physical activity participation and developing interventions for individuals with intellectual disabilities is crucial. The 2006 Convention on the Rights of Persons with Disabilities (CRPD) asserts the right of individuals with disabilities to inclusion in all aspects of cultural, recreational, leisure, and sports activities (Article 30) (Nations, 2006). They should be encouraged to participate and have opportunities to organise and engage in disability-specific sports and recreational activities, with equal access to appropriate instructions, training, and resources. The recent World Health Organization (WHO) physical activity guidelines (Bull et al., 2020) include recommendations for physical activity and sedentary behaviour for individuals living with disabilities and chronic conditions, aligning with guidelines for adults without disabilities in Norway (Bahr, 2009; Helsedirektoratet, 2019). However, awareness and promotion of physical activity for individuals with intellectual disabilities in Norway remain limited (Ingebrigtsen & Aspvik, 2009), necessitating attention from the government, health institutions, and researchers.

1.1 Intellectual disability

Individuals with intellectual disabilities constitute 1-3% of the global population (Maulik et al., 2011; Patel et al., 2020). Intellectual disability, as defined in the International Classification of Diseases – 10 (ICD-10) and Diagnostic and Statistical Manual of Mental Disorders – V (DSM-V), is a deficit in intellectual functioning and adaptive behaviour that begins during the developmental period and influences functioning (WHO, 2019). The DSM-V divides it into three domains of influence (Association, 2013). The first domain is conceptual, encompassing knowledge, reasoning, memory, executive function, and abilities such as reading, writing, and mathematics. The second domain is social, where individuals with intellectual disabilities may struggle with social interactions due to communication difficulties and challenges in maintaining friendships. The third domain is practical, which includes personal care, organising daily life, attending school, employment, and managing finances. The disability must originate before the age of 18 years and involves an intellectual functioning two standard deviations below the population average (IQ < 70). Many individuals with intellectual disabilities are unable to function independently in society.

Diagnosing intellectual disability requires an assessment of the individual’s cognitive and adaptive functions, using standardised instruments administered by qualified professionals (Patel et al., 2020). The degree of intellectual disability is categorised within different domains with corresponding IQ ranges: mild (IQ 50–69), moderate (IQ 35–49), severe (IQ 20–34), and profound (IQ < 20) (WHO, 2019). The aetiology of intellectual disability can be divided into genetic abnormalities or environmental exposure (Patel et al., 2020). Within genetic abnormalities, a distinction can be made between syndromic or non-syndromic intellectual disability. Non-syndromic intellectual disability is defined as intellectual disability being the only feature, with no co-morbidities or dysmorphisms (Jansen et al., 2023). Individuals with syndromic intellectual disabilities have one or more co-morbidities, such as autism spectrum disorder (ASD), attention deficit hyperactivity disorder, heart disease, facial dysmorphisms, and other congenital conditions. The most common chromosomal cause of intellectual disability is trisomy 21 or Down syndrome, and the most common gene-specific syndrome is Fragile X (Karam et al., 2015). Exposure to toxins during pregnancy (e.g., drugs, alcohol use), and maternal diseases during pregnancy or birth injuries (Patel et al., 2020) can yield Intellectual disabilities caused by environmental factors.

1.2 Physical activity

The WHO recommends that all adults regularly engage in either aerobic or muscle-strengthening physical activity. The suggested weekly volume is 150-300 minutes of moderate intensity or 75–150 minutes of vigorous intensity. This is to mitigate the risk of non-communicable diseases and all-cause mortality (Bull et al., 2020). The 2020 update to these guidelines, compared to the previous ones from 2016 (WHO, 2016), includes specific recommendations for individuals with disabilities, chronic diseases, and pregnant women, as well as additional guidelines for the elderly. The updated guidelines also emphasise the importance of reducing sedentary behaviour, asserting that any increase in physical activity, regardless of intensity, is beneficial.

1.2.1 Physical activity level in the general population

Despite the well-known benefits of regular physical activity, participation levels are declining globally (Hallal et al., 2012). This increase in inactivity, a global pandemic (Kohl et al., 2012), imposes a significant economic burden on healthcare systems worldwide (Ding et al., 2016). It is estimated that only about 30% of the general population meets the WHO’s recommended levels of physical activity. Inactivity levels are higher in Western countries compared to Southeast Asian or African countries (Guthold et al., 2018). In Norway, 22%–30% of the population is sufficiently active according to WHO guidelines (Hansen et al., 2019; Sagelv et al., 2019). The WHO member states aim to reduce physical inactivity by 10% by 2025 (Bull et al., 2020).

The average Westerner spends approximately 9-10 waking hours per day in sedentary pursuits (Hansen et al., 2019), which is associated with all-cause mortality, increased metabolic risk factors, cardiovascular disease, type 2 diabetes, and certain types of cancer (Biswas et al., 2015; Ekelund et al., 2019; Patterson et al., 2018). Recent research involving data from four cohort studies in Norway, Sweden, and the United States between 2006 and 2019, with 11,989 participants, indicates that the mortality risk associated with sedentary behaviour decreases when individuals engage in more than 22 minutes per day of moderate-to-vigorous physical activity (MVPA) (Sagelv et al., 2023). This suggests that future interventions should primarily aim to increase MVPA levels rather than solely focusing on reducing sedentary time. However, the WHO maintains that any level of physical activity is better than none (Bull et al., 2020; Klenk & Kerse, 2019).

1.2.2 Physical activity levels in individuals with intellectual disability

In a widely-cited systematic review from 2016, only 9% of the 3159 adults with intellectual disabilities met the physical activity recommendations (Dairo et al., 2016). Subsequent studies have found that only 6 to 11% of this population are sufficiently active (Melville et al., 2018; Oreskovic et al., 2020; Oviedo et al., 2017). These studies categorised physical activity levels by intensity and found that while many individuals with intellectual disabilities engage in light physical activity, few achieve high levels of MVPA. Hsu et al. (2021) conducted a study on 60 participants with intellectual disabilities living in Taiwanese group homes. The study used objective measures of physical activity and fitness levels, revealing an average of 275 minutes of light physical activity and 17 minutes of MVPA per day. Similarly, Oreskovic et al. (2020) studied 52 adults with Down syndrome and found that participants spent an average of 6.9 hours a day on sedentary activity, 2.7 hours on light activity, and 12 minutes on MVPA.

Faust and Morin (2022) included participants who achieved the recommended level of at least 150 minutes of MVPA per week in their study. They found that those engaging in high-frequency and high-intensity training had a lower Body Mass Index. In contrast, those with only moderate frequency and intensity of physical activity required more orthopaedic and physiotherapy consultations. In a study by Borland et al. (2020) involving 605 participants with intellectual disabilities, 42% reported participating in sports or physical activity over the past three months. Studies comparing individuals with and without intellectual disabilities have consistently found lower levels of physical activity participation in the former group (Oviedo et al., 2019; Zwack et al., 2022).

Individuals with intellectual disabilities who lead inactive lifestyles are at a high risk of developing metabolic syndrome (48.6%), being overweight or obese (69-87%), and having increased osteopenia and osteoporosis risks (30-40%) (Lynch et al., 2022). Furthermore, the prevalence of multimorbidity in non-selected populations is high (79%) (Lynch et al., 2022; Olsen et al., 2021). According to proxy-reported measures, these individuals spend approximately 12 hours a day on sedentary activities such as watching TV, working with computers, or riding in a car or bus (Melville et al., 2017). Harris et al. (2019) found that the mean sedentary time per day was 8 hours, which is comparable to findings in the general population (Hansen et al., 2019). Prolonged sedentary time of more than 9.5 hours per day is associated with an increased risk of mortality (Ekelund et al., 2019).

In a comprehensive health check program involving 725 participants, both physical activity and sedentary time were measured through a structured interview and physical examination. Sedentary behaviour was defined as screen time, with 52% of participants spending more than four hours a day using a screen (TV, tablet, or smartphone). Research has shown that increasing levels of MVPA can counteract the harmful effects of sedentary behaviour (Sagelv et al., 2023). Therefore, future physical activity promotion for adults with intellectual disabilities should aim to improve MVPA levels in this population.

1.2.3 Physical activity correlates in adults with intellectual disability

Several cross-sectional studies have explored factors associated with the lack of physical activity participation among adults with intellectual disabilities (Ascondo et al., 2023; Bauman et al., 2012; Temple & Walkley, 2007). However, correlational research only assesses statistical associations and does not provide evidence of a causal relationship between factors and physical activity. The most common factor associated with low physical activity participation is physical mobility problems (Borland et al., 2020; Cartwright et al., 2017; Jacinto et al., 2021; Kreinbucher-Bekerle et al., 2022). Older age predicts lower physical activity participation and a higher frequency of sedentary behaviours (Hsu et al., 2021; Oviedo et al., 2019). Another study found a negative association between moderate physical activity and sleep apnoea, endocrine conditions, physical health conditions, and anxiety disorders (Fleming et al., 2022).

Living alone without support was associated with prolonged periods of sedentary behaviour (Oreskovic et al., 2020). Melville et al. (2018) found that having a mild intellectual disability, living in supported accommodation or independently rather than with family, and being obese were associated with higher screen time. Harris et al. (2019) detected prolonged sedentary behaviour during weekdays. Participation in day-activity programs or educational programs was associated with low physical activity levels in one study (Hsieh et al., 2017), but a higher step count in another (Oviedo et al., 2019).

Several predictors of physical activity have been identified. Living with family or in supported accommodation, as opposed to living alone, and being able to express pain were positively associated with increased participation (Borland et al., 2020; Faust & Morin, 2022). Younger age, better subjective health status, and previous experience with sports predicted higher physical activity participation (Hsieh et al., 2017; Walsh et al., 2018). Franco et al. (2023) specified the type of physical activity (individual sports, team sports, and non-regulated physical activity) in their results. They found that more men participated in sports, whereas more women engaged in non-regulated physical activities.

Other barriers of participating in physical activity include insufficient resources or limited engagement from service providers (Laxton et al., 2023; Mahy et al., 2010), communication challenges between family members and paid caregivers (Cartwright et al., 2017), lack of independent access to community exercise facilities, and infrequent engagement in community-based exercise programs (Stancliffe & Anderson, 2017). Future research should aim to identify specific barriers to physical activity participation to develop tailored interventions for adults with intellectual disabilities who have low physical activity levels.

1.2.4 Measurement of physical activity and sedentary behaviour

Measuring physical activity and sedentary behaviour can be achieved through various methods. Objective measurements are argued to be the most accurate for individuals with intellectual disabilities(Elinder & Wallén, 2023). However, self-reported or proxy-reported measurements are considered more acceptable and easier to use in larger samples (Melville et al., 2018). Dairo et al. (2017) explored the feasibility of using accelerometers in conjunction with the International Physical Activity Questionnaire – Short (IPAQ-S). The study found substantial agreement between reports on being active or inactive between the IPAQ-S and accelerometer data. Despite this, the IPAQ-S has been reported to both underestimate and overestimate levels of physical activity when compared to accelerometer data (Oliveira et al., 2023; Perez-Cruzado & Cuesta-Vargas, 2018). A systematic review by Leung et al. (2017) investigated accelerometer-measured physical activity in an intellectually disabled population. The review highlighted the lack of uniformity in reporting protocols across studies, despite similar device placement and accelerometer type. This inconsistency hampers the comparison of results across different studies. Therefore, Agiovlasitis et al. (2023) emphasised the need for common guidelines or cutoff points for reporting objectively measured activity.

In the same review, Leung et al. (2017) noted that six out of 17 studies included children and adolescents, and all studies involved participants with mild-to-moderate intellectual disability. The compliance and acceptability of using measurement devices varied widely, from 44% to 100%, with only four studies reporting less than 80% compliance. Wrist-worn accelerometers, which are generally more acceptable and have higher wear time but are less accurate in estimating energy expenditure than hip-worn accelerometers, were not used in any of the studies (Quante et al., 2015). Commercial activity trackers have only been examined in two studies involving individuals with intellectual disabilities (Ptomey et al., 2022; Savage et al., 2022). These trackers offer several advantages, including consistent data display, increased likelihood of frequent use (Henriksen et al., 2020) and real-time data availability. Further exploration of commercial activity trackers for the intellectually disabled population is recommended.

1.3 Motivation for physical activity in intellectual disability

Motivation, a driving force that influences the strength and persistence of an individual’s behaviour (Deckers, 2005), plays a crucial role in physical activity. Despite numerous theories on motivation for regular physical activity, the literature lacks insight into its promotion among individuals with intellectual disabilities.

Bandura (1998) social cognitive theory posits that motivation for behavioural change is enhanced when individuals possess high self-efficacy, have positive outcome expectations about a specific behaviour and receive social support. This theory, which has been applied to understand motivation for physical activity among individuals with intellectual disabilities, suggests that mastery belief, vicarious experience, social persuasion, and positive physiological feedback are key motivators (Bossink et al., 2017; Temple, 2007).

Barriers to physical activity participation have been associated with inadequate financial and political support, lack of psychosocial support, personal disinterest in physical activity, and low self-efficacy (Dixon-Ibarra et al., 2017). Conversely, Mahy et al. (2010) identified support from others, engaging and routine physical activities, and familiarity with the activity setting as facilitators for individuals with Down syndrome. They underscored the importance of support in all aspects of physical activity. However, participation barriers include lack of support, disinterest in physical activity, and physiological factors such as overweight or heart conditions. Most research has focused on individuals with mild-to-moderate intellectual disability, suggesting the need for further studies encompassing all levels of intellectual disability (Bossink et al., 2017).

Self-determination theory categorises motivation into three types: absent (amotivation), internally driven (intrinsic), and externally influenced (extrinsic). Intrinsic motivation refers to doing an activity for the inherent satisfaction of the activity itself, and is reliant on phycological needs such as competence, autonomy and relatedness (Ryan & Deci, 2000). It is the strongest form of motivation. Extrinsic motivation refers to performing an activity to reach an outcome. There are several stages of extrinsic motivation, with a continuum from external motivation to integrated regulation. The behavioural change is less likely to occur when motivation is primarily external, driven by compliance and external rewards. When the extrinsic motivation derives from personal importance or awareness and synthesis with oneself, it is more likely that behavioural change will occur, and that the motivation will become intrinsic. Research has shown that individuals with mild-to-borderline intellectual disabilities exhibit varying levels of extrinsic motivation (Frielink et al., 2017). However, the motivational factors for those with severe intellectual disabilities remain less explored. The theory's emphasis on autonomy as an intrinsic motivator could be crucial for individuals with intellectual disabilities, who often face challenges to their personal control (Bergström, 2014). Despite understanding the link between physical activity and health benefits, most individuals with intellectual disabilities may lack the ability or resources to change their lifestyle without external assistance (Pitetti et al., 1993). A qualitative study by Kuijken et al. (2016) found that individuals with mild-to-moderate intellectual disability understand the concept of healthy living but struggle to translate this knowledge into action. Dixon-Ibarra et al. (2018) highlighted the absence of clear physical activity policies in group homes as a barrier to promoting a healthy environment for individuals with intellectual disabilities. It is also suggested that support persons' engagement in physical activity could positively influence the physical activity levels of individuals with intellectual disabilities (Heller et al., 2003). Therefore, the motivational factors of these individuals should be considered when designing future health promotion interventions.

1.4 Physical activity interventions for people with intellectual disability

Numerous well-conducted studies have not found significant improvements in physical activity levels among intervention groups of individuals with intellectual disabilities compared to control groups. This includes theory-based interventions with a randomised controlled study design (Melville et al., 2015; Overwijk et al., 2022; Ptomey et al., 2022). A cluster-randomised study involving older adults in the Netherlands reported marginal effects and significant missing data, despite thorough preparation and the use of day-activity centres for intervention (van Schijndel-Speet et al., 2017). Previous controlled studies primarily included adults with mild-to-moderate intellectual disability, and the effect sizes were small (Bergström, 2014; Bossink et al., 2017). Interventions varied, encompassing walking programmes (Melville et al., 2015; Shields et al., 2013), educational programs (McDermott et al., 2012; van Schijndel-Speet et al., 2017), aquatic exercises (Boer & de Beer, 2019) and community-based programs (Bergström, 2014). Studies reported improvements in physical fitness indicators, such as balance and muscle strength (Boer & Moss, 2016)(Boer & Moss, 2016), psychological well-being (Lante et al., 2011) perception of social competence (Hutzler & Korsensky, 2010) and work routines (Bergström et al., 2013) following increased physical activity. Findings suggest the need for a more flexible approach (Sundblom et al., 2015) greater theoretical underpinning in intervention design, the use of randomised controlled trials (RCTs), and improved translation of interventions to community-based settings (Hsieh et al., 2017).

1.5 Technological interventions to increase physical activity in people with intellectual disability

Technologies to enhance physical activity levels in individuals with intellectual disabilities have been investigated. A scoping review of stimulation-regulating technology programs for individuals with intellectual and multiple disabilities found that 15 out of 42 studies utilised video games (e.g., Wii gaming, virtual reality, Xbox, Light Curtain devices) to encourage physical activity, while the remainder employed response-contingent stimulation technology (Lancioni et al., 2022). Notably, none of these studies used mobile technology to augment physical activity levels. The majority of these studies (33 out of 42) had fewer than 10 participants, indicating that this area is under-researched. A Swedish study tested and evaluated a web-based physical activity promotion program (Fjellstrom et al., 2022; Fjellström et al., 2024). The intervention study reported an increase in physical activity levels post-intervention compared to baseline and an 83% attendance rate during web training sessions (Fjellstrom et al., 2022). The program's evaluation underscored the importance of staff support in various aspects of intervention delivery (Fjellström et al., 2024). Pérez-Cruzado and Cuesta-Vargas (2017) conducted a pilot randomised controlled trial with an educational intervention, supplemented by physical activity reminders via a mobile app, for four individuals with mild intellectual disability. Martinez-Millana et al. (2022) developed a motivational mobile app for indoor cycling and assessed user acceptance, but did not include physical activity measures.

In Norway, many individuals with intellectual disabilities possess smartphones or tablets, which could be used for tailored physical activity interventions. However, this potential has not been explored in clinical studies. Recent studies have not promoted the use of mobile health apps and activity trackers to objectively measure physical activity levels in adults with intellectual disabilities. Other research has demonstrated the measurable benefits of mobile technology for health-related behaviours and daily life in individuals with intellectual disabilities (Enkelaar et al., 2021; Raspa et al., 2018).

1.6 Individuals with intellectual disabilities in research

Individuals with intellectual disabilities, recognised as full citizens with equal rights to societal inclusion (WHO, 2011), are frequently excluded from medical research (Feldman et al., 2014). This exclusion was investigated in high-impact medical journals (Feldman et al., 2014), including the *New England Journal of Medicine*, *The Lancet*, *Journal of the American Medical Association*, *Annals of Internal Medicine*, *Public Library of Science Medicine*, and *British Medical Journal* (Feldman et al., 2014). Of the articles reviewed, a mere 2% (six studies) included individuals with intellectual disabilities. The investigation also examined whether modifications or accommodations were made to facilitate the inclusion of these individuals. The findings revealed that 90% of the studies were designed in such a way that individuals with intellectual disabilities would be automatically excluded. A systematic review by Brooker et al. (2015) discovered that public health cohort studies passively excluded individuals with intellectual disabilities, while RCTs actively did so. For the ecological validity of all public health cohort studies, it is crucial that the participant pool reflects the entire population, which should include 2-3% of individuals with intellectual disabilities. Therefore, future research must explore how to include individuals with intellectual disabilities in health research.

2 Objectives of this thesis

The overarching aim of this thesis is to examine the participation of adults with intellectual disabilities in physical activity. This examination involves investigating motivational factors, utilising mobile health (mHealth) support tools, and identifying barriers to participation. The specific objectives are as follows:

Aim 1: To investigate the motivation for physical activity among individuals with intellectual disabilities through family members and staff.

Aim 2: To develop, test, and evaluate the feasibility and acceptability of mobile health interventions for physical activity. This aim also includes exploring the feasibility and acceptability of activity trackers and study procedures.

Aim 3: To examine how physical activity levels correlate with barriers to participation, age, sex, living situation, and health conditions. Additionally, we will identify barriers significantly associated with sedentary activity levels, adjusted for physical activity correlates.

3 Methods

This research project was designed to assess a physical activity intervention, utilising mHealth apps, aimed at encouraging motivation and participation in physical activity among individuals with intellectual disabilities. A qualitative study was undertaken to understand the motivational factors influencing physical activity participation in this group (Paper I). The results from the study were used as a starting point for developing applications that could stimulate physical activity in the target population. Following the development, a mixed-methods pilot study was conducted to evaluate the feasibility and acceptability of the intervention, procedures, and physical activity measurement (Paper II). To enhance understanding of physical activity behaviour and participation barriers, physical activity data from the cross-sectional North Health in Intellectual Disability (NOHID) study were analysed (Paper III).

3.1 Design

Paper I employed an abductive qualitative design (Kardorff et al., 2004). An explorative, empirically driven approach was used, drawing on existing literature to investigate the motivation for physical activity participation among individuals with intellectual disability. Data collection occurred between February and May 2018.

Paper II presented a mixed-methods pilot feasibility study, using a concurrent triangulation approach, to assess the feasibility and acceptability of the study procedures, intervention, and measures. Strategies for enhancing inclusion in community or public health studies are associated with research design (Skivington et al., 2021) and the use of complex interventions. An intervention is deemed complex if it involves multiple components, considers the delivery context, targets a range of behaviours, and evaluates intervention delivery (Skivington et al., 2021). The inclusion of supplementary qualitative components in complex interventions is increasingly prevalent (Curry et al., 2013). Incorporating a qualitative component into a clinical trial can help describe implementation processes and provide insights into the success or failure of interventions. It can also indicate whether the real-world effectiveness of interventions is enhanced or limited. Qualitative findings can elucidate the ineffectiveness of an intervention by explaining negative results, thereby informing future research (Curry et al., 2013). Quantitative methods were used in Paper II to collect objective physical activity data, questionnaires, and feasibility measures. Qualitative methods were employed to explore the acceptability of study participation, the use of the intervention (mHealth tool), and the use of physical activity measurements. Data collection took place between May 2021 and January 2022.

The data utilised in Paper III originated from the NOHID study, a cross-sectional, multi-centre investigation encompassing five municipalities in Norway’s northern and central regions, namely Tromsø, Balsfjord, Narvik, Malvik, and certain areas of Trondheim. The University Hospital of North Norway (UNN) in Tromsø, in collaboration with St. Olavs Hospital in Trondheim, spearheaded the NOHID study. The data collection spanned from October 2017 to December 2019, and the analysis was conducted using quantitative methods. Figure 1 overviews the design of three papers included in this thesis.

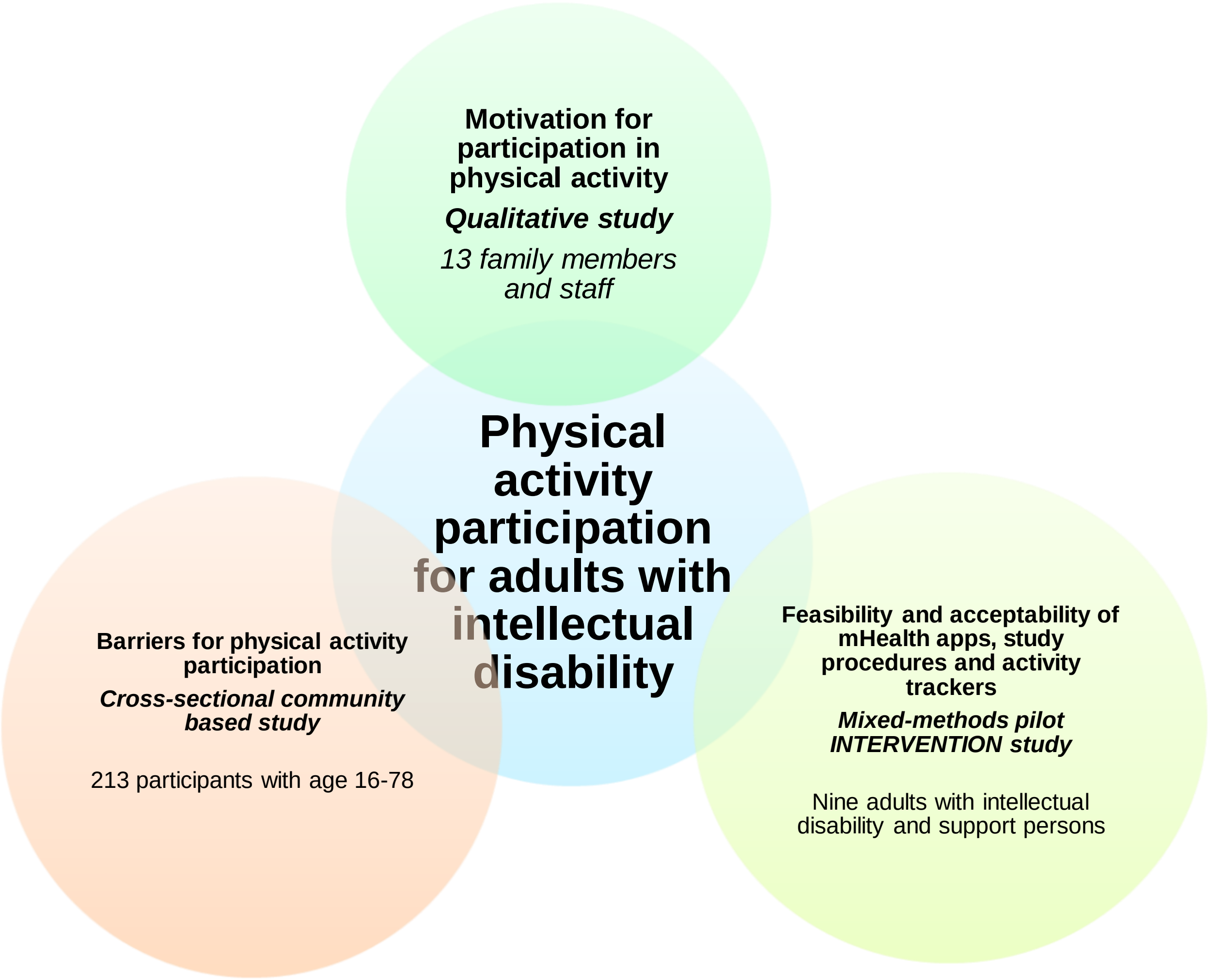


Figure 1: *Overview of the three papers included in this thesis.*

3.2 Study population

Paper I employed a purposeful sampling strategy (Patton, 2015) to recruit eight family members of individuals with intellectual disabilities and five healthcare workers from various levels of intellectual disability services. The healthcare workers, chosen for their experience with the user group, represented a diverse range of positions and settings, including specialised and community-based intellectual disability services and day care centres. The family members, selected for their experience or insights into physical activities for individuals with intellectual disabilities, were related to individuals with a range of intellectual disabilities, ages, familial relationships, and living conditions.

Paper II conducted a mixed-methods pilot trial involving nine participants with intellectual disabilities, identified through their participation in the NOHID study (Olsen et al., 2021) and by municipal staff leaders. The study included both adults and young adults, requiring participants to be at least 16 years old. The participants, ranging in age from 16 to 36 years, had varied living conditions. Of these, eight had moderate intellectual disabilities, and seven were female. Each participant had the support of a family member or staff member throughout the study.

Paper III included participants from the NOHID study, with a total of 214 participants in the main study (Olsen et al., 2021). One participant was excluded from the analysis in paper III, resulting in 213 participants. Eligibility for the study required a verified diagnosis of intellectual disability according to the International Statistical Classification of Diseases and Related Health Problems (ICD-10) 10th revision criteria (WHO, 2019), registered community support, a minimum age of 16 years, and residence in one of the municipalities of Tromsø, Balsfjord, Narvik, Malvik, or parts of Trondheim in Norway. Participation rates varied by region, with 140 of the 266 eligible individuals in the northern region participating, a rate of 53%. The included participants, with a mean age of 36.2 years, were younger than the excluded participants and nonparticipants, who had a mean age of 42.3 years (Olsen et al., 2021). Central Norway had lower participation rates, resulting in a sample of 74 participants with age and sex distributions comparable to those of the northern participants (Olsen et al., 2021).

Table 1: *Participants characteristic from Papers I, II and III*

	Paper II	**Paper II**	**Paper III**
Age, years			
Median (range)	21 (13-52)	28 (19–30)	32.5 (16-78)
Gender, n (%)			
Female	2 (25)	7 (77)	95 (44)
Male	6 (75)	2 (22)	119 (56)
Level of intellectual			
disabilities, n (%)	0	1 (11)	82 (39)
Mild	4 (50)	8 (89)	56 (26)
Moderate	3 (38)	0	49 (23)
Severe	1 (12)	0	17 (8)
Profound	0	0	9 (4)
Unknown			
Occupation, n (%)			
Regular paid work		1 (11)	1 (0.5)
Work with support		3 (33)*	76 (35.5)
Day centre activity		4 (44)	44 (21)
Attending school		2 (22)	0
Other			50 (23)
Missing			43 (20)
Living situation, n (%)			
Lives independently		1 (11)	25 (12)
Lives with family		2 (22)	41 (19)
Apartment in group home with care		6 (67)	147 (69)
CFCS, n (%)			
Level 1		5 (56)	122 (57)
Level 2		2 (22)	55 (26)
Level 3-5		2 (22)	36 (17)

*: One participants had work with support and day center activity

3.3 Data collection

In Paper I, data were gathered through two focus group discussions and two individual interviews. An interview guide, inspired by existing literature on motivational factors for physical activity (Heller et al., 2003; Mahy et al., 2010; Temple, 2007) and informed by social cognitive theory and self-determination theory, was prepared to structure the interviews and ensure comprehensive coverage of key areas. The same theoretical framework was employed for data analysis. Semi-structured focus group interviews were conducted with eight family members and three healthcare workers. These discussions were supplemented with two in-depth individual interviews with a day care centre staff member and a community residence leader (Kvale, 2015). The focus group interviews, led by an experienced researcher (CA) and observed by the PhD fellow and co-author (AA), lasted between one and two hours. The participants' enthusiasm for the topic enriched the discussion dynamics. The individual interviews were led by the researcher and lasted approximately one hour each. All interviews were recorded and transcribed verbatim by a doctoral fellow.

In Paper II, research nurses from the UNN's clinical trial unit managed data collection and storage. Invitation letters were distributed to 50 participants from the NOHID study database, 20 from a local daycare centre, and four from a local high school, either by post or through the leaders of the respective institutions. Following signed informed consent from the participants or a family member, the research nurses liaised with a family member or staff member from the group home or daycare centre to complete the screening. All participant interactions at screening, baseline, 4-week follow-up, and 12-week follow-up were conducted by research nurses from the clinical trial unit. Baseline and follow-up conversations were held over the phone, and questionnaires were emailed at baseline, 4 weeks, and 12 weeks. Activity trackers were delivered to the participants' homes by the PhD fellow at 4 and 12 weeks post-baseline assessment. A goal-setting meeting, which included goal attainment scaling and the introduction of two mHealth applications, was conducted bu the PhD fellow after the baseline assessment at the participants' preferred location. After the final follow-up at 12 weeks, all participants were invited to a qualitative interview, lasting between 20 minutes and 2.5 hours, at their preferred location. During the goal-setting meeting and qualitative interviews, six out of nine participants with intellectual disabilities were present, with participants answering all questions in two of these sessions. An overview of these procedures is presented in Figure 1.

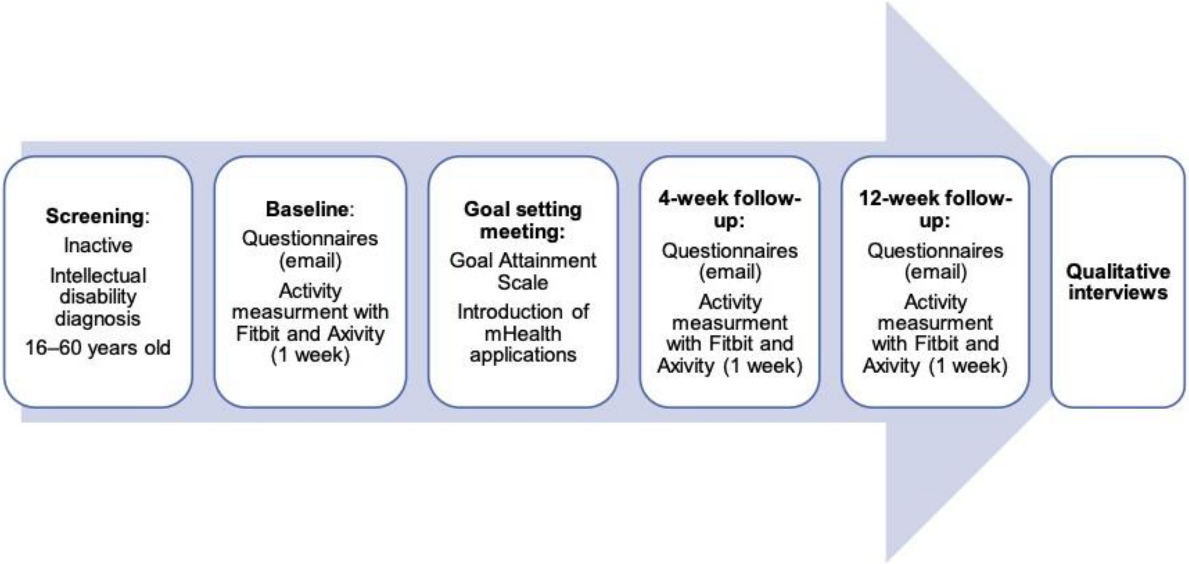


Figure 2: *Procedures from Paper II*

Potential participants for Paper III were identified via specialised services for intellectual disabilities at the UNN and St. Olavs Hospital. Additionally, information was accessed about individuals with intellectual disabilities receiving services from the municipalities of Tromsø, Balsfjord, Narvik, Malvik, and parts of Trondheim. Eligible participants received invitations, followed by phone calls to their guardians or next of kin. Research assistants with healthcare backgrounds, including research nurses, nurses for the intellectually disabled, and physiotherapists, conducted recruitment and data collection. Data were collected through structured interviews using the POMONA-15 (P15) Health Indicators Questionnaire (Perry et al., 2010) and additional questionnaires such as the Gross Motor Function Classification Scale (GMFCS). Interviews involved participants, caregivers, and supporters. In 98 interviews, both an individual with an intellectual disability and a support person were present. In seven interviews, only the individual with an intellectual disability was present, and in 107 interviews, only the support person was present. Questionnaires were completed at the hospital research unit, in participants' homes, at other preferred locations, or via telephone interviews. Participants' medical records provided information about the level of intellectual disability and other health conditions.

3.4 Intervention

3.4.1 Application development

The primary application used in Paper II was named Active Leisure (Norwegian: Aktiv Fritid). It is an advanced activity planner based on a platform developed by Smart Cognition AS, a non-profit Norwegian company that donates its profits to projects improving living conditions for people with disabilities. The developers, who are close relatives of individuals with intellectual disabilities, received feedback from user representatives (family members and staff working with individuals with intellectual disabilities) in a reference group and from experts in the research group during the development process. Although this application is a commercial product, Smart Cognition added specific features for this study: the ability to register activities, simple rewards for completing activities, and the ability to add new, predefined activities to the mobile application.

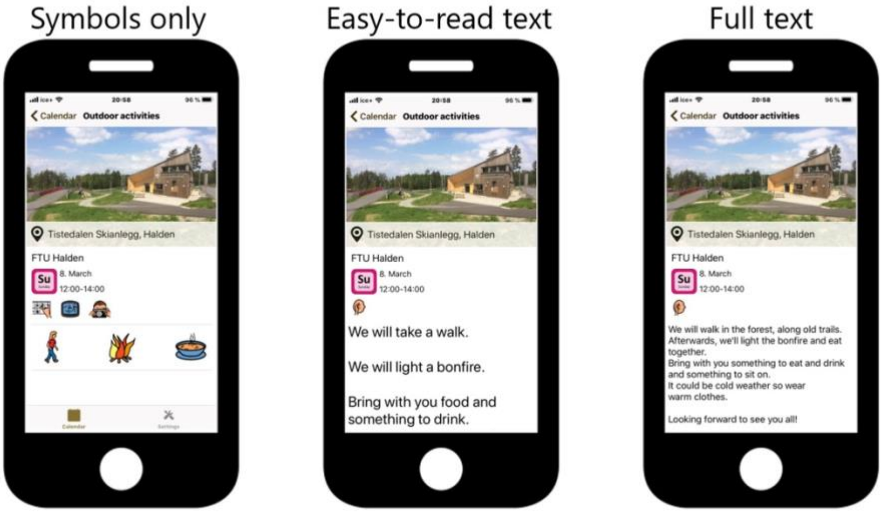
An additional mobile health exercise application (mHealth app) was developed to supplement the Active Leisure planner. This application, named Sorterius (Stellander et al., 2022), is an augmented reality game inspired by the popular game Pokémon Go. The idea for the application originated from the findings of the qualitative study in Paper I and was refined through discussions in reference groups. During one of these meetings, an individual with an intellectual disability tested the prototype. Sorterius was conceptualised and implemented as part of a master's thesis project in computer science in spring 2021 (Stellander, 2021). At that time, COVID-19 restrictions prevented comprehensive user testing with individuals with intellectual disabilities. However, a usability test was conducted with eight teachers working with individuals with intellectual disabilities to refine the game before its use in a pilot study.

3.4.2 Goal-setting meeting

In Study II, Goal Attainment Scaling (GAS) was employed as part of the intervention to identify self-management goals that participants aimed to achieve. The researcher, participants, and proxy respondents completed the questionnaire. Each participant selected goals, and the corresponding behaviours indicating goal attainment were defined by the participants or caregivers/staff. Up to three concrete and achievable goals were defined by each participant in collaboration with a support person and a researcher. For instance, one participant aimed to ‘walk home from work two days a week’, while another aimed to ‘go swimming with my family every week’ and ‘walk to the grocery store three days per week’. Five different goal attainment levels were used for scoring, ranging from ‘no change’ to ‘much better-than-expected outcome’ (numbered -2, -1, 0, +1, +2). All scores were initially set to -2 (no change) at the intervention meeting. After a set follow-up period of 12 weeks, goal attainment was evaluated during a qualitative interview.

3.4.3 Application use in the intervention

During the goal-setting meeting, a digital activity planner named Active Leisure was introduced. This application offers individualised activity solutions with various interface options for tailoring, such as symbols only, easy-to-read text, plain text, or read aloud. The planned activity, its time, and location were displayed with a picture and the preferred text option. Upon completion of an activity in the planner, a simple reward, such as a smiling face or shareable picture, was provided. All activities added to the planner were entered through a web application, based on the goals set by each participant during the goal-setting meeting. The researcher added all daily activities and new activity goals to the app. Activity planner was primarily used by individuals with intellectual disabilities and their support persons together, including family members or healthcare providers.



Calendar Outdoor activities

Tistedalen Skianlegg, Halden

FTU Halden

Su 8. March

12:00-14:00

Calendar Outdoor activities

Tistedalen Skianlegg, Halden

FTU Halden

Su 8. March

12:00-14:00

We will take a walk.

We will light a bonfire.

Bring with you food and something to drink.

Calendar Outdoor activities

Tistedalen Skianlegg, Halden

FTU Halden

Su 8. March

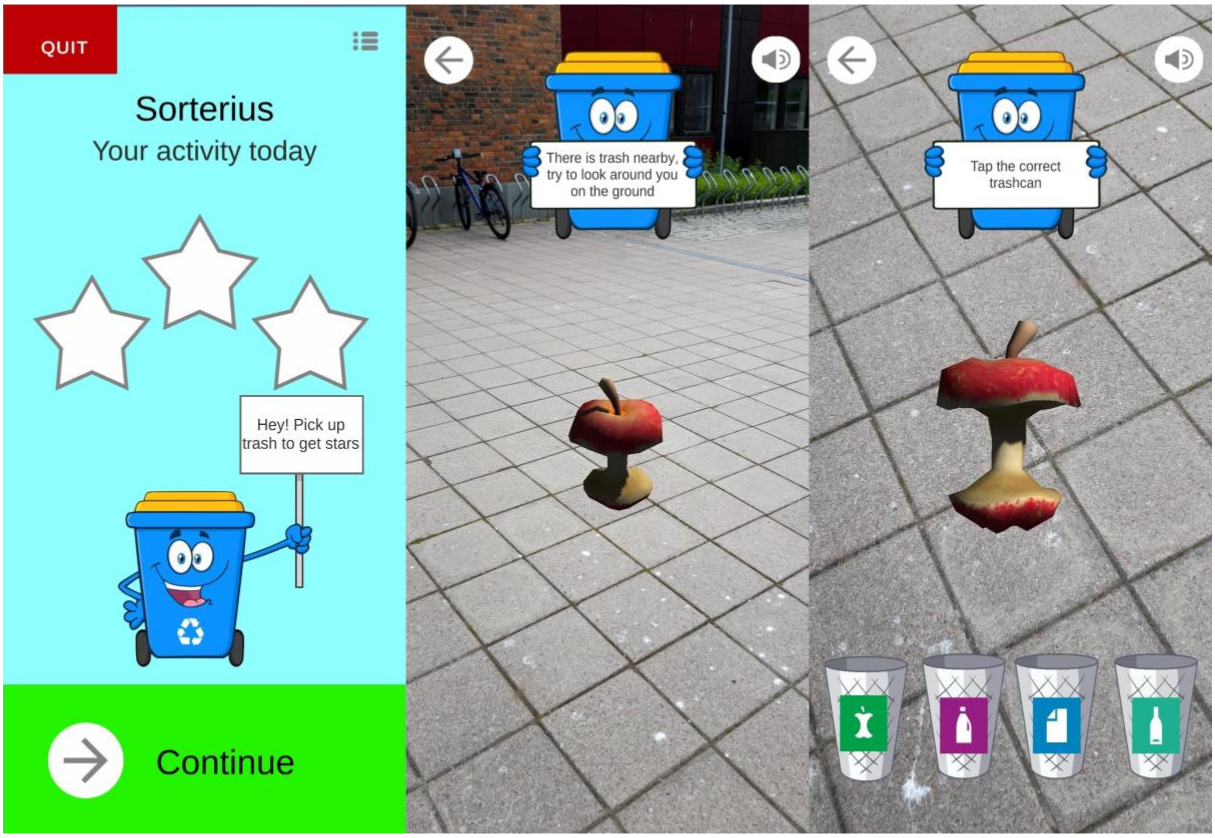
12:00-14:00

We will walk in the forest, along old trails.
Afterwards, we'll light the bonfire and eat together.
Bring with you something to eat and drink and something to sit on.
It could be cold weather so wear warm clothes.

Looking forward to see you all!

Figure 3*: Interface option in the Active Leisure application*

Another application, Sorterius, was also part of the intervention. In this game, individuals walk in the real world while using their mobile phones. Through the phone's camera, the individual sees virtual waste appearing on the ground, which can be picked up (i.e., clicked) and sorted into the correct waste bins. For example, plastic waste goes into the plastic bin. Depending on the chosen difficulty level, the individual is presented with one (easy), two (medium), or four (hard) bins. Upon collecting a set number of items, the individual receives a virtual reward, such as stars and positive feedback. It is possible to add daily step goals and a weekly goal, tailored for each individual. The Sorterius app is continuously developing, and the version used in this project is freely available for Android and iPhone.



Hey! Pick up trash to get stars

There is trash nearby, try to look around you on the ground

Tap the correct trashcan

Figure 4: *Pictures showing the different steps of how to play the Sorterius game*

3.5 Measures

Papers II and III utilise similar measures, while Paper I employs qualitative methods without collecting quantitative measures. An overview of these measures is provided in Table 2. The central measurements in Paper II were selected based on their relevance to physical activity levels, participation, and support. All measures are described in a published protocol for a future randomised controlled e-health intervention and in a protocol for the pilot study (Michalsen et al., 2022; Michalsen et al., 2020). Paper III's data were extracted from a health indicator study that incorporated measures of health and use of health services. Accordingly, the analysis in Paper III included measures of physical activity levels, information on barriers to physical activity participation, and relevant health measurements.

3.5.1 Physical activity

For Paper II, the main outcome was steps per day measured using two different activity trackers: Fitbit Versa and Axivity. The decision to use a Fitbit Versa (Fitbit LLC, CA, US) smartwatch on the non-dominant wrist was informed by a small feasibility study at the UiT Arctic University of Norway (Hempel, 2020). This study indicated a preference for devices with screens over those without or with small screens, and for different wristband colours. Although the use of Fitbit for objective physical activity measurement has not been validated in a population with intellectual disabilities, it has been used in an intervention study for individuals with intellectual disabilities and autism (Savage et al., 2022). The accuracy of the Fitbit device has been tested in a rehabilitation population (Farmer et al., 2022). We offered several choices regarding device colour, size, and band material. The devices were distributed on the same day as the baseline assessment. Participants were required to wear the Fitbit device for at least three consecutive days, with a minimum of 500 steps per day, for the measurement of daily steps to be valid (Bergström, 2014).

Additionally, all participants were instructed to use the Axivity (Axivity Ltd., Newcastle, UK) on their dominant wrist. Participants who agreed to use only one of the activity trackers chose the Fitbit device, as it was the chosen device for testing in a later randomised controlled trial (Michalsen et al., 2020). Data from the Axivity device were not analysed in Paper II, except for days of valid measurement.

Paper II incorporated both objective and proxy-measured physical activity. The International Physical Activity Questionnaire-Short Form (IPAQ-S) was employed to gauge subjective physical activity through proxies for individuals with intellectual disabilities (Craig et al., 2003). The IPAQ-S, a seven-item questionnaire, evaluates physical activity at four intensity levels over the preceding week: 1) vigorous-intensity activity (e.g., aerobics); 2) moderate-intensity activity (e.g., leisure cycling); 3) walking; and 4) sitting. The questionnaire was scored continuously by calculating the volume of activity based on its energy requirements, expressed in metabolic equivalents (METs), to yield a total MET minutes per week score. According to the IPAQ-S scoring protocol, high physical activity levels were defined as reaching between 1500 and 3000 MET minutes/week, moderate levels as between 600 and 1500, and insufficiently active or inactive as under 600 MET minutes/week. This scale has been validated in the general population (Lee et al., 2011), and a feasibility trial in a population of individuals with intellectual disabilities found substantial agreement between instruments on being active or inactive (Dairo et al., 2017).

In Paper III, physical activity was measured using the POMONA-15 interview, which includes a modified version of the Saltin Grimby Physical Activity Level Scale (SGPALS) (Grimby et al., 2015). The SGPALS posed the question, ‘How much of your leisure time have you been physically active in the last year?’ with four response categories: 1) ‘Regular participation in hard training or sports competitions more than once a week’; 2) ‘Engagement in jogging, other moderate sports, or heavy gardening for at least four hours each week’; 3) ‘Walking, cycling, or other forms of light exercise for at least four hours a week’; or 4) ‘Reading, TV, or other sedentary activities’. Additionally, the questionnaire included a question about work activity: ‘If you are in paid or unpaid work, how would you describe your work?’ The response categories for this question were: 1) Mainly sedentary activity (e.g., desk work); 2) Work involving walking (e.g., sales, light industrial work, teaching); 3) Work involving heavy lifts (e.g., care work, construction); and 4) Heavy manual labour (Sagelv et al., 2019). These questions have been used in Norway’s most comprehensive and longest-running population study, the Tromsø study (Hopstock et al., 2022).

In Paper III, we assessed the participants’ overall physical activity levels by combining responses to the SGPALS question about leisure physical activity and the question about activity levels during paid or unpaid work. This combination formed a variable we labelled 'total physical activity'. During this process, participants who reported 'reading, TV or other sedentary activities' (response category 4) as their leisure physical activity level, but also reported engaging in 'work that involves walking', 'work that involves heavy lifts', or 'heavy manual labour', were reclassified into the physical activity category 'walking, cycling or other forms of light exercise at least four hours a week' (response category 3). This adjustment, primarily from sedentary to light activity, affected 21 participants.

In the same paper, we included a single question from P15 on barriers to participation in physical activity in our analysis. The question was: 'Do you encounter difficulties participating in physical activity for the following reasons?' It listed 15 different barriers, each requiring a 'yes' or 'no' response. If participants could not relate to any of the provided barriers, two additional response choices were available: 'cannot answer/unclear/don't know' and 'refuse to answer'. Participants were asked to identify multiple barriers. A 'yes' response was categorised as a barrier to participation in physical activity. The listed barriers included: 'use of wheelchair/mobility impairments', 'insufficient funds', 'lack of transport options', 'inability to use public transport', 'lack of companionship', 'prohibition', 'need for assistance with no available help', 'fatigue', 'time constraints', 'lack of activities at the day care centre', 'lack of exercise activities', 'dislike of exercise', 'health-related issues', 'severity of intellectual disability', and 'age'.

3.5.2 Demographics and health status (P15)

In Papers II and III, we utilised the POMONA-15 (P15) health indicators questionnaire (Perry et al., 2010) to gather demographic data such as age, gender, living situation, education, and work status. In Paper III, we used P15 to collect health indicators for adults with intellectual disabilities. This questionnaire, developed collaboratively by 13 EU member states, aimed to evaluate health disparities between individuals with intellectual disabilities and the general population (Perry et al., 2010). The P15 questionnaire encompassed a wide range of medical conditions, including but not limited to asthma, allergies, diabetes, cataracts, hypertension, heart attacks, stroke, chronic obstructive pulmonary disease/emphysema, arthritis (both osteoarthritis and rheumatoid arthritis), osteoporosis, peptic ulcers, various forms of cancer such as leukaemia, migraine, recurrent headaches, constipation, thyroid disorders, and epilepsy. The National Office for Health Improvement and Disparities also recorded frequently occurring conditions like skin and musculoskeletal problems.

In Paper III, we included physical health conditions with a prevalence of 25% or more (Olsen et al., 2021) in further analyses. Multimorbidity was defined, following WHO guidelines (WHO, 2019), as the presence of one or more physical health conditions in addition to a diagnosis of intellectual disability. Notably, diagnoses of Down syndrome, autism, or cerebral palsy were considered underlying diagnoses rather than physical health conditions. We obtained weight information from informants for 194 out of 213 participants, with 9% of the data missing. For a subset of participants (n = 50) from the Tromsø region, weight measurements were taken at the clinical trial unit.

3.5.3 Gross motor function and communication

In Papers II and III, we employed the GMFCS to evaluate gross motor function. Originally developed for individuals with cerebral palsy (Palisano et al., 1997; Palisano et al., 2008), the GMFCS boasts high inter-rater reliability (McCormick et al., 2007). Although the extended and revised versions of the scale (GMFCS E&R) have been used in studies involving adults with intellectual disabilities (Dijkhuizen et al., 2018), formal validation for this population is yet to be established. The GMFCS E&R categorises gross motor functioning into five levels, with lower levels indicating superior function:

Level 1: Individuals may have limitations in advanced motor skills (e.g., speed and balance) but can generally walk without restrictions.

Level 2: Individuals at this level often require handrails for stairs and can walk unaided, though they may occasionally use mobility aids such as crutches or wheelchairs.

Level 3: Individuals typically rely on mobility aids indoors and use wheelchairs outdoors.

Level 4: Individuals predominantly depend on wheelchairs for mobility.

Level 5: This level signifies the need for a wheelchair and additional support for sitting.

In Papers II and III, we also used the Communication Function Classification System (CFCS) to assess communication levels. The CFCS poses seven questions related to types of communication: speech, sound (exemplified as ‘ah’), gesticulation/eye movements/pointing, signing, non-technological communication aids, and technological communication aids. The CFCS classifies communication functions into five levels, with lower levels indicating superior skills: I) Effectively sends and receives messages with both unknown and known communication partners. II) Efficient but slower pace as a sender and/or receiver with both unknown and known communication partners. III) Effectively sends and receives messages only with known communication partners. IV) Inconsistently sends and/or receives messages with known communication partners. V) Rarely efficiently sends and receives messages, even with known communication partners.

The CFCS has demonstrated high inter-rater reliability in individuals with cerebral palsy (Hidecker et al., 2011). Although it has been used in individuals with intellectual disabilities, validation among adults with intellectual disabilities remains to be conducted.

3.5.4 Mental health, challenging behaviour, and self-efficacy

In Paper III, we used the Moss Psychiatric Assessment Schedules (Check) (MPAS), formerly known as the PAS-ADD Checklist, to identify potential mental illnesses in individuals with intellectual disabilities of all levels (Moss, 2012). The MPAS comprises three subscales: Condition, Affective/Neurotic Disorder, and Psychotic Disorder. Each subscale has a specific threshold score; scores at or above this threshold suggest the need for further clinical or mental health assessments. Independent replication of the MPAS-Check's psychometric properties demonstrated acceptable internal consistency. The MPAS-Check was found to be sensitive to variations between diagnostic groups, with an overall sensitivity of 66% and a specificity of 70% (Sturmey et al., 2005).

In Papers II and III, we used the Aberrant Behaviour Checklist-Community (ABC-C) (Aman et al., 1985) to assess challenging behaviours. This scale, validated in a Norwegian population with neurodevelopmental disabilities (Halvorsen et al., 2019), consists of 58 items divided into five subscales: irritability, social withdrawal, stereotypical behaviour, hyperactivity/noncompliance, and inappropriate speech. It functions as a proxy measure, requiring input from individuals familiar with the person with intellectual disability. Each item is scored on a scale ranging from 0 (least) to 3 (most).

In Paper II, we used the Self-Efficacy/Social Support for Activity for Persons with Intellectual Disability Scale (SE/SS-AID) to assess participants' self-efficacy in activities and their receipt of social support from others (Lante, 2007). This questionnaire includes four subscales, one of which measures self-efficacy in overcoming barriers to leisure physical activity. The remaining three subscales measure the social support for leisure activities from family members, care staff, and friends of individuals with intellectual disabilities. The scale has been validated for self-reporting in individuals with mild-to-moderate intellectual disabilities and has been used by proxy respondents (Peterson et al., 2009). The questionnaire was translated into Norwegian following standard guidelines.

3.5.5 Community integration, health-related quality of life and goal attainment

In Paper II, we used the EuroQol-5D-5L (EQ-5D-5L) to measure health-related quality of life (Richard, 1996). This scale comprises five domains: mobility, self-care, usual activities, pain/discomfort, and anxiety/depression. Each domain is scored from 1 (no problem performing a task) to 5 (unable to perform a task). The overall index score, calculated based on the normative values of Nordic participants without intellectual disabilities (Wittrup-Jensen et al., 2009), ranges from zero to one, with scores closer to one indicating a higher health-related quality of life. Although the EQ-5D-5L has been used in research involving individuals with intellectual disabilities, a significant proportion of these individuals experienced difficulties in responding (Russell et al., 2018). The EQ-5D-5L can be completed by a proxy respondent familiar with the individual, and the 5L version has been validated for use with people with dementia (Michalowsky et al., 2022).

In Paper II, we used the Community Integration Questionnaire (CIQ) to assess participants' integration in their community (Willer et al., 1994). The CIQ, comprising 15 items related to home, social integration, and productive activities, assigns scores of 0, 1, or 2 depending on the level of integration. A maximum total score of 12 indicates a high level of community integration. Originally developed for individuals with acquired brain injury, the CIQ can be completed by self-report or by a caregiver familiar with the individual. It has shown promising psychometric properties for people with other disabilities (Turcotte et al., 2019).

In Paper II, we reported the GAS as normalised T-scores using the calculations provided in the manual (Kiresuk et al., 2014). A mean score of 50 with a standard deviation of 10 corresponded to the achievement of the goal (score of 0). We calculated the overall attainment scores for all goals set by the participants, each of whom set two or three goals for physical activity. The GAS has demonstrated good responsiveness and sensitivity to change and has been used in studies involving individuals with intellectual disabilities (Willis et al., 2018).

Table 2: *Included measures from Papers I, II and III*

	Paper I	*Paper II*	*Paper III*
Demographics			
Age	x	x	x
Gender	x	x	x
Living situation	x	x	x
Work status		x	x
Level of intellectual disability	x	x	x
Diagnosis			
Down syndrome		x	x
Autism		x	x
Cerebral Palsy			x
Body Mass Index		x	x
Physical Activity			
IPAQ-S (proxy report)		x	
Steps/day, objective measure		x	
Intensity level, objective measure		x	
Sedentary activity		x	x
Barriers for physical activity participation		x	x
Other measures			
Gross motor function		x	x
Communication function		x	x
Community Integration Questionnaire		x	x
Social Support and Self-efficacy in physical activities		x	
Health-related *quality of life*		x	
Goal attainment scaling		x	
Qualitative interview	x	x	

3.6 Ethical considerations

In medical research, researchers must strike a balance between inclusivity of all potential beneficiaries and the protection of particularly vulnerable individuals (Feldman et al., 2014). The inclusion of vulnerable groups, such as individuals with intellectual disabilities, presents a challenge due to the additional ethical considerations, planning, caution during data collection, and dissemination of results.

Practical challenges may arise when including individuals with intellectual disabilities in research. These challenges encompass obtaining informed consent, ensuring comprehension of outcome measures, and adherence to study instructions (Brooker et al., 2015; Mulhall et al., 2018). Recruitment difficulties often occur, typically due to the need for gatekeepers or facilitators to access potential participants (Bossink et al., 2017). This process can lead to the exclusion of the least able due to overprotectiveness or loss of information (Doody, 2018). Limited resources in municipal care or group homes can further restrict participation options (Wouters et al., 2019). Studies have reported missing data and low participation rates, especially among individuals with severe intellectual disabilities (Bossink et al., 2017; Wouters et al., 2019). These issues suggest that the challenges of inclusion lie both in the scientific methods employed and the characteristics of the individuals with intellectual disabilities.

In Paper II and Paper III, informed consent was obtained from individuals with intellectual disabilities if they were capable of decision-making. If an individual was unable to provide consent, a close relative did so on their behalf. Participants were informed of their right to withdraw from the study at any time without treatment consequences. However, this information was not tailored to specific needs, such as easy-to-read text or illustrative procedures. An individual with an intellectual disability may not fully understand the concept of research participation. The participants with an intellectual disability were positive to participate in the study and wear measurement devices but may not have comprehended how physical activity was measured trough the devices. Future interventional studies on physical activity should consider and adapt to these ethical issues.

In Paper I, informed consent was provided solely by family members or staff included in the study. They consented on their own behalf, as representatives for individuals with intellectual disability either through their knowledge as a parent, sibling, staff member or health care worker. Some of the participants were members of user organizations or for sport federations for individuals with intellectual disability.

In paper III, much of the information in this study was provided by the support person for the individual with an intellectual disability, which means that the individual did not provide all their own health information. This issue, common in studies involving individuals with lower cognitive function, can complicate the generalisation of data to individuals with intellectual disabilities (Doody, 2018).

Ethical approval for Papers I and II was granted by the Regional Committees for Medical and Health Research Ethics in Norway (number 2016/1770) and by the data protection officer at the UNN. Paper III received approval from the Committee for Medical Research Ethics, Health Region North (2017/811), and data protection officers at UNN and St. Olavs Hospital.

3.7 Data analysis

In Paper I, data analysis incorporated thematic analysis (Greenhalgh & Taylor, 1997). The first author transcribed the interviews verbatim, repeatedly reading them to discern emerging themes. These transcriptions were reviewed and annotated by the two co-authors, who also provided feedback on the initial analysis. The transcriptions were subsequently coded, and themes were identified. Through author discussions, main themes were discerned by clustering similar subthemes (Malterud, 2002). Each category and subcategory were exemplified using excerpts from the focus group and individual interviews. Distinctions were made between individual, contextual, and interaction factors. The social cognitive theory, particularly the concept of self-efficacy (Bandura, 1978) and Self-determination Theory (Ryan & Deci, 2000) were instrumental in understanding the subcategories related to individual factors. Contextual factors were understood through previous research on the barriers to and facilitators of physical activity participation (Mahy et al., 2010; Temple, 2007). Interactional factors emerged as the most prominent themes, contributing new knowledge.

Paper II employed a concurrent triangulation mixed-method approach (Schoonenboom & Johnson, 2017). This method involved the simultaneous collection and separate analysis of quantitative and qualitative data. The final interpretation combined both data types, with qualitative data enriching the quantitative findings. Quantitative statistical analyses were conducted using SPSS 28 software (IBM Corp.), based on the data type and distribution. Descriptive statistics were presented as medians with interquartile ranges, means, 95% confidence intervals, and categorical data frequencies. Variable distributions were examined. Adhering to the CONSORT 2010 extension, participant outcome measure effects (from baseline to follow-up) were explored using nonparametric statistics (related-sample Wilcoxon signed-rank test) (Wurz & Brunet, 2019). Change tendency with a 10% significance level was reported, alongside minimal clinically important individual differences of 10% in steps from baseline to follow-up (Bergström et al., 2013).

The qualitative interviews were transcribed and analysed using thematic analysis (Greenhalgh & Taylor, 1997). The first author read the interview transcripts multiple times, selecting and further analysing data on activity measurements, app use, and research project participation.

The selected text was coded into themes. These codes were compared for differences and similarities, and condensed into meaningful categories and subcategories (Malterud, 2002). The preliminary analysis was reviewed and annotated by the contributing authors. Following author discussions, main themes were identified by grouping similar subthemes and comparing them with the quantitative feasibility analysis results (Wurz & Brunet, 2019). Finally, the quantitative data were supplemented with qualitative information (Creswell & Hirose, 2019). For instance, interviews elucidated the reasons for missing data at certain measurement points.

In Paper III, descriptive statistics provided an overview of the data. Continuous variables, such as age, were presented as means with standard deviations or medians with ranges. Categorical variables were expressed as percentages of the defined categories. The variable 'total physical activity' was analysed on a four-level scale (sedentary behaviour, light activity, moderate activity, and vigorous activity), which was dichotomised into 'active' (encompassing light, moderate, and vigorous activities) and 'sedentary' in some analyses. Associations between the dichotomised physical activity groups were examined using One-Way ANOVA for the continuous variable of age and Pearson's chi-square test or the nonparametric Fisher exact test for categorical variables.

Significant barriers associated with the dichotomised physical activity level in cross-tabulation analysis were further explored in binary logistic regression analyses, with the dichotomised level of physical activity (sedentary/active) as the dependent variable. The primary independent variables were age, level of intellectual disability, gross motor function, epilepsy, and Down syndrome.

Adjustment variables were included based on prior literature (level of intellectual disability) or due to a statistically significant association with physical activity in the initial analysis ($p < .05$). In the multivariate logistic regression analyses examining the associations between dichotomised levels of physical activity and barriers, adjustments were made for the following variables in various combinations: age (continuous), level of intellectual disability (mild, moderate, severe, or profound), gross motor function classification (level 1-2 /level 3-5), epilepsy (yes/no), and Down syndrome (yes/no). The diagnosis of cerebral palsy was excluded due to the small sample size (n = 24) and its moderate correlation with gross motor function. Subsequently, the entry method was applied. Multicollinearity was assessed to ensure that none of the variables were highly correlated with each other, with a Spearman's correlation cutoff of 0.7. Model fit was evaluated using the Hosmer–Lemeshow goodness-of-fit test, and the degree of pseudo-explained variance was reported using Nagelkerke's R value.

4 Results: Summary of papers

4.1.1 Summary of Paper I

Objective: This study aimed to understand how individuals interacting with those with intellectual disabilities perceive their participation in and motivation for physical activity. It also sought to explore the facilitation of physical activity in the Arctic region and to involve family members or staff representing individuals with severe intellectual disabilities.

Methods: Employing an abductive qualitative design, data were collected through two focus group interviews involving healthcare workers and family members, supplemented by two individual interviews. A thematic analysis was conducted, with Social Cognitive Theory and Self-Determination theories forming the theoretical reference framework. These concepts influenced various aspects of the research process, including the development of the interview guide and the theoretical abstraction of themes and subthemes.

Results: The findings suggest that motivations for physical participation can be categorised into three main themes. The first is individual motivation, where individuals are motivated when the activity is enjoyable and offers social rewards. Individuals with intellectual disabilities must understand the health benefits of physical activity and to be aware of their bodily signals during activity. Many such individuals also show an initial interest in technology that can enhance physical activity. The second theme is contextual, highlighting the importance of the supporter of the individual with an intellectual disability having a personal interest in physical activity. This enthusiasm can increase the motivation of individuals with intellectual disabilities. The supporter or supporting team needs to have the necessary resources, such as transport, sufficient personnel, required tools for the activity, and favourable weather conditions. The presentation of an activity can also influence the motivation of the target user. The final theme is the interaction of individual and contextual factors, implying that the activity should be a joint effort between the individual with an intellectual disability and the supporter. The predictability of activities is vital for maintaining motivation, and reinforcing the behaviour with rewards during the activity strengthens the individual's self-efficacy and increases the likelihood of the behaviour being repeated.

Conclusions: To enhance motivation for physical activity, the interaction between individuals with intellectual disabilities and their supporters should be supportive and foster mastery experiences. At the individual level, factors such as enjoyment, social rewards, and the use of technology as motivational factors for participation in physical activity warrant further exploration in future research. Support and engagement in the context could serve as prerequisites for motivation and participation in physical activity and should be considered when developing interventions for individuals with intellectual disabilities.

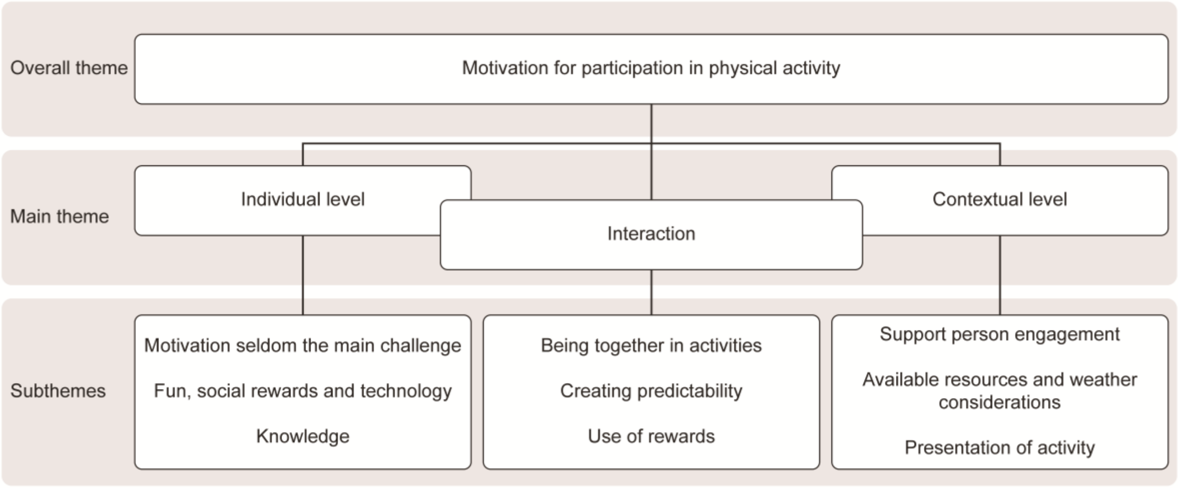


Figure 5: *Model from the results of the qualitative study with themes and structures.*

4.1.2 Summary of results from Paper II

Objectives: This pilot intervention study aimed to assess the feasibility and acceptability of using innovative mobile health (mHealth) support systems to promote physical activity among individuals with intellectual disabilities.

Methods: Nine individuals with intellectual disabilities, aged 16–36 years, exhibiting a low level of physical activity, were included in this convergent triangulation mixed-method design. Two mHealth support systems (apps) were developed, tested and evaluated. Physical activity was measured using a Fitbit smartwatch, an Axivity accelerometer, the International Physical Activity Questionnaire-Short Form (IPAQ-S), and Goal Attainment Scale (GAS). Data were collected through online questionnaires and activity trackers at pre-intervention, mid-intervention (four weeks), and post-intervention (12 weeks) stages. Semi-structured qualitative interviews were conducted with participants and/or a family or staff member following a 12-week follow-up period. Data were analysed using conventional nonparametric statistics and thematic analyses.

Results: The response rate to the trial was 16%, with a retention rate of 100%. The quality of the data was high, with the exception of approximately 30% missing data from Fitbit activity trackers at the 4- and 12-week follow-up stages. Challenges to feasibility included rashes from devices, size, non-acceptance, and loss of motivation. Participants and family members/staff expressed interest in the study theme and satisfaction with the data collection method. All but one participant achieved their physical activity goals. Most participants reported satisfaction with the apps, finding them enjoyable and useful as reminders to engage in physical and other activities. Social support for physical activity among family members increased. However, regular use of the apps required support from staff and family members.

At the 12-week follow-up, two of the nine participants (22%) had increased their physical activity, as measured by steps per day with Fitbit.

Conclusions: To the best of our knowledge, this is the first study to examine the impact of specially developed mobile apps and wrist-worn activity trackers on the physical activity of adults with intellectual disabilities. The acceptability and feasibility of combining goal attainment with tailored mobile applications to increase physical activity are promising. This study aligns with previous research highlighting the challenges of increasing physical activity, which necessitates the involvement of family members, staff, and stakeholders. Future comprehensive studies should include participants from a broader area and aim for more significant engagement of staff and stakeholders.

4.1.3 Summary of results from Paper III

Objectives: This study had two objectives: firstly, to investigate the relationship between physical activity levels and barriers to participation, considering factors such as age, sex, living situation, and health conditions; secondly, to identify barriers significantly associated with sedentary behaviour after adjusting for these correlates.

Methods: The NOHID study, a cross-sectional, community-based survey, utilised the POMONA-15 health indicator questionnaire. This study incorporated the physical activity questions from the POMONA-15 questionnaire, aligned with those in the Tromsø study, and a list of 15 barriers to physical activity participation. Occupational and leisure physical activity levels were combined to form a single question measuring overall physical activity. Both univariate and multivariate logistic regression analyses were conducted to identify significant barriers associated with a sedentary lifestyle.

Results: The sample comprised 213 participants, with a mean age of 36 years, 56% of whom were male. Approximately one-third of the participants had severe or profound intellectual disabilities. Among the participants, 35% reported predominantly sedentary activities, 52% mainly light physical activity, 7% moderate physical activity, and only 3.7% regular vigorous physical activities. In multivariate logistic regression analyses, after adjusting for variables such as age, level of intellectual disability, gross motor function, and epilepsy, the following barriers were significantly associated with sedentary behaviour: severity of intellectual disability, unavailability of activities at day-activity centres, dependence on a wheelchair, health-related issues, and inability to use public transportation.

Conclusions: This study underscores various barriers to physical activity participation among individuals with intellectual disabilities. Identifying these barriers is crucial to inform future health interventions for this population. Specifically, there is an increasing need to enhance physical activity opportunities within day-activity centres, tailor programmes for wheelchair users, and improve access to physical activity facilities.

5 Discussion

The thesis aimed to investigate the participation of adults with intellectual disabilities in physical activity, focusing on motivation, the use of mHealth apps, and barriers to participation. The primary findings suggest that while these individuals are motivated to engage in physical activity, they require social support, engagement, enjoyment, predictability, and doing activities together to enhance their participation.

Two mHealth apps for physical activity were tested and evaluated, revealing that while the apps were engaging, they necessitated support for regular use. The study procedures demonstrated good feasibility, evidenced by a 100% retention rate at baseline and follow-up, goal-setting meetings, qualitative interviews, and less than 1% missing data within questionnaires. However, the use of activity trackers was less successful due to 30% missing data at follow-ups, skin rashes, diminished motivation, and difficulties in understanding the purpose of activity measurements. The study theme, procedures, and mHealth apps were deemed acceptable as they facilitated structure and inclusion in activities, emphasised physical activity, and offered flexibility in study delivery. Of the nine participants, two increased their physical activity; all but one achieved their goals after 12 weeks, and family support significantly increased from baseline to the 12-week follow-up.

Barriers to physical activity were identified in 213 participants with intellectual disabilities. The results showed a sedentary activity level of 35%, light physical activity in 52%, and MVPA level of 11%. After controlling for age, level of intellectual disability, gross motor function, epilepsy, and Down syndrome in the multivariate regression analysis, significant barriers related to sedentary activity levels were found to be wheelchair use, lack of available activities at the day care centre, severity of intellectual disability, health-related issues, and inability to use public transport.

5.1.1 Interaction of individual factors and context

The qualitative study on motivational factors for physical activity in individuals with intellectual disabilities identified three key themes: individual, contextual, and interactional. The most prominent finding was that the interaction between individuals with intellectual disabilities and their contexts mediated their motivation to participate in physical activity. This interaction, facilitated through joint participation in activities, predictability, and the use of rewards, strongly influenced their physical activity participation.

Although the primary source of information was the support persons (family or staff) of individuals with intellectual disabilities, this finding is consistent with other studies showing the importance of enjoyment in the individual and support from family members and staff (Heller et al., 2003; Mahy et al., 2010; Temple, 2007). The Self-Determination theory (SDT) and Self-Efficacy from the Social Cognitive theory (SCT) were used as theoretical frame of references (Bandura, 1978; Ryan & Deci, 2000). Both theories are suitable for understanding the individual motivational and the contextual. The SDT describes internalization as vital for motivation to move from external to intrinsic and the SCT focuses on modelling and vicarious experience as part of motivation for behavioural change. Nonetheless, neither the SDT or SCT describes the interaction between the individual and the context as essential for the motivation. In SDT, autonomy support is described as a contextual contribution that can alter motivation, but the theory still focuses on individual processes as determining for the behaviour. In SCT, self-efficacy and outcome expectancies are also related to processes within the individual. In individuals with intellectual disability, internal regulation and intrinsic processes can be difficult to retrieve, either because of the disability in intellectual functioning or because of communicational barriers between the researcher and the individual with intellectual disability.

The finding of the interactional motivation in the current thesis can be seen as a socially driven interaction between the individual with intellectual disability and their support persons, that can increase or decrease depending on the responses from the individual or the context. The socioecological model, which proposes four levels contributing to a person's health behaviour—intrapersonal factors (demographic, biological, psychological, and cognitive), interpersonal factors (social support), physical environment (costs and scenery), and policy (laws and regulations)—has been used in previous research to understand physical activity behaviours (Bauman et al., 2012; Sallis et al., 2006; Woods et al., 2021). This model has also been applied to understanding physical activity correlates in systematic reviews, including individuals with intellectual disabilities and autism spectrum disorders (Liang et al., 2020; Vancampfort et al., 2022). In the socioecological model, health behaviours are complex and involve not only the individual and their interaction with the context but also the broader society (Sallis et al., 2006). Therefore, changes in health behaviours need to occur at all levels, not just at the individual level, for behavioural change to be sustainable. The interactional factors of motivation for participation in physical activity identified in this study could potentially represent the intrapersonal factors, interpersonal factors, and the environment from the socioecological model. These factors include the characteristics of the individual with intellectual disability, engagement with the support person, available resources at the facilities, joint participation in activities, predictability in the activity, and use of rewards. However, the study did not consider whether the promotion of physical activity is part of municipal regulations or promotion programs. Future studies may benefit from involving community leaders and policymakers in the development and delivery of physical activity promotion. This approach ensures that all areas of the socioecological model are included, potentially leading to a sustainable increase in the behavioural change in physical activity.

The integration of interactional factors from Paper I into the findings of Paper II, a mixed-methods pilot study, revealed consistent patterns of physical activity participation. Two key findings emerged from this study: social support from family members significantly increased from baseline to follow-up, and all but one participant achieved one or more goals for improved physical activity participation. The achievement of physical activity goals might have been facilitated by the increased social support from family members. In essence, the interaction between individual goal-setting and family support may have contributed to the achievement of these goals. A systematic review of intervention studies aimed at improving physical activity levels in individuals with intellectual disabilities found no difference in increased physical activity levels between the experimental and control groups in six out of nine studies. However, a multi-component Swedish study by Bergström et al. (2013) reported a significant increase in physical activity levels. In this study, both adults with intellectual disabilities and their caregivers or staff were involved in the intervention. This finding could suggest that the increased levels of physical activity could be attributed to the support from caregivers or staff, in addition to the involvement of individuals with intellectual disabilities, as seen in the interactional factor from Paper I.

Another study that found a significant difference in physical activity levels between the experimental and control groups observed that physical activity levels remained high in the experimental group three months after intervention ended, but decreased in the control group post-intervention (Shields et al., 2013). In this study, the experimental group had 10-week supervised resistance training program. It could be suggested that the benefit of the training program was the assistance in establishing routine and predictability for physical activity (Hassan et al., 2019), which was also found as part of the interactional theme in paper I.

In paper III, five different barriers were significantly related to sedentary behavior, when controlling for physical activity correlates. Two barriers significantly related to sedentary behaviour were the lack of available activities at the day care centre and the inability to use public transport. These barriers could be seen in the as part of the contextual theme from paper I. Both these barriers can be overcome by changing the context of individuals with intellectual disabilities, particularly at the societal level. This includes incorporating more physical activity in day care centres as a policy for all municipalities and ensuring public transport meets inclusive design guidelines and standards (Park & Chowdhury, 2022).

Three barriers significantly associated with sedentary behaviour were identified, which are not directly linked to individual preferences or motivation. First, the use of a wheelchair or mobility issues, common among individuals with severe intellectual disabilities (Patel et al., 2020), is an inherent characteristic of the individual and is typically unchangeable. However, environmental adaptations and supportive measures can potentially alter physical activity behaviour. Thus, the barrier or the potential for change is an interactional factor, dependent on the individual’s motivation and the context’s capacity to create opportunities for physical activity behaviour improvement. Many studies note that mobility issues are prevalent frequent barriers to participation in physical activities among individuals with intellectual disabilities (Borland et al., 2020; Cartwright et al., 2017; Jacinto et al., 2021; Kreinbucher-Bekerle et al., 2022). Second, health-related issues were significantly associated with increased sedentary behaviour. Individuals with intellectual disabilities may have health disorders, such as heart disease or lifestyle diseases, which they perceive as prohibiting physical activity participation. Other studies have found health problems, such as obesity, to be predictors of more sedentary lifestyles (Melville et al., 2018). Despite physical activity being recommended for treating several health conditions (Ekelund et al., 2019), this barrier can be interpreted as a knowledge gap or reluctance to find suitable physical activities for individuals with health problems. The third barrier identified was the severity of the intellectual disability. While some scholars found severe intellectual disability to be a barrier to participation (Borland et al., 2020), others found it to be a predictor of physical activity participation (Franco et al., 2023; Oviedo et al., 2017). Arguably, individuals with more severe intellectual disabilities have more support staff or live longer with their families due to their complex care needs, thereby receiving more direct support. However, this group requires closer follow-up, more transport to activities, and has fewer adapted physical activities available (Bossink et al., 2017). Hence, the barrier is not related to individual characteristics but is more related to contextual factors for physical activity participation, as the support given to the individual is crucial for more frequent participation.

5.1.2 Innovation

Paper II, to the best of our knowledge, is the first study to investigate the influence of specially designed mobile health applications, in conjunction with wrist-worn activity trackers, on the physical activity of adults with intellectual disabilities. This innovative pilot study introduced a unique intervention developed within the research project. User representatives were included in reference groups during development, and applications at various stages underwent usability testing with user groups, support persons, and researchers.

The design of the applications was meticulously considered, taking into account aspects such as colour schemes, text or symbol usage, and user interface options (Lanyi & Brown, 2010). The context in which the applications are used is another crucial factor. Many study participants and adults with intellectual disabilities in Norway live in group homes or their own apartments with support, interacting with staff frequently. The staff's perceptions, engagement, and interactions with the applications are vital for daily use. In the pilot study, many staff members sought additional information and reported that participants with intellectual disabilities did not independently use the applications. A Norwegian study introduced a technological solution, the memo planner, to enhance participation and self-determination in adults with intellectual disabilities in community-based home care

(Söderström et al., 2021). The findings indicated that technology implementation heavily relied on staff teamwork and communication (Söderström et al., 2023). Despite successful implementation of the memo planner for individuals with intellectual disabilities, staff evaluations revealed initial project conflicts and struggles. In the mixed-methods pilot trial, the applications were used for a mere 12 weeks, followed by a qualitative evaluation. In contrast, Söderström et al. (2023) implemented the technology over a year, resolving most staff-related technology management conflicts and integrating the memo planner as a resource in the community-based home care unit. Future mHealth interventions promoting physical activity for individuals with intellectual disabilities could extend beyond 12 weeks and include a one-year follow-up to assess the technology’s ongoing relevance.

Efforts to enhance physical activity levels using technological solutions have yielded promising results, but most studies comprising small samples (Lancioni et al., 2022). The relevance of technological health interventions increased during the COVID-19 pandemic, yet this remains an under-researched area with significant potential due to flexible intervention delivery, customisation, and easy data access. In Norway, approximately 200 projects were initiated to implement healthcare service technologies across various municipalities between 2013 and 2016 (Knarvik et al., 2017). However, only 5% targeted individuals with cognitive or physical disabilities.

A web-based training programme for adults with intellectual disabilities in Sweden provided participants with 50-minute moderate-intensity web training thrice weekly over 12 weeks. The intervention led to a significant increase in physical activity levels, as measured by the IPAQ-SF questionnaire. The programme’s success was largely attributed to staff involvement and support throughout the intervention (Fjellström et al., 2024). This underscores the importance of motivated and engaged staff in promoting physical activity, a factor also identified in Paper I and the mixed-methods pilot trial. Many participants reported increased engagement in web sessions when staff participated, aligning with the interactional factor for motivation, which posits that motivation for physical activity participation increases when staff or family members join the activity.

In the mixed-methods study, staff expressed satisfaction with the study theme but felt inadequately informed before the introduction of the mHealth apps. They cited summer substitutes and lack of support from management and municipal leaders as challenges in following up on the mHealth app and supporting participants in their physical activity participation. Future trials involving technological health delivery could ensure management and staff involvement in all stages of intervention delivery, and staff engagement and training could be prioritised before the intervention's introduction.

The use of goal setting in a technological intervention for physical activity for individuals with intellectual disability has, to our knowledge, not been done elsewhere in research or commercially. Goal attainment as the intervention for physical activity has, as far as we know, been found in one other study including youth and children with intellectual disability (Willis et al., 2018). Goal setting is part of the internalization of motivation, according to the SDT, and could potentially be important in the motivation towards physical activity in individuals with intellectual disability (Deci & Ryan, 2000).

One significant advantage of developing technological solutions, specifically mobile apps promoting physical activity, is their accessibility. Tailored mHealth interventions for individuals with intellectual disabilities can enhance access to physical activity promotion, not only for those residing in municipalities with numerous adapted leisure activities but also for smartphone or tablet owners. In Norway, many municipalities are small and have low budgets, which means that they have less adapted leisure physical activities available for individuals with intellectual disabilities. The use of technology for health promotion offers easy access, but require constant updates and support to stay relevant, which can be costly. Even so, updating technical solution can be cheaper than developing adapted leisure activities for each municipality. A suggestion is to have national funding of technical solutions, which would improve accessibility and opportunity of physical activity promotion across all municipalities in Norway.

5.1.3 Participation for all

This thesis aims to enhance understanding of physical activity participation among individuals with intellectual disabilities. Unlike the International Classification of Functioning, Disability, and Health (ICF) by the World Health Organisation (WHO, 2007), participation in this thesis is defined as ‘being there’. The goal is to develop mHealth interventions for physical activity, understand motivational factors for participation, and identify barriers to physical activity. This is to foster the inclusion of individuals with intellectual disabilities in physical activities, as stipulated in the 2006 CRPD (Article 30) (United Nations, 2006). Research can potentially create opportunities for greater inclusion and improved physical activity participation for this group.

5.2 Methodological discussion

When planning, conducting, and disseminating research on individuals with intellectual disabilities, many aspects must be considered. Ethical considerations are paramount, especially when involving vulnerable groups such as individuals with intellectual disabilities. Assumptions have been made that individuals with limited cognitive functioning are at risk for exploitation and harm due to their inability to provide informed consent and vulnerability to coercion (McDonald, 2012). Research ethics boards are often cautious in approving research involving individuals with intellectual disabilities, which can deter researchers from including them in their studies (McDonald, 2012). In planning a research project, it is necessary to consider who is likely to benefit from and want to participate in the research, while also ensuring protection for those who may be vulnerable (Feldman et al., 2014). It is crucial to obtain valid informed consent from persons with intellectual disabilities and adjust instruments for them to comprehend the purpose of the research. Simultaneously, researchers must adhere to the standardisation of included measurements to maintain research integrity (Feldman et al., 2014).

This thesis presents three different studies with unique designs and various methods to ensure high data quality. The quality of research depends on internal and external validity, referring to study errors and generalisability. In cohort studies, the collected data must represent a specific population or reflect the variation within a chosen population in a selected area (Wang & Cheng, 2020). Cross-sectional studies studies aim to analyse data from a population at a single point in time, often used to study the prevalence of health outcomes in a population or to determine the different features of a population (Wang & Cheng, 2020). In qualitative studies, the study sample should represent different aspects of the problem that the researcher aims to explore, and the sampling procedure should be based on reaching a saturation point rather than including more participants (Kvale, 2015). Pilot feasibility studies aim to test the feasibility and acceptability of interventions and evaluate the design to make decisions about progression to the next stage of evaluation (Skivington et al., 2021).

5.2.1 Study design

5.2.1.1 Paper I

The qualitative study employed an abductive design (Kardorff et al., 2004), chosen due to its relevance to the study's focus: the motivation of individuals with intellectual disabilities to participate in physical activity. This design, explorative and empirically driven, utilised existing literature to develop an interview guide. Motivational theories, such as Self-Determination Theory and Social Cognitive Theory, informed the guide's development and the analysis of results. Furthermore, findings from previous studies on the same topic were instrumental in shaping the interview guide (Mahy et al., 2010; Temple, 2007). Data were collected through focus groups and individual interviews.

In qualitative research, the researcher must assess the validity of the research topic and the transferability of the findings within the research context (Malterud, 2011). This study involved two focus groups and two individual interviews. One focus group consisted of family members, staff members, and healthcare workers. The decision to separate family members and staff was made to facilitate open discussion about motivational factors and barriers to physical activity participation. However, this pre-data collection decision may have resulted in the loss of potentially valuable insights from interactions between family members and staff.

To ensure internal validity in focus group-based qualitative research, a shared understanding of the discussion questions between the participants and the researcher is crucial (Malterud, 2012). To this end, explanatory questions were included during the interviews. The researcher must also monitor group dynamics during focus group interviews and intervene when the discussion becomes dominated by a single topic or participant. In this study, an experienced qualitative researcher served as the moderator, while a PhD fellow and a co-author took notes and observed, allowing the moderator to focus on guiding the discussion.

External validity in qualitative research pertains to the trustworthiness of the results and is defined in terms of credibility, dependability, and transferability (Graneheim & Lundman, 2004). Transferability refers to the applicability of a study’s findings to other settings or populations. In this study, the discussion centred on motivation towards physical activity among individuals with intellectual disabilities. Given that participants likely had an initial interest in the topic, they may not represent the broader population of family members or staff working with individuals with intellectual disabilities. Additionally, all participant lived in a defined geographical area (Tromsø). Thereby the participants may not represent the population of family members of individuals with intellectual disability and staff working with individuals with intellectual disability.

The relevance of the population to the discussion topic increases the likelihood that the themes discussed in a focus group reflect experiences that others can learn from (Malterud, 2012). The family members in the focus group represented individuals with a range of intellectual disabilities, ages, familial relationships, and living conditions. They also had experience with or thoughts about physical activity among people with intellectual disabilities. The healthcare workers held various positions (leaders and non-leaders) and were affiliated with a range of services catering to individuals with intellectual disabilities, including specialised and community-based services and day care centres. Even so, in the focus group interview with staff, only three participants were present. The other two staff members were interviewed individually, because of practical reasons. This might have influenced the discussion in the focus group and is a limitation of the study.

A comprehensive theoretical examination of the findings can enhance their transferability by viewing them from a wider perspective (Kitzinger, 1994). This was demonstrated in the discussion of Paper I.

5.2.1.2 Paper II

Mixed-method designs can be primarily quantitative with qualitative as a secondary component, or qualitative with quantitative data supplementing it (Schoonenboom & Johnson, 2017). The latter is often employed when developing questionnaires or measurement tools. Both methods can be equally weighted, with each research question incorporating both methods. The timing of presenting equal components and their influence on the results is crucial. Paper II utilised a mixed-method pilot feasibility and acceptability study design with a concurrent triangulation approach for data integration. This involved gathering data from quantitative measurements, questionnaires, and activity data separately but concurrently with qualitative material. Although data collection was not simultaneous, data analysis was performed concurrently, and data were integrated for result interpretation.

Dependence, or the extent to which the presentation of each method relies on others, must also be considered (Creswell & Hirose, 2019). For instance, if qualitative results in a study guide the development of questionnaires, the data would be integrated in both the method and data analysis. In Paper II, interview data were collected after the questionnaire data, making the methods independent of each other. This independent inquiry into the data led to the merging of the data in the results. Quantitative data were supplemented with information from the qualitative material in the results presentation. For example, interviews provided insights into why there was more missing data at one measurement point than at others.

External validity pertains to the applicability of a study’s findings to a target population or other populations. The small sample size of the pilot study limits its generalisability to larger populations. Nine out of 10 participants were included (Michalsen et al., 2022). Most participants were female, with a median age of 28 years. Given that the male-to-female ratio in intellectual disability diagnosis is 2:1 (Maulik et al., 2011), the pilot study sample did not accurately represent the population of individuals with intellectual disabilities. The young age of the participants could influence the results, as older populations of individuals with intellectual disabilities may have different experiences with technology and health statuses. Additionally, the pilot study only included one arm of a future RCT. As the study was not a randomized controlled pilot and feasibility study, the comparability of the pilot study to a future randomized controlled trial can be limited. The study’s focus on an mHealth intervention to promote physical activity could also influence who consented to participate, as such an intervention requires higher motivation than an observational study. The participants or their next of kin may have had an interest in improving physical activity levels or wished for the staff in a group home to be more engaged in physical activities, thereby influencing the external validity of the findings.

Ecological validity refers to the applicability of a study’s results to the natural setting of a target population. In this study, the intervention was introduced at the participants’ preferred locations, primarily group homes, apartments, and daycare centres. The person who knew the participant best, either a family member or a staff member working in the group home, received the instructions to use the application. By introducing the intervention in the participants’ natural environment, higher ecological validity was achieved.

5.2.1.3 Paper III

The NOHID study employed a cross-sectional design, a prevalent approach in epidemiological research that entails data collection from a specific population at a single point in time (Wang & Cheng, 2020). This method is particularly effective for determining the prevalence of health conditions and other variables of interest within a group.

However, caution is required when interpreting causal relationships in cross-sectional studies. Due to the simultaneous data collection, establishing the sequence of causes and effects can be challenging. For instance, the relationship between physical activity levels and health conditions in this study could be reciprocal. Poor health might decrease physical activity, or inversely, a lack of physical activity could lead to health decline. Despite these complexities, the study aimed to investigate the association between barriers and physical activity participation, adjusting for factors such as age, level of intellectual disability, gross motor function, epilepsy, and Down syndrome diagnosis.

Invitations to participate were extended to all adults with intellectual disabilities residing in the target municipalities. To reach those not involved in healthcare services, the study was advertised through various platforms, including local television and radio stations, community organisations, internal hospital newsletters, and municipal administrative leadership. Collaboration with municipal authorities and access to hospital records facilitated the identification of individuals with intellectual disabilities receiving healthcare services. Despite these efforts, a segment of the population, particularly those with mild intellectual disabilities, may not have been reached. Consequently, the external validity of the study sample cannot be guaranteed.

This study investigated the association between barriers for participation in physical activity and physical activity correlates. In the logistic regression analysis, confounding variables were controlled for based on physical activity correlates found in the literature and from significant correlations in bivariate analysis. Even so, there is a possibility that other variables can influence the association between the barriers and sedentary activity.

The study used a questionnaire to measure levels of physical activity and barriers for physical activity barriers. Neither level of physical activity nor the barriers have been measured objectively or observed, which is a limitation of the study. In most studies conducted on physical activity or sedentary behaviour, recommendations for future research focus on obtaining precise estimates of sedentary behaviour and recognising specific groups in need of intervention. However, this study employed a well-known questionnaire presented in an interview setting, also used in both previous studies in adults with intellectual disability (Haveman et al., 2011), and repeatedly in Norwegian population studies (Hopstock et al., 2022; Morseth & Hopstock, 2020). There is a lack of evidence of physical activity behaviour in the intellectually disabled population, specifically in the Nordic region.

5.2.2 Bias

Bias or systematic errors in the design, procedure, or dissemination of research results are prevalent and can compromise the quality of the study (Grimes & Schulz, 2002). Bias can occur in participant selection or measurement use, potentially leading to over- or underestimation of exposure and outcome frequencies. Consequently, these errors may flaw the study’s results. Systematic errors cannot be reduced by increasing the sample size or altering parameters; prevention is the only solution.

Selection bias refers to the lack of comparability between the groups under study and the populations (Grimes & Schulz, 2002). In both Paper II and III, participants were younger than the general population with intellectual disabilities (Maulik et al., 2011). In Paper III, the inclusion rate was 53%, and the included participants were younger than nonparticipants, who had a mean age of 42.3 years (Olsen et al., 2021). Therefore, older participants may have been excluded from both studies.

Exclusion of older participants may be due to their generally poorer health, leading to less participation. The prevalence of dementia is higher in older individuals with intellectual disabilities than in the general population (Walsh, 2008). In older populations with intellectual disabilities, the individual’s parent may no longer be alive, and other legal representatives, such as siblings or lawyers, may be responsible. These representatives may have less incentive to participate in research on behalf of individuals with intellectual disabilities. Another reason for excluding older populations, specifically in Paper II, may be the introduction of technological solutions for physical activity promotion. Older people are often less familiar with technology and less interested in using it for health promotion.

Recall bias refers to inaccurate or incomplete recall of past events or experiences (Grimes & Schulz, 2002) and is common in studies using self-reports as outcome measures. In paper III, the P15 questionnaire was used and performed as an interview. In seven of the interviews, the person with intellectual disability was the only one present. In 107 interviews, only the support person was present and in 98 interviews both the person with intellectual disability and the support person was present. Thereby, in 107 interviews the support person responded on behalf of the individual with intellectual disability, which could introduce a discrepancy between what is believed to be true and the actual truth. Subjective assessments are prone to greater variability compared to objective measurements (Perez-Cruzado & Cuesta-Vargas, 2018). For example, two staff members assessing the physical activity level of a person with an intellectual disability might provide differing evaluations. However, many of the questions in this study aimed to collect objective data, such as age, level of intellectual disability, and health conditions, which are less susceptible to such variability and observer bias. In using questionnaires in an interview setting, leading questions can prompt social desirability bias, where respondents provide answers, they believe the interviewer wants to hear (Grimes & Schulz, 2002). Another potential bias is the tendency to respond in the affirmative or negative way to questions, regardless of the actual content. Clinically, it's observed that some individuals with intellectual disabilities may consistently respond with 'yes' or 'no' to all questions, sometimes contradicting their true intent.

Information bias can be caused by errors in the collection of data, measurement tools or in the interpretation of data. The questionnaire used in paper III has previously been validated and used in a population with individuals with intellectual disability (Folch et al., 2019; Haveman et al., 2011; Perry et al., 2010). In paper II, some of the questionnaires used were validated for the intellectual disability population (Halvorsen et al., 2019; Peterson et al., 2009), while others have previously been used studies including this population (Russell et al., 2018; Turcotte et al., 2019; Willis et al., 2018).

5.3 Study implications

The primary contributions of these findings include enhanced understanding of the motivational factors for physical activity, the application of mobile health technology in physical activity interventions, and the identification of barriers to physical activity participation among adults with intellectual disabilities. This knowledge is instrumental in devising future interventions and public health initiatives aimed at promoting physical activity among all individuals with intellectual disabilities. Individuals with disabilities have the same rights as the general population to participate in all sports and leisure activities, and their physical activity recommendations are similar (Bull et al., 2020). However, numerous studies have indicated that adults with intellectual disabilities are less active than the general population (Dairo et al., 2016; Oviedo et al., 2019; Zwack et al., 2022). This inactivity is linked to the development of metabolic syndrome, obesity, increased risk of osteoporosis, and multimorbidity (Lynch et al., 2022; Tyrer et al., 2019). Therefore, there is a need for more effective promotion of physical activity in the daily lives of adults with intellectual disabilities. As research in this area expands, it is anticipated that health promotion strategies or interventions designed to increase physical activity levels will be more successful.

5.3.1 Clinical implications

- The motivational factors identified in the qualitative study can guide clinicians working with individuals with intellectual disabilities to motivate them to increase their daily physical activity.
- Some of the applications developed in the mixed-methods pilot study are freely available at the moment and may be used to encourage physical activity participation.

- The experience gained from developing tailored mHealth applications can assist other developers in customising physical activity applications for the intellectually disabled population.
- The knowledge gained from the mixed-methods pilot trial using objective activity measurement can be applied to measure physical activity in the intellectually disabled population in clinical settings.
- The identified barrier, ‘No available activities at the day care centre’, presents opportunities for incorporating daily physical activity sessions in day-activity centres for adults with intellectual disabilities.
- There is a need for tailored exercise programmes for wheelchair users in both clinical settings and for research purposes.
- Support and transportation for physical activities can be improved to increase physical activity participation among individuals with intellectual disabilities.

5.3.2 Future research

- The findings from this qualitative study on motivational factors for physical activity participation can serve as a theoretical basis for developing future physical activity interventions.
- The feasibility and acceptability of the study procedures in the mixed-methods pilot trial can inform future research on how to conduct intervention studies involving technological solutions for physical activity promotion and physical activity measures.
- Experiences with missing data and the feasibility of using physical activity measurements may be beneficial in future research projects involving participants with intellectual disabilities or other related groups.

- The barriers to physical activity participation identified in the cross-sectional study could inform the development of future interventions for promoting physical activity in the intellectually disabled population.

5.3.3 Planned research within the research project

The Sorterius app (Dybwad, 2023; Luzi, 2023; Stellander, 2021) is undergoing testing in a pilot study included in an educational program funded by Erasmus, taking place in Valencia and Lisbon. This program, called the MOVE-it project, also involves another exercise app developed within in the research project of this thesis, AGA Treningskompis (Eilertsen, 2021). This app is freely available on the Appstore or Google Play. The pilot study, designed to include 100 participants, will have its findings published.

Based on the experiences from the pilot study of this thesis, there are plans to conduct a comprehensive randomised controlled trial (Michalsen et al., 2020). Furthermore, a comparative study between the use of Fitbit Versa and Axivity measurement devices in indivudals with intellectual disability is scheduled for the following year.

6 Conclusion

This thesis explores the participation of adults with intellectual disabilities in physical activity. It investigates their motivation, utilises mHealth applications, and identifies barriers to participation. Motivation was from the analysis categorized into individual, contextual, and interaction motivation. Individual motivation revolves around enjoyment, social rewards, and health awareness. Contextual motivation includes support from the environment and resource availability. Interaction motivation involves engaging in activities together, predictability, and positive reinforcement during activities.

In the innovative mixed-methods pilot and feasibility study, findings were linked to the interactional factors from the qualitative study. Social support from family members increased from baseline to follow-up, and all but one participant achieved one or more goals for improved physical activity participation. This achievement could be attributed to increased social support from family members.

Barriers to physical activity, identified in a cross-sectional study, were mostly related to individual factors such as wheelchair use, health-related issues, and the severity of the intellectual disability. Two barriers, the lack of available activities at day care centres and the inability to use public transport, were related to contextual factors. These findings can guide future interventions and potentially inform policies on physical activity at the societal level.

One innovative study in this thesis developed, tested, and evaluated mobile health interventions to promote physical activity among individuals with intellectual disabilities. This pioneering study developed specially tailored technological interventions for this group and objectively measured physical activity in a feasibility trial. By developing technology to promote physical activity for individuals with intellectual disabilities, these interventions can be accessible to all mobile phone or tablet owners, regardless of whether they live in areas with many adapted activities or in remote areas with fewer activities offered.

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Paper I

Michalsen, H., Wangberg, S. C., Anke, A., Hartvigsen, G., Jaccheri, L., & Arntzen, C. (2020). Family members and health care workers’ perspectives on motivational factors of participation in physical activity for people with intellectual disability: A qualitative study. *Journal of Intellectual Disability Research, 64,* 259–270. https://doi.org/10.1111/jir.12716

JIDR Journal of Intellectual Disability Research
Published on behalf of mencap and in association with IASSID

Family members and health care workers' perspectives on motivational factors of participation in physical activity for people with intellectual disability: A qualitative study

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Abstract

Background People with intellectual disabilities (ID) have lower levels of physical activity than the general population. The aim of this study was to understand the motivational factors of participation in physical activity for people with ID from the perspectives of the family members and staff.

Method An abductive qualitative design was used. Social Cognitive Theory constituted the theoretical frame of reference of the study. Two focus group interviews with health care workers and family members and two individual interviews with health care workers were conducted at their workplace. A thematic analysis was performed.

Results Three main themes were identified. According to support persons, motivation could be promoted at the individual level by fun, mastery, social setting, technology and knowledge about health behaviours. At a contextual level, physical activity was mediated by engagement with support individuals and available resources. At an interactional level, individuals were more motivated if the interaction was featured by joint activities, predictability and the use of rewards.

Conclusions Motivation for participation in physical activity might be promoted at the individual, contextual and interactional levels. The interactions between individuals with ID and their support persons should work in a supportive way and strengthen mastery experiences. Support and engagement in the context could serve as a prerequisite for motivation and participation in physical activity and should be considered when

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developing interventions for physical activity for individuals with ID.

Keywords intellectual disability, motivation, participation, physical activity, technology

Introduction

Compared with the general population, individuals with intellectual disabilities (IDs) have worse health, lower levels of physical activity (PA) and higher barriers for participation in activities and access to health care (Walsh 2008; Evans *et al.* 2012; Hilgenkamp *et al.* 2012; Balogh *et al.* 2016; Temple *et al.* 2017; Wouters *et al.* 2019). PA is the term used to describe bodily movement produced by skeletal muscles that require energy expenditure (World Health Organization 2004, 2010) and can be further defined by types of activities and intensity categories. As PA has positive effects on cardiovascular and psychosocial health factors, as well as brain health (Piercy *et al.* 2018), the identification of effective interventions for use in everyday settings is important. Specifically, motivation of individuals with ID is a crucial concern (Hutzler and Korsensky 2010).

Motivation refers to a driving force that elicits a particular action and affects the nature of an individual's behaviour in both strength and persistence (Deckers 2005). Several studies have examined the barriers to and facilitators of participation in PA (Heller *et al.* 2003; Temple 2007; Mahy *et al.* 2010). Perceived self-efficacy, social support and peer modelling are factors that facilitate the participation in PA of individuals with ID (Temple 2007; Bossink *et al.* 2017). The identified barriers to participation in PAs include lack of financial, political and/or psychosocial support, as well as a lack of personal interest in PA and a lack of self-efficacy (Dixon-Ibarra *et al.* 2017; Temple *et al.*2017). The perceptions of PA and other health behaviours among individuals with ID correspond to the carer and staff descriptions of barriers and preferences (Heller *et al.* 2003; Temple 2007; Mahy *et al.* 2010; Kuijken *et al.* 2016). Most research on PA for individuals with ID have focused on mild-to-moderate ID, and future research should include the study of individuals with more severe ID (Bossink *et al.* 2017). The majority of these studies are from central Europe and the USA, and no studies have been conducted in the Arctic region.

To understand the motivation and participation in PA for individuals with ID, studies have utilised health behavioural theories. In Social Cognitive Theory (SCT) (Bandura 1978), the concept of self-efficacy states that the beliefs people have about their capabilities constitute a basis for action and also regulate motivation. These self-efficacy beliefs can be strengthened through mastery experiences and social modelling influence. According to Self-Determination Theory (SDT) (Ryan and Deci 2000), motivation can be classified as (1) not present (amotivation), (2) leading to engagement in activity because it is enjoyable in itself (intrinsic) or (3) driven by external requests or rewards (extrinsic). Previous research has confirmed that individuals with mild-to-borderline ID can display different levels of extrinsic motivation (Frielink *et al.* 2017). The focus of SDT on autonomy as intrinsically motivating could constitute an interesting perspective in this field of study because of the frequent threats to personal control of people with ID (Bergström *et al.* 2014). Motivation can also be framed as a socioculturally constructed phenomenon (Daniels *et al.* 2007). In this frame of reference, motivation is always already embedded and shaped by particular contexts (Daniels *et al.* 2007).

As previous research indicates that interpersonal and other environmental factors contribute to the promotion of PA for individuals with ID, the authors aimed to explore how the individuals who interact with individuals with ID understand their participation in and motivation for PA. Our additional aims involved an investigation as to how PA could be facilitated in the Arctic regions and the inclusion of family members or staff who represent individuals with more severe ID.

Methods

We conducted two semistructured focus group interviews with family members and health care workers. Focus group interviews are suitable because they facilitate dialogue and the elaboration of experiences and ideas among colleagues (Malterud 2012) and is useful for exploring specific sets of issues as well as permitting the researcher to use the group interactions as research data (Kitzinger 1994). To ensure greater variety in the sample of professionals and services, we supplemented the data with two individual in-depth interviews with health care workers (Kvale 2015). The interview guide and analyses of results were inspired from the SCT (Bandura 1978), definition of motivation from the SDT (Ryan and Deci 2000), the sociocultural learning theory (Daniels *et al*. 2007) and previous research on barriers and facilitators for PA (Temple 2007; Mahy *et al*. 2010). The interview guide helped structure the interview and ensured that key areas were covered and discussed. Central themes were to describe a regular day and challenges, preferences, facilitators and motivating factors for engaging in physical activity.

Design

An abductive qualitative design was utilised (Kardorff *et al*. 2004). To understand new aspects of participation and motivation for PA, it was relevant to use an explorative, empirically driven approach, with portions of the existing literature on the topic as a basis.

Participants

A purposeful sampling strategy was used to recruit participants (Patton 2015). Health care workers and family members were interviewed separately, as we believed that this would create a more open environment for the individuals to speak freely about the motivational factors and barriers to participation in PA (Malterud 2012). The study was approved by the Committee for Medical Research Ethics (No. 2016/1770).

Health care workers

We invited participants with different roles (leaders/nonleaders) who worked in four different settings (specialised and community-based intellectual disability services, as well as day care centres). The services are predominantly for people with moderate, severe or profound ID. A focus group interview with three participants was conducted (Morgan 1997) in which participants provided important information and were regarded as representing information-rich cases (Patton 2015). Additionally, we conducted two in-depth individual interviews (Kvale 2015) with the leader of a community residence and a representative of a day care centre. The interviews took place at their work place, and the main topics from the focus group interview guide were used. Table 1 provides an overview of the participants.

Family members

We invited family members of individuals with varying degrees of intellectual disability, age and family relationship, as well as living conditions, with the help of user organisations and the networks of the authors. Table 2 provides a full overview of the participants. For the purpose of anonymisation, some characteristics of the participants have been changed.

Data collection

The interviews lasted between 1 and 2 h. C. A. led the focus group interviews (as the moderator) and H. M. observed the interviews, took notes and clarified questions throughout the interviews (as the secretary) (Malterud 2012). The individual interviews were led by H. M.

Table 1 Sociodemographic characteristics of health care workers

Profession	Gender	Work experience (years)	Workplace	Data collection method
Intellectual disability nurse	Male	8, 5	Home-based care	Focus group
Intellectual disability nurse	Male	9	Home-based care	Focus group
Physiotherapist	Female	2, 5	Specialised health care	Focus group
Leader of community residence	Female	7	Community residence[†]	Individual interview
Teacher	Female	3, 5	Day care centre	Individual interview

[†] Community residence: municipal service that provides supportive care around-the-clock.

Table 2 Family members' relations to the individuals with intellectual disabilities and characteristics of the individuals with intellectual disabilities. Some characteristics are changed for the purpose of anonymisation

Relation to person with ID	Gender of person with ID	Age of person with ID	Living conditions of person with ID	Level of ID
Mother	Male	20	At home with family	Severe ID
Mother	Male	19	At home with family	Moderate ID
Father	Female	25	Supported living†	Moderate ID
Father	Male	16	At home with family	Profound ID
Father	Male	22	Community residence‡	Moderate ID
Mother	Male	13	At home with family	Moderate ID
Sister	Male	52	Community residence‡	Severe ID
Father	Female	23	Supported living	Severe ID

ID, intellectual disability.
†Supported living: individuals living in their own apartment with part-time supervision from staff.
‡Community residence: municipal service that provides supportive care around-the-clock

All participants were enthusiastic about the topic, which influenced the dynamic of the discussions and the richness of the data. As the introductory questions stimulated dialogue and discussion, the interview guide was mainly used as a checklist to ensure that key topics were covered. All participants were found to be information-rich cases. The interviews were recorded using an MP3 recording device and transcribed verbatim by H. M. After the individual interviews, the transcripts were examined, and the investigators concluded that data saturation was reached.

Data analysis

After the interviews, preliminary analyses were presented to a reference group (researchers in the project group and some of the family members and health care workers from interviews) for their feedback before continuing with the analysis. Preliminary results were also presented at a seminar with experienced researchers, who commented on and further improved the analysis before it was finalised, to ensure the dependability and trustworthiness of the results (Tjora 2012).

A thematic analysis (Greenhalgh and Taylor 1997) was then conducted. The interview transcripts were read several times by the first author (H. M.) to identify emerging themes. The interviews were then read and commented by A. A. On the one hand, C. A. read and commented on the first analysis of the material. The text of the transcriptions was transformed into specific codes, which were compared by differences and similarities and condensed into meaningful categories and subcategories. Through discussions among the authors and other researchers and with feedback from the reference group, the main themes were identified by grouping similar subthemes and linking them to theories and perspectives. Throughout the analysis, the SCT concept and sociocultural perspectives became central to understanding motivation as a relational phenomenon and the role of the context in initiating and adapting for individual participation in PA. The authors were from different professions with competence in rehabilitation medicine, behavioural change theories, use of technology and qualitative research methodology, and the setting was an exploration of motivational factors for possible later use in technology-supported activity. Regarding the analysis, the authors had no previous experience with the research problem at hand and few preconceptions and expectations prior to data collection and analysis.

Results

We identified one overarching theme (motivation for participation), three main categories and nine subthemes. The main finding was that motivation could be socially constructed through mediation of engagement in activities and external support. An overview of the findings is given in Table 3 and summarised in Fig. 1.

Table 3 Summary of results

Main themes	Subthemes	Codes
Individual level	Motivation seldom the main challenge	Difficulty initiating activities
		Motivation often present
		Varying levels of exhaustion
	Fun, social rewards and technology	Being social in activities is rewarding for many
		Purpose of the activity is important
		Use of technology rewarding
	Knowledge	Lack of knowledge in what constitutes good health
		Reduced knowledge about healthy behaviours in support persons
		Health education for individuals with ID not a priority for support persons
Contextual level	Support person engagement	Many factors depend on support person's interest in physical activity
		Engagement in support person increases levels of physical activity
	Available resources and weather considerations	Not enough resources/personnel available
		Variation in weather conditions in the arctic climate is a barrier
	Presentation of activity	Willingness to join activities depends on a positive presentation of activities
Interaction between levels	Being together in activities	Giving support in activities by participating together with individuals with ID is important
	Creating predictability	It is important to create predictability in the physical activity
	Use of rewards	Rewards can be used to reinforce the physical activities
		Showing achievements to others is very rewarding

Individual level

Motivation is not always the challenge.

Both family members and health care workers identified the main issue as a lack of initiation of PA for individuals with ID, rather than a lack of motivation. Understanding how people with ID were motivated to participate in PA was challenging and could vary in different situations, but most of the participants believed that motivating the individuals to participate was not the most difficult part.

> … there are many, if I speak on behalf of the institution I work in, who want to go hiking and be out in the nature, and who have the motivation to participate. (leader of community residence)

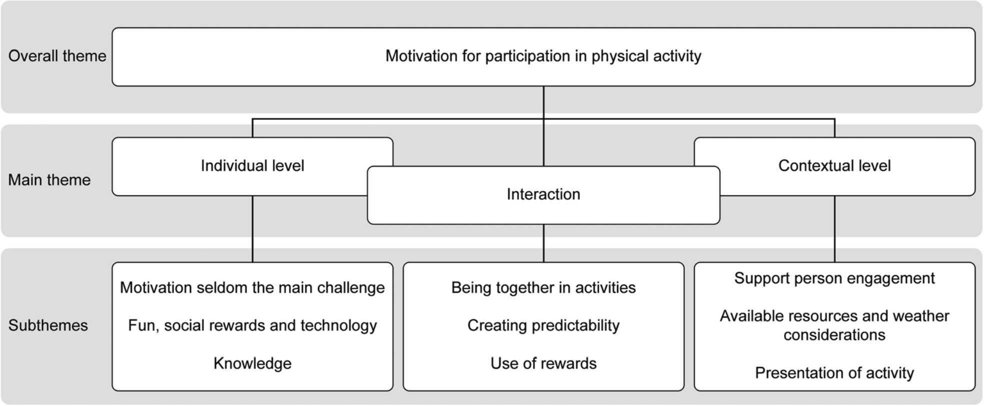

Figure 1. Results from the qualitative study. Themes and structure.

> I am of the impression that Sophie could walk on water if she was motivated to do so. It is just very difficult for me to figure out what actually motivates her nowadays … (mother)

Difficulties in completing an activity could reduce motivation, such as problems with getting dressed, difficulties in travelling to the site of the activity, or problems in executing the physical movements.

> It depends on practical stuff, like how to put the skis on. That is the most difficult thing when going skiing. For most of the ski trips that are unsuccessful, everything goes wrong when he struggles with putting his ski boots or skis on, and gets tired and gives up. (sister)

The participants also questioned the level of intensity of PA, with many stating that individuals with ID participated in activities but rarely achieved a level of moderate or vigorous PA.

> … it's difficult finding physical activities that would improve her fitness shape. She rarely breaks a sweat or feel out of breath when she exercises … (mother)

Fun, social rewards and technology

Individuals with ID were more likely to participate in PA when the activity was fun and enjoyable. Activities were observed to be enjoyable if they were in a social context, described as being part of a team, meeting peers and identifying with a group.

> He loves his friends and being part of a team. He could go to the North Pole if that was the case, as long as he was part of the team … (mother)

Several individuals were more motivated to perform PA when the activity had a different purpose than the activity itself, such as enjoying a meal at the end of a trip or doing practical chores as part of the PA.

> … we always have to find things to recycle and walk by a container and throw it in. And there is no lunch before we have been out walking for a while, and then it's just a matter of how long you can stretch it. (mother)

> … it's the same for our boy, as I hear others talk about, that it should be another purpose with the activity than the activity itself. The best is to bring a good lunch to eat on the top of a mountain or do practical chores like walking by the grocery store to a recycling bin. (father)

Several individuals enjoyed swimming and horseback riding. Others enjoyed listening to music while moving around or while watching a programme on a tablet or a TV. It was reported that most of the individuals with ID (especially the younger individuals) were interested in technology. Some used technological devices in PA settings.

> She has two, an iPhone she uses to find things she wants to watch on her iPad (music videos), and a PC as well … (mother)…. he is allowed to sit on a small trampoline whilst watching his iPad or the TV, and if he gets excited, he starts jumping. And he can watch the film to the end whilst jumping if the film is very funny… (father)

Knowledge, interests and misunderstandings

Some of the health care workers mentioned that as individuals with ID may lack knowledge of risk factors for ill health, they could benefit from learning more about health and how PA will have a positive impact on their lives. In some cases, individuals with ID would misinterpret bodily signals from PA as signs of sickness and associate the activity with something negative and harmful.

> … they might be frightened if they feel their heart pounding harder than they are used to, and think that they are ill or something … I think it has to do with the knowledge basis they have. How much knowledge they have will affect how they interpret the body's signals. If they have more knowledge about how the body reacts to excessive physical activity, they might not react this way. (leader of community residence)

In contrast, family members were more concerned about the level of knowledge, interest and enthusiasm that health care workers had concerning PA and how that could influence the individuals with ID. They believed that it would not necessarily help individuals with ID gain knowledge.

> … he cannot just understand for himself why it is important to exercise, that it is important to be physically active. He can say that he is using energy when he is active, but that is because I have triggered him to think that it is important. (mother)

Contextual level

Support person engagement

All participants agreed that the contexts surrounding the individuals with ID played a large role in their motivation and execution of PA. The attitudes concerning PA and health in the people close to the individuals with ID were observed to be important predictors of PA by all participants.

> … Some of my staff are really active and like to do new things, and if they do not manage to get the user interested, they try a different approach. They always bring the right clothes according to the weather … I think it has a lot to do with the attitude of the staff. Do not get me wrong, but I think if the staff want to be inside and relax, it is very easy to do so. (leader of community residence)

> … When it comes to those with ID, maybe moderate or severe ID, I think the staff plays a much larger role. Because the staff needs to be motivated as well. (physiotherapist).

Most of the family members were worried that the staff would never show the same interest and enthusiasm as the family members did in supporting a physically active lifestyle.

> … it is hard to make the staff see his skills when it comes to physical things. It's just too easy to see his epilepsy as a problem and be anxious about it. (father)

Several individuals also mentioned that they wished that they had an 'instruction manual' for their family member, so that staff would know how to motivate and make adjustments so that the individual with ID could be more physically active.

> … I have said to the staff 'come join us on cross country skiing and see how easily it's done'. And some actually do so. But then you have people working on shift and some are quite old and … it's just very complicated and exhausting for the family to always teach new staff how to do things. (sister).

Available resources and weather considerations

In the group of health care workers, the availability of resources was often mentioned as an important condition to be able to take individuals with ID to perform PA. Insufficient staffing, a lack of time and insufficient preparation for changing weather conditions were mentioned as barriers.

> The challenge is for those who do not have many resources around them. You're at work and have maybe five people to look after during your shift. And everyone should get dinner and have individually adjusted activities in the afternoon. So that is where the problem is, because one of the users might want to go swimming and you cannot leave the other four users behind. And is just hard sometimes … (leader of community residence)

Presentation of activity

Many of the participants, especially the health care workers, pointed out that if they identified the right way of presenting the activity to the individual, then it was more likely to motivate the individual to participate in that activity. By simply asking the individuals with ID if they wanted to exercise, the workers observed that this would most often lead to a negative response.

> … asking 'do you want to go for a walk', you are more likely to get a negative reply, because it is a personal question. If you say 'let us go for a walk' or 'what should we do today? Should we go for a walk?', it helps motivate the individual to participate. It's easier to bring them with us. (teacher)

Interaction between individual and context

Examples of cites in relation to subthemes are given in Table 4.

Being together in activities

Many of the stories concerning success factors for PA focused on the interaction between individuals with ID and their environments. If the support personnel and/or family members were successful in influencing

Table 4 Examples of interview cites from the theme Interaction between individual and context

Theme: Interaction between individual and context

Subthemes	Cites
Being together in activities	… the support person should not just get the individual into the pool – he should join him in the pool. In our home, the support person shows up, brings my son to the arena and sits on the scaffold and pays attention to what my son does. I wish that he could actually join him in his workout. Many of the individuals with ID will have much greater advantages and better workouts if they had their support person with them all the time to motivate them and help them. (father)
Creating predictability	… one thing I've been thinking a lot about, and that is making the activity predictable is very important. And there is of course a challenge to understand how this would work. After a while, in my experience, he has learned that if he is prepared for what's coming next, and we help him to do so, it's so much more fun for him to participate. (mother)
Receiving rewards	… in my experience it seems like it should be something there. If it's not something very concrete. My son needs to understand why he should do different things. What the goal or intention is for doing these things. Either it is the good lunch afterwards or he can use his iPad when we are done doing the activity. (mother)

the individual with ID in a motivating way, the individual would have a positive attitude towards the activity. Motivational support could include performing the PA with the individual, providing positive feedback, cheering the individuals on when they were active and reinforcing their positive experiences with the PA. Other types of support, such as practical support and economical support, were also mentioned as contributing to participation in PA.

Creating predictability

Making the PA predictable and creating a sense of control for individuals with ID were also important aspects of motivation for PA. The use of different tools, such as visual support in communicating about the PA, going to the arena and examining it beforehand or making PA a part of their daily routine, also helped the individual to feel more in control. One father said that it was more likely that his son or his peers would feel excited about participating in athletics when they had been there a few times before and knew what they were getting into.

Receiving rewards

Rewards could make PA more interesting. However, many of the participants believed that it was difficult to identify rewards that were not unhealthy foods. The other rewards that were mentioned as effective included a high degree of praise or positive feedback to the individuals. If they received a medal after participating in PA, the reward was not the medal itself, but the praise when showing the medal to the staff or family members afterwards.

Discussion

The findings of the current study suggest that individuals with ID could be more motivated to participate in PA if the activities occur as an interaction between the individual and their context, which could be mediated by engagement with support people and available resources. At an individual level, individuals with ID can be motivated for PA if they experience the activity as fun, occurring in a social setting or used in combination with technology. An interaction through joint participation in activities, predictability and the use of rewards appears to have the strongest influence on participation in PA.

In this study, the main source of information was from the environment around the individual with ID, not the individual himself or herself. By emphasising the sociocultural frame of reference (Daniels *et al.* 2007), we found that motivation is an interpersonal emerging phenomenon continuously shaped by particular practice. This makes it is difficult to capture the intrinsic motivational factors involved in participating in physical activity. Positive emotions such as engagement and excitement might be observable features that can be interpreted as an expression of motivation. However, based on our results, the definition of motivation according to the SDT (Ryan and Deci 2000) does not capture the complexity of this cognitive feature. Motivation can be seen as a socially driven interaction between individuals with ID and their support persons that can increase or decrease depending on the responses from the individual or the context. These findings can be important when developing interventions for PA and adjusting the everyday contexts for individuals with ID.

Consistent with previous studies (Temple 2007; Mahy *et al.* 2010), motivation is dependent on how fun and interesting the PA is perceived to be. It is likely to believe that the motivation individuals with ID show towards PA is displayed as an interest for the activity or enjoyment during participation. Another potentially useful finding for intervention development is the interest in technology by the group of youths and young adults with ID. Technological developments, like serious games, have previously been proven to be effective interventions for improving social, practical and conceptual skills for individuals with ID (Tsikinas and Xinogalos 2018).

The results demonstrate that engagement in PA by support persons is particularly important. Support persons or others who interact with individuals with ID on a daily basis should have an initial interest for PA or be concerned about increasing PA levels for the individual with ID. Heller *et al.* (2003) underlines that support persons should be motivated to perform PA themselves, as this would influence the individual with ID to be more active. Activities should be planned in cooperation between support persons and the individual with ID while considering motivational factors. In contrast, a lack of available resources functions as a contextual barrier for participation (Mahy *et al.* 2010; Bergström 2014; Bergström *et al.*

2; Kuijken *et al.* 2016). Inadequate staffing, little knowledge about the health benefits of PA and unclear PA policies in the community residence or day care centre could influence the participation in PA of individuals with ID. Dixon-Ibarra *et al.* (2017) argue that a lack of clear PA policies in group home settings creates a barrier to health-promoting environments for people with ID. Individuals with ID rely heavily on support from others in their everyday life, and possibilities to maintain good health will therefore vary depending on the services and care that they receive (Krahn *et al.* 2006).

The findings are consistent with SCT (Bandura *et al.* 1999), in that self-efficacy appeared to be related to the intention to perform PA. Self-efficacy was positively influenced by previous mastery experience with the PA, as well as modelling by other individuals. This emphasises the need for preparation and explanation of the activity to ensure high self-efficacy and opportunities to strengthen it further through more mastery experiences. Conversely, the results of this study demonstrated that where the individuals with ID had a negative experience with PA (e.g. skiing) early in the process, then many individuals lost their motivation and stopped participating in the activity. Therefore, the planning for progressive mastery by the individual is essential.

Arctic weather conditions may require extra human resources and equipment for outdoor activities. Many participants found the planning and execution of outdoor PA during winter to be challenging. For both the support person and the individual with ID, changing weather conditions and preparations for outdoors could disturb motivation and participation in PA. Individuals with ID who displayed sedentary behaviour often mentioned weather as a barrier. This research suggests that individuals with ID may not have the strategies to cope with this adversity alone and need assistance to overcome this barrier.

Study strength and limitations

The present study had several limitations. Most of the participants who participated in the study had an initial interest in PA, as well as being physically active themselves. Additionally, as the initial aim of this study was to understand the motivation for PA participation through the perspectives of family members and health care workers, we did not interview individuals with ID themselves. Future studies could explore the motivation for PA from the perspective of less active participants and could also focus on interviews with individuals with ID themselves. Nevertheless, our findings are consistent with previous studies (Heller *et al.* 2003; Mahy *et al.* 2010). Furthermore, while there were relatively few participants who completely contributed with information, a strength of the current study is that the participants represented a varied sample of individuals with ID. These findings could be relevant outside this research context.

Conclusion

Promotion of PA should include both individuals with ID, family members and staff, and it should work in a supportive way to strengthen mastery experiences. Fun, social rewards, predictability and the use of technology as motivational factors for participation in PA on an individual level are interesting possibilities that should be explored further. The promotion of PA in individuals with ID should also take a contextual approach by exploiting the cooperation and interaction between individuals with ID and their support persons. Future PA interventions for this group should focus on engaging the support persons in physically activities themselves and on increasing their knowledge about the importance of PA and ways to motivate individuals with ID.

Acknowledgements

The authors would like to thank all participants who were involved in the study for contributing to such an important research topic.

Conflict of Interest

The authors declare that they have no conflict of interest.

Source of Funding

The study was conducted with grants from the North Norwegian Health Authorities (HNF1353-17).

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Accepted 13 January 2020

Paper II

Michalsen, H., Henriksen, A., Pettersen, G., Hartvigsen, G., Wangberg, S., Thrane, G., Jahnsen, R., & Anke, A. (2023). Using mobile health to encourage physical activity in individuals with intellectual disability: A pilot mixed methods feasibility study. *Frontiers in Rehabilitation Sciences*, *4*, 1225641. https://doi.org/10.3389/fresc.2023.1225641

frontiers | Frontiers in Rehabilitation Sciences

TYPE Original Research
PUBLISHED 24 August 2023
DOI 10.3389/fresc.2023.1225641

OPEN ACCESS

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RECEIVED 19 May 2023
ACCEPTED 04 August 2023
PUBLISHED 24 August 2023

CITATION
Michalsen H, Henriksen A, Pettersen G, Hartvigsen G, Wangberg S, Thrane G, Jahnsen R and Anke A (2023) Using mobile health to encourage physical activity in individuals with intellectual disability: a pilot mixed methods feasibility study.
Front. Rehabil. Sci. 4:1225641.
doi: 10.3389/fresc.2023.1225641

Using mobile health to encourage physical activity in individuals with intellectual disability: a pilot mixed methods feasibility study

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Background: Many individuals with intellectual disability (ID) have a sedentary lifestyle. Few interventions aimed at increasing their level of physical activity (PA) have shown lasting effects.
Aim: To assess the feasibility and acceptability of a pilot intervention study using innovative mobile health (mHealth) support systems to encourage PA in individuals with ID.
Methods: Nine individuals with ID and a low level of PA, aged 16–36 years, were included in the present convergent triangulation mixed method design. Two mHealth support systems (apps) were developed and tested. PA was measured with a Fitbit smartwatch, accelerometer, the International Physical Activity Questionnaire—Short Form (IPAQ-S), and Goal attainment scaling. Data were collected through online pre-, mid- (4 weeks), and post-intervention (12 weeks) questionnaires and activity trackers. Semi-structured qualitative interviews with participants and/or a family or staff member were held after the 12-week follow-up. Data were analyzed using conventional nonparametric statistics and thematic analyses.
Results: The response rate and retention to the trial were 16% and 100%, respectively. Data quality was high, except for missing data from Fitbit activity trackers of approximately 30% from the 4- and 12-week follow-up stages. The feasibility challenges with activity trackers include rashes, size, non-acceptance, and loss of motivation. Participants and family members/staff reported interest in the study theme and were pleased with the data collection method. All but one participant achieved their PA goals. Most participants reported being satisfied with the apps as they were enjoyable or provided a reminder for performing physical and other activities. Social support for PA among family members also increased. However, app support from staff and family members was needed, and apps were not used regularly. Two of nine participants (22%) had increased their PA measured as steps per day with Fitbit at the 12-week follow-up.

Abbreviations
CFCS, Communication Function Classification System; CIQ, Community Integration Questionnaire; GAS, Goal Attainment Scale; ICD-10, International Classification of Diseases, 10th edition; ID, Intellectual disability; IQ, Intelligence quotient; IQR, Interquartile range; MET, metabolic equivalents; mHealth, Mobile health; PA, Physical activity; RCT, Randomized controlled trial; SE/SS-AID, Self-efficacy/Social support for Activity for Persons with Intellectual Disability Scale.

Conclusions: The acceptability and feasibility of using tailored mobile applications in natural settings to increase PA among adults with ID are promising. This study aligns with previous studies in showing the challenges to increasing PA, which requires the inclusion of family members, staff, and stakeholders. The intervention requires modifications before a randomized controlled trial can be conducted.

KEYWORDS

intellectual disability, physical activity, mobile health app, technology, mixed methods, activity trackers

1. Introduction

Considerable evidence shows that physical activity (PA) yields numerous benefits for individuals with mild and moderate intellectual disability (ID) (1). Reported benefits include health advantages, such as increased cardiovascular and muscular capacity (2), while inconsistent results are found for improved social network and mental health (3). However, individuals with ID are less physically active than the general population (3, 4), and evidence for the intervention effects of improving PA levels is inconsistent (5, 6). Recent studies show that individuals with ID engage in more sedentary activities compared to the general population (3). A study comparing PA levels between individuals with and without ID found that adults without ID engaged in more light activities and had less sedentary time (7). Only 9% of adults with ID achieve the recommended levels of minimum 150 min of moderate-to-vigorous physical activity (MVPA) (4), compared to one out of five in the general population (8). Counting self-reported PA, about 63% of the general population reached recommended PA levels (9). Using steps per day as a measure, 7%–45% of the ID population reach a level of 100,000 steps per day (4). Developing methods to limit sedentary time and increase activity at any level can considerably improve health and reduce mortality among individuals with ID (10, 11).

The use of technologies to improve levels of PA has been explored to some extent. Lancioni et al. (12) published a scoping review of programs using stimulation-regulating technologies to promote PA in people with intellectual and multiple disabilities. Fifteen of the 42 studies included used video games (e.g., Wii gaming, virtual reality, Xbox, Light Curtain devices). None of the other 27 studies used mobile applications to promote PA in ambulatory adults with ID. Pérez-Cruzado and Cuesta-Vargas (13) published a pilot randomized controlled trial with four people (age undisclosed) with mild ID in the intervention group. The intervention was education, followed by reminders of PA through a mobile app with questionnaires as outcome measures. Martinez-Millana et al. (14) developed a motivating mobile app for indoor cycling and investigated user acceptance; however, no measures of PA were included.

In Norway, many individuals with ID have a smartphone or tablet that can be used for tailored PA interventions; however, this has not been tested in clinical studies. A previous study showed that individuals with ID are motivated to participate in PA and show an interest in technology (15). We have not found any previous studies promoting PA with the use of mobile apps and activity trackers to objectively measure levels of PA in adults with ID. Other studies have shown the measurable benefits of using mobile technologies for health-related behaviors and everyday life for individuals with ID (15–21). Few applications are available for promoting PA in individuals with ID, and the development of such technology in PA promotion is needed.

In the ID population, many studies have used objective PA measurement (22–24). Accelerometers are often the preferred measure, with both hip and wrist placements (22). Few studies have used commercialized activity trackers as an objective measure of PA in the ID population (25). Dario et al. (26) investigated the feasibility of using accelerometers together with the International Physical Activity Questionnaire—Short (IPAQ-S). Results showed that there were substantial agreements between reports on being active or inactive between the more acceptable and user friendly IPAQ-S and accelerometer data. However, IPAQ-S use has been found to both underestimate (4) and overreport levels of PA (27), compared to the accelerometer-measured PA levels.

According to the World Report on Disability, health promotion efforts targeting this population can improve lifestyle behaviors and these individuals have the right to be included in all PA programs (28). Specifically, a flexible approach is important when including individuals with complex cognitive challenges in health research (29). Testing procedures and interventions in pilot trials can improve the chances that a large-scale study will successfully achieve its objectives and perhaps lead to successful practical implementation (30). Additionally, using a mixed methods design can expand and strengthen the conclusions of a study (31). To increase the possibility of promoting PA in adults with ID, it is necessary to develop interventions with innovative applications.

This study aimed to investigate the feasibility and acceptability of a pilot intervention study using innovative applications developed to encourage PA in adults with ID. In this pilot study using a mixed methods approach, feasibility was investigated quantitatively and qualitatively through recruitment, trial retention, and completeness of data, and through the missing data analysis. Acceptability was explored qualitatively through satisfaction with the study procedures, activity measurement, and mobile applications.

2. Methods

2.1. Study design

A prospective pilot feasibility study with a concurrent triangulation mixed method approach (32) was carried out. Figure 1 provides an overview of the study procedures.

2.1.1. Ethical considerations

The study was sought from and granted approval by the Regional Committees for Medical and Health Research Ethics in Norway (number 2016/1770) and by the data protection officer at the University Hospital of North Norway. The study included an intervention directed at a vulnerable group and proceeded cautiously. When possible, informed consent was obtained from the individuals with ID, if the person had the decision-making capability to consent. In addition, in the case the person with ID was unable to consent, a close relative provided the informed consent on behalf of the person with ID. The participants are informed that they may withdraw from the study at any time without consequences for the treatment.

2.2. Procedure and recruitment

Individuals had to possess the following characteristics to be eligible for the study: (1) ICD-10 (International Classification of Disease, 10th revision) diagnosis of ID (mild, moderate, severe, or profound); (2) low levels of PA (specified under); (3) aged 16–60 years, (4) no medical reason not to increase PA; (5) capable of walking with or without support; (6) capable of providing written informed consent if not obtained from a legal representative; and, (7) living in the municipality of Tromsø, Norway.

Individuals with ID were recruited over a 6-month period starting from May 2021. They were identified through their participation in the Norwegian Health in Intellectual Disability (NOHID) study (33), and through staff leaders at the municipal level, who identified potential participants. Research nurses from the clinical trial unit of the University Hospital of North Norway were responsible for data collection and storage. The second author (AH) was responsible for outlining the procedures for setting up and securing the registration of data from the activity measurements.

Invitation letters were sent to 74 participants from the NOHID study database, through a local day care center and high school. Letters were distributed to potential participants by post or handed to leaders of the day care center and high school, with no follow-up after they were sent. After receiving signed informed consent from the participants and/or a family member, the research nurses contacted a family member or staff member from the group home and completed the screening. The Physical Activity Readiness Questionnaire (34) was used to screen for medical contraindications to participation. The participants' carer or a staff member was asked the question, "How much of (the participants') leisure time has (they) spent being 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, watching TV or other sedentary activities. The question has been used in the surveys for PA in the general population (35) and the ones including individuals with ID (33, 36). If participants were reported doing mainly light PA

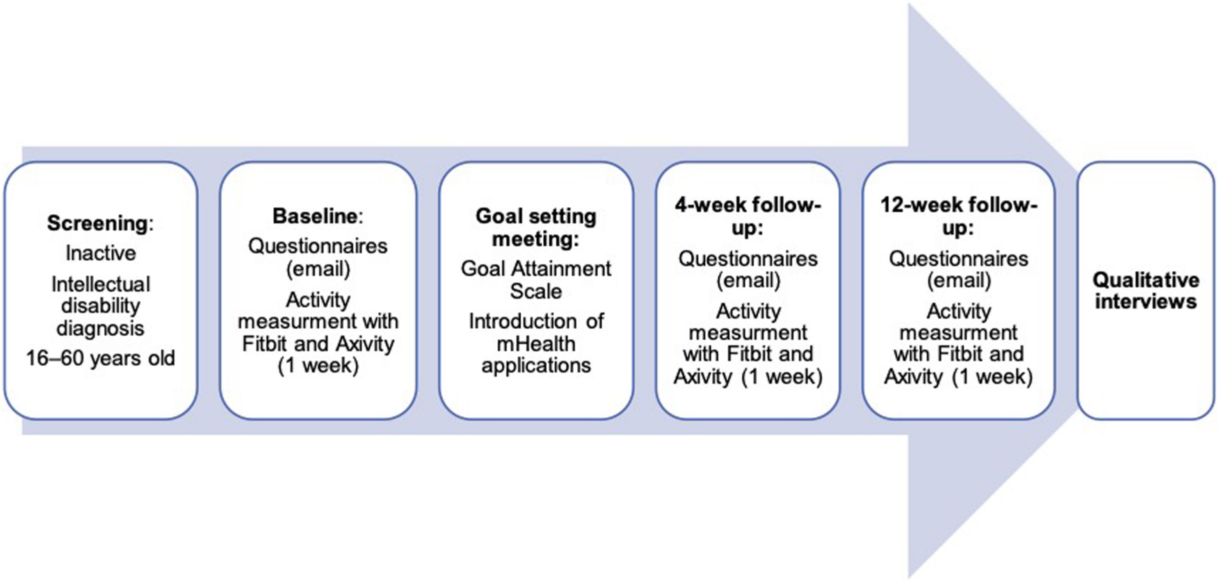


FIGURE 1
Pilot mixed methods study design.

(response category 3) or primarily sedentary activities (response category 4), they were included in the study.

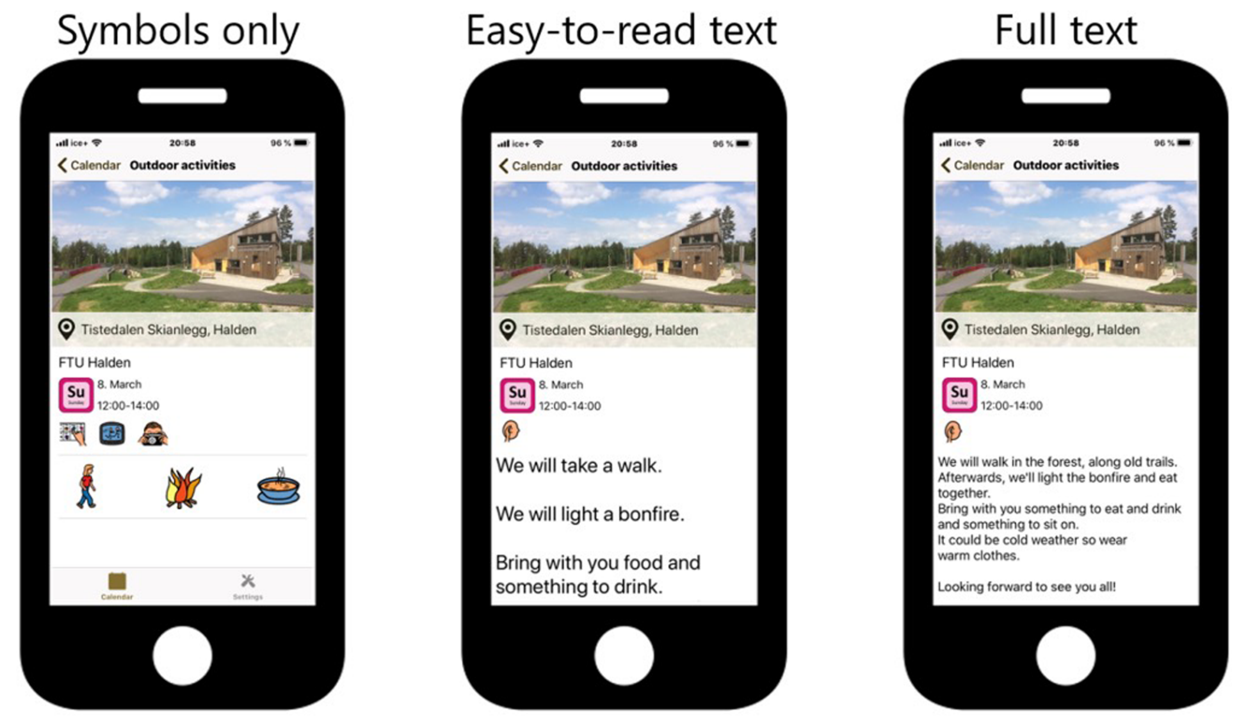
For participants who passed the screening, baseline conversations were held over the telephone with a family or staff member immediately after the screening. Questionnaires were sent securely via e-mail, using the electronic system Research Electronic Data Capture (REDCap). This is a web-based system that is compliant with relevant regulations and security requirements. In case of missing questionnaire data, the family or staff member was contacted and given a reminder. Two activity trackers (Fitbit and Axivity), to be worn for 7 consecutive days, were handed to participants. According to the instructions, Fitbit was worn on the non-dominant hand and Axivity on the dominant hand.

After the baseline assessment, all participants were invited to a meeting with the main author (HM) to set goals for PA using the Goal Attainment Scaling (GAS) (37). During this meeting, participants were given a smartphone (iPhone) if they did not have one, with the developed applications (hereafter “apps”) installed. If they had their own phones, the researcher installed the apps included in the intervention on them. The researcher inserted all the usual PAs or leisure activities into one of the apps (an activity planner) through a web app and added the new activities defined in the GAS. The follow-up after four weeks included a phone call from the research nurses with questions about how they experienced participation, how the technology was working, and whether there were any problems with the activity trackers, and an e-mail containing the follow-up questionnaires. The same procedure was followed for the 12-week follow-up. The apps were available for use for 12 weeks after their introduction. All participants and their family or staff members were asked to participate in a qualitative interview after the 12-week assessment. The time and place for the interviews were agreed upon between the family or staff members and the first author (HM), who also conducted all interviews.

2.3. Application development

This pilot study was part of a project aimed at developing and testing innovative apps that promote PA in individuals with ID (14, 38, 39).

The main app used in this pilot trial was named Active Leisure (Norwegian: *Aktiv Fritid*). It consists of an advanced adjusted activity planner based on a platform developed by the organization Smart Cognition AS (Smart Cognition AS, Norway), a non-profit business where profits are given as grants to projects contributing to better living conditions for people with disabilities. The developers were close family members of individuals with ID. In the development process, feedback was given from the user representatives in our reference group, as well as from the experts in the research group. The app offers individualized solutions for activities that are presented with pictures. Various interface options are available for tailoring (symbols only, easy-to-read text, plain text, or read-aloud), as shown in **Figure 2**. After completing the activity, a simple reward was provided (e.g., a smiling face or shareable picture). All the activities added to the activity planner were inserted through a web application. The activity planner was mostly used together by individuals with ID and a support person (family



We will take a walk.

We will light a bonfire.

Bring with you food and something to drink.

We will walk in the forest, along old trails.
Afterwards, we'll light the bonfire and eat together.
Bring with you something to eat and drink and something to sit on.
It could be cold weather so wear warm clothes.

Looking forward to see you all!

FIGURE 2
Interface options of the Active Leisure app: symbols only, easy-to-read text, or plain text. The app also has read-aloud capabilities.

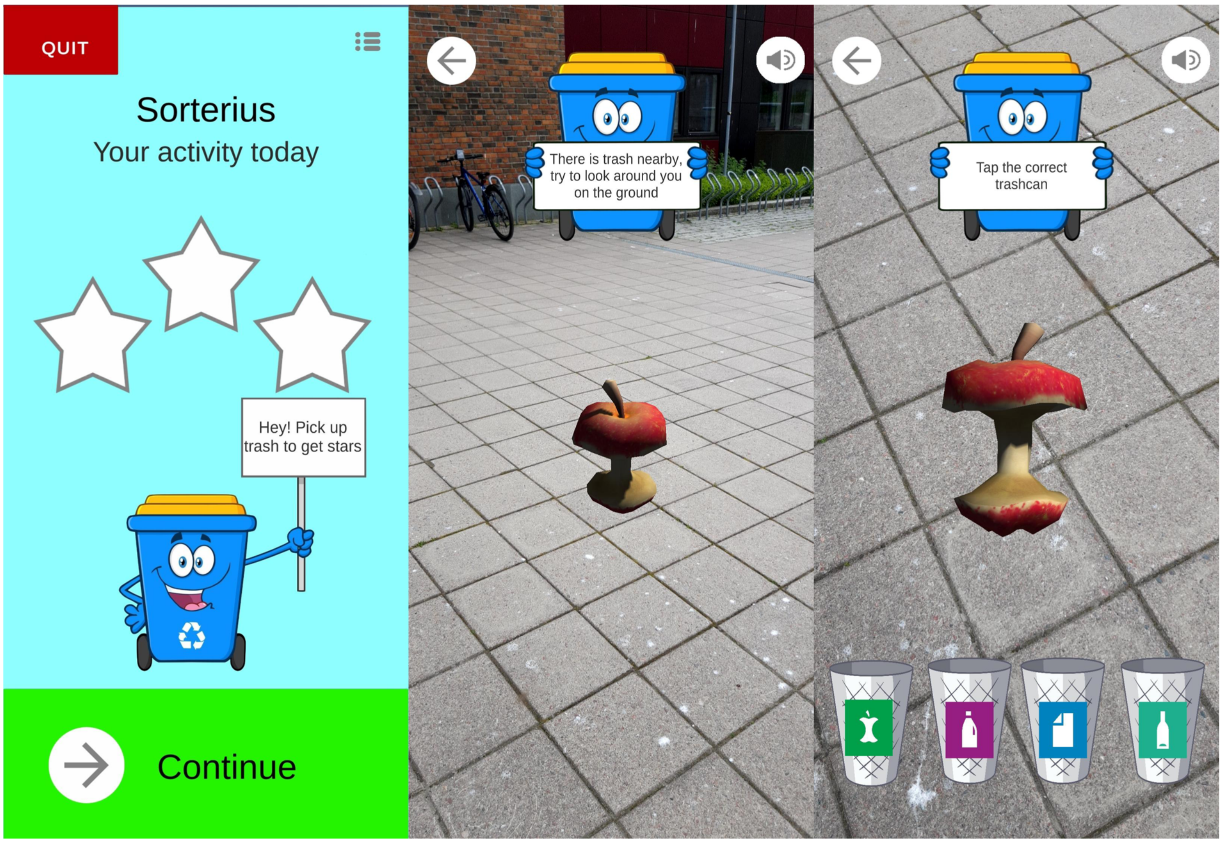


FIGURE 3
The augmented reality app "Sorterius" (42).

member or healthcare provider). Although this app is an off-the-shelf solution, Smart Cognition implemented (and included in the standard application) the following features specifically for our needs: possibility to register activities, simple rewards when registering activities as completed, possibility to add new, pre-defined activities in the mobile app.

An mHealth exercise app was also developed that could be added to the Active Leisure planner. This app is called Sorterius (40) and is an augmented reality game inspired by the popular game Pokémon Go. The idea for the app came from a previous qualitative study (15), and it has been discussed and presented in reference groups consisting of family members and staff of individuals with ID. At one of the reference group meetings, an individual with ID was present to test the prototype.

Sorterius was conceptualized and implemented as part of a Master's thesis project in computer science (41) during the spring of 2021. At the time, Covid restrictions prevented us from testing the game among people with ID. However, we conducted usability tests among eight people working with people with ID to improve the game before it was used in the present study. More details about the implementation of the game can be found in the thesis (41).

In this app, individuals walk in the real world while using a mobile phone. Through the camera of the phone, the individual observes virtual waste appear on the ground. The waste can then be picked up (i.e., clicked) by the player, whose task is to sort the waste into the correct waste bins, e.g., plastic waste goes into the plastic bin. There are three difficulty levels, and depending on the level chosen, the individual is presented with one (easy difficulty), two (medium difficulty), or four bins (hard difficulty). When a set number of items is collected, the individual receives a virtual reward (e.g., stars, and positive feedback). Adding goals for the steps per day, as well as a weekly goal is possible and could be tailored to each individual. A screenshot from the app is shown in **Figure 3**.

Sorterius is under continuous development. The version used in the current projects is freely available for Android (https://play.google.com/store/apps/details?id=no.uit.ifi.sorterius) and iPhone (https://apps.apple.com/us/app/sorterius/id1610130479).

2.4. Goal-setting meeting

During the goal-setting meeting, participants and their caregivers or staff members provided information about their current activities. All participants formulated two or three goals to increase their PA, together with their caregiver or staff member. The new goals were selected (43), formulated, and added to the Goal Attainment Scaling (44). Observable behaviors that reflected the degree of goal attainment were defined. Five different goal attainment levels, ranging from "no change," "goal achievement" to "much better than expected outcome" (numbered −2 to +2, while 0 is goal achievement), were used. For example, one female participant went swimming once a month, which was defined as a score of −2 at baseline. Her new goal was to go swimming once a week (goal achievement, score of 0). By the 12-week follow-up, she had gone swimming once a week (the defined goal), and achieved a score of 0 on the GAS, indicating goal achievement. Another example was that one participant did not have any planned PAs during the weeks of summer (score −2) and set a goal to walk to and from the grocery store twice a week to buy bread. During the summer months, the participant went to the grocery store and back at least thrice a week, which indicated a "better than expected" outcome (score of 1).

The achievement of the goals set in the GAS was discussed during qualitative interviews.

2.5. Measures

An overview of the outcome measures used in the study is presented in **Table 1** (45).

2.5.1. Activity measurement with activity trackers

All participants were asked to wear a Fitbit Versa (Fitbit LLC, CA, US) smartwatch on the non-dominant wrist and an accelerometer, Axivity X3X (Axivity Ltd, Newcastle, UK), on the dominant wrist. Participants who only agreed to use one of the activity trackers chose the Fitbit device, as PA output from this device will be used to assess main study outcomes in a later definite trial. The choice of having two activity trackers was based on the idea of doing a comparison study of the devices in the ID population later in the research project. Except for days of valid measurement, data from the Axivity device are not presented in the current study.

The use of Fitbit for objective PA measure has not yet been validated in the ID population but has been used in an intervention study for individuals with ID and autism (25). The accuracy of using Fitbit has been tested in a rehabilitation population (46). We provided several choices regarding the device color, size, and color and material of the band. Devices were distributed on the same day as the baseline assessments. Participants had to wear the Fitbit device for at least three consecutive days, with a minimum of 500 steps per day for the measurement of steps per day to be valid (47).

In this study, steps per day from the Fitbit device were the main outcome. Data from the Axivity device will be analyzed and used later.

TABLE 1 Outcome measures used in the study.

Measurement tool	Measuring	Type of measure
Activity trackers		
Steps per day	PA, activity trackers	Primary outcome
Questionnaires International Physical Activity Questionnaire	Levels of PA	Secondary outcome
EuroQol-5D	Health-related quality of life	Secondary outcome
Aberrant Behavior Checklist–Community	Challenging behavior	Secondary outcome
Community Integration Questionnaire	Integration in community	
The Self-Efficacy/Social Support for activity for persons with intellectual disability scale	Self-efficacy and social support in PA	Secondary outcome
Goal attainment scaling (GAS)	Goal achievement	Method, secondary outcome

PA, Physical activity.

2.6. Questionnaires

The included questionnaires in the pilot study were chosen as possible individual, interpersonal or environmental correlates to participation in physical activity or sedentary behavior (3), such as aberrant behavior, communication, health related quality of life, living situation, self-efficacy/social support for PA, and integration in the community. PA was measured with a questionnaire due to known problems with missing data on accelerometers (5).

Information regarding age, sex, and living conditions was collected. Living situations were classified as living independently, living with family, or living in a group home with care (48). Information regarding the degree of ID was obtained from participants' medical records. The degree of ID was categorized as mild (IQ: 50–69), moderate (IQ: 35–49), severe (IQ: 20–34), or profound (IQ: <20) (49). The Communication Function Classification System (CFCS) (50) was used to register communication levels.

The International Physical Activity Questionnaire—Short Form (IPAQ-S) was used to measure proxy-reported PA levels (51, 52). The IPAQ-S is a 7-item questionnaire that assesses PA in the past seven days at four intensity levels: (1) vigorous-intensity activity, such as aerobics; (2) moderate-intensity activity, such as leisure cycling; (3) walking; and, (4) sitting. It was scored as a continuous measure by calculating the volume of activity based on its energy requirements, defined in metabolic equivalents (METs), to yield a score in total MET minutes per week (53). Per the IPAQ-S scoring instructions, reaching between 1,500 and 3,000 MET minutes per week is defined as having high PA levels, between 600 and 1,500 is moderate, and under 600 MET minutes is defined as insufficiently active or inactive. This scale has been validated in the general population (54), and substantial agreement between instruments was found in a feasibility trial in the ID population (26). The same study found excellent agreement between IPAQ-S scores from participants with ID and their proxies.

To measure health-related quality of life, the generic EuroQol-5D-5l (EQ-5D-5l) was used (55). The scale is divided into five areas/items: mobility, self-care, usual activities, pain/discomfort, and anxiety/depression. Each item is scored from 1 to 5, where 1 indicates no problem in performing a task and 5 indicates an inability to perform a task. The overall index score was calculated based on the normal values of a population of Nordic participants without ID (56). No index scores have been found for the ID population. The index score is reported between zero and one, and scores closer to one indicate a higher health-related quality of life. The feasibility of using this scale in research that includes individuals with ID has been explored, with a high proportion experiencing difficulties in answering (57). The EQ-5D can be completed via a proxy respondent who know the person well (58), and the 5l version is validated for proxies of people with dementia (59).

To assess challenging behavior, the Aberrant Behavior Checklist-Community (ABC-C) was used (60). The checklist consisted of 58 items divided into five subscales: irritability, social withdrawal, stereotypy, hyperactivity, and inappropriate speech. It is a proxy measure that requires the knowledge of the person with ID. Each item is scored on a scale of 0–3 (with 3 indicating the most severe). The questionnaire was validated for use in a Norwegian population with neurodevelopmental disabilities (61).

The Community Integration Questionnaire (CIQ) was used to obtain information on how connected participants were in their communities (62). The CIQ consists of 15 items related to home and social integration, and productive activities. The scores were 0, 1, or 2 depending on the level of integration, with a maximum total score of 12, indicating a high level of community integration. This scale is developed for persons with aquired brain injury and can be completed by self-report or by a close caregiver (62). Promising psychometric properties for people with other disabilities have been found (63).

To assess self-efficacy and social support in a PA setting, the Self-Efficacy/Social Support for Activity for Persons with Intellectual Disability Scale (SE/SS-AID) was used (64). It is a questionnaire consisting of four subscales: the first (6 items) measures self-efficacy for overcoming barriers to leisure PA, and the last three measure social support for leisure activities from family members (7 items), care staff (6 items), and friends of individuals with IDs (5 items). The scale has been validated for self-reporting and use by proxy respondents in the ID population (64) and translated into Norwegian using standard guidelines (65).

The GAS was reported as normalized T-scores. A mean score of 50 with a standard deviation of 10 corresponded to the achievement of the goal (score of 0) (44). The scale has been validated as having good responsiveness and sensitivity to change (66) and has been used in studies including individuals with ID (31).

2.7. Feasibility

The feasibility measures included recruitment, adherence to the study, adherence to the use of apps and activity measures, and data quality, which were assessed as a percentage of missing data. Recruitment was assessed by (1) response rate, the proportion of participants who provided written consent for the number of invitations sent out; and, (2) inclusion rate, the proportion of individuals included from the number of consenting ones.

Completeness of data was defined as a percentage of missing questionnaire data, percentage of non-participation in goal-setting meetings, and qualitative interviews. In addition, reasons for missing data were explored in the qualitative material.

2.8. Acceptability

Acceptability of the trial methods and intervention was assessed via qualitative interviews. In line with other studies (67), acceptability was defined as satisfaction with the study as a whole (procedures, contact, and information), satisfaction with the measurement of PA by activity trackers, and satisfaction with the use of the apps.

The qualitative interviews were held after the 12-week assessment. They were semi-structured using an interview guide categorized into two sections. Section one focused on feasibility and acceptability of procedures, the use of activity measurement, how the mHealth support was used, and participant, caregiver or staff experiences in all aspects of the study. Section two focused on technology and motivation for physical activity, and will be analyzed in a later publication.

The interviews were audiotaped, and then transcribed verbatim and anonymized. The interviews lasted from 20 min to 2.5 h. The interviews were held at the participants' preferred places: home ($n = 6$), the day center they attended ($n = 1$), or the hospital ($n = 2$).

2.9. Data analysis

In this study, quantitative and qualitative data were gathered and analyzed separately. In the final interpretation of the results, data from both methods were brought together with the qualitative data supplementing the quantitative data.

Appropriate quantitative statistical analyses were performed using the SPSS 28 software (IBM Corp.) according to the type and distribution of data. The descriptive statistics were presented as medians with interquartile ranges, means with standard deviations, 95% confidence intervals, and frequencies of categorical data. The distribution properties of the variables were also examined. Following the CONSORT 2010 extension, estimates of the effects of participant outcome measures (from baseline to follow-up) were explored using nonparametric statistics (related-sample Wilcoxon Signed Rank Test) (68). A tendency toward change with a significance level of 10% was reported. The minimal clinically important individual difference in steps per day was defined as a 10% change from baseline to follow-up (47).

The transcribed interviews were analyzed using thematic analysis (69). The interview transcripts were read several times by the first author to identify emerging themes. Data on the use of activity measurement, use of technology (in general and in using the apps), and experiences of participation in the research project were selected and further analyzed. The text from the transcripts was transformed into specific codes. The codes were compared based on differences and similarities, and condensed into meaningful categories and subcategories (69, 70). The preliminary analysis was read and commented on by the authors, AA and GP. Subsequently, following discussions among the authors, the main themes were identified by grouping similar subthemes and linking them to the results of the quantitative analysis of feasibility.

Mixed analyses were also conducted after quantitative and qualitative data were gathered and analyzed separately (32). In the final interpretation of the results, data from both methods are brought together and supplement each other. In this study, quantitative data were supplemented by information in the qualitative material. For instance, in the event of missing data, interviews have shed light on why there are more missing data at one point of measurement than at others. The quantitative data analysis was performed independently of the qualitative analysis (32).

3. Results

3.1. Feasibility

This pilot study aimed to include ten participants (39). In total, 12 individuals of the 74 invited provided signed informed consent, resulting in a response rate of 16%. The remaining 12 individuals were screened for participation. Two individuals did not meet the inclusion criteria of a low level of PA and one dropped out before the baseline assessments. This meant that nine individuals with ID participated at baseline, which gives an inclusion rate of 75% of those who consented.

All nine participants (100%) who were included in the study took part in goal-setting meetings and qualitative interviews, resulting in a 100% retention rate. From the questionnaires, all (100%) were filled out at baseline, eight (88%) at the 4-week follow-up, and nine (100%) at the 12-week follow-up. Data quality, assessed as a percentage of missing data in each received questionnaire, was <1%.

Days of valid measurements (minimum of three days of measurement) for the Fitbit device showed that all nine (100%) participants had valid measurements from baseline, five (66%) at the 4-week follow-up, and seven (77%) at the 12-week follow-up. For the Axivity, days of valid measurement were seven (77%) at baseline, six (66%) at the 4-week follow-up, and five (55%) at the 12-week follow-up.

Missing data analysis from the qualitative data showed that at the 4-week follow-up one participant lost motivation and threw both measurement devices in the trash. For the second participant, who wore the Fitbit device longer than one week and charged the device with a private charger, data was not possible to retrieve when the device was sent back. The same participant lost motivation at the 12-week follow-up and did not wear any of the devices. The third participant got a rash from the metal and rubber band on the Fitbit device and wore only the Axivity at the 4- and 12-week follow-ups. The fourth missing at 4-weeks follow-up had small wrists and both devices were too large. It was still possible to retrieve some of the data at the 12-week follow-up, but there were uncertainties about the quality of the activity data.

Data retrieved from the Fitbit measurement did not display wear-time or how much time the participant spent sleeping. There were also more missing data when looking at intensity of the PA for the 4-week and 12-week follow-up than for the step count. It was thereby difficult to analyze activity data using intensity categories (sedentary time, light, moderate, and vigorous) from the Fitbit measurements. From the Axivity device, wear-time and time spent in different levels of activity were available, but not analyzed. Data from the Fitbit device were defined as the main outcome in the current pilot trial.

In the qualitative interviews, participants with ID attended six out of nine interviews. Only two of the six participants were active throughout the interviews. In three interviews, only a family member or staff member participated.

3.2. Participant characteristics

The participants' personal characteristics are listed in **Table 2**. The mean age of the participants was 27 years (SD = 7.25), and seven participants were female. Four participants attended day center activities, and four worked either regularly or with support. Most participants had a moderate level of ID. All participants walked without aid or support. Two participants could communicate effectively with both known and unknown communication partners, but had slower progress in their speech. Two individuals had articulation difficulties and could communicate effectively only with their known communication

TABLE 2 Participant characteristics.

	Participants
	N = 9
Age, years	
Median (range)	28 (19–30)
Gender, *n* (%)	
Female	7 (77)
Male	2 (22)
Level of ID, *n* (%)	
Mild	1 (11)
Moderate	8 (88)
Severe/Profound	0
Occupation, *n* (%)	
Regular paid work	1 (11)
Work with support	3 (33)[a]
Day center activity	4 (44)
Attending school	2 (22)
Living situation, *n* (%)	
Lives independently	1 (11)
Lives with family	2 (22)
Apartment in group home with care	6 (67)
CFCS, *n* (%)	
Level 1	5 (56)
Level 2	2 (22)
Level 3	2 (22)
Level 4–5	0

ID, intellectual disability, CFCS, Communication Function Classification System.
[a]Some individuals attended both schools and worked with support.

partners. The remaining participants did not have any communication difficulties.

3.3. Estimation of possible effects

3.3.1. Physical activity measured as steps per day

The participants' PA levels from the Fitbit device (steps) are presented in **Table 3**. The median (IQR) steps for the participants were 5,080 (3,269–7,251) at baseline ($n = 9$), 7,734 (4,770–9,176) at the 4-week follow-up ($n = 5$), and 5,057 (1,968–7,240) at the 12-week follow-up ($n = 7$). A numeric tendency toward an increase in mean steps per day from baseline to the 4-week follow-up was based on five participants, three with a clinically important increase in steps per day. Of the seven participants with measurements at baseline and the 12-week follow-up, two showed a clinically important increase in PA. Estimations of possible changes revealed no overall differences in steps per day between the time points. In terms of individual steps per day, one participant had more than 10,000 mean steps at baseline, six had approximately 5,000 mean steps or more, and one had less than 2,000 mean steps per day.

3.3.2. GAS

A positive change occurred in goal attainment between the goal-setting meeting and end of the study, with a 10% significance level ($p = 0.085$) (**Table 4**). Goal achievement equals a T-score of 50, and the median score for evaluation of the GAS score at the end of the study is 45.4 (IQR: 37.7–51.4) for the whole group. Four participants set three goals, and the rest set two goals to increase PA. Only one participant had no goal achievement at the end of the study, seven had goal achievement (0) or better than expected (+1) for one or more goals, and one had much better than expected (+2) for one of the two goals.

TABLE 4 Results from questionnaires.

Measure	Baseline sum $N = 9$, median (IQR)	4-week sum $N = 8$ median (IQR)	12-week sum $N = 9$, median (IQR)
IPAQ-short	947 (286–1,377)	825.6 (421–1,179.3)	660 (186–1,391.3)
CIQ	15 (11.8–17.3)	16 (13.3–17.4)	15 (13.4–18.6)
SE/SS-AID			
Self-efficacy PA	6,5 (6–8.8) $N = 8$	8.5 (3–11.5)	8 (4–11)
Social support family*	**10 (7.5–12)**	**12 (10.5–14)**	**12 (0–6)** $N = 8$
Social support staff	8 (5.5–11.5)	7 (4.3–11.8)	10 (5.5–11.5)
Social support friends	6 (2.5–8)	4 (1.3–9.5)	4 (0.5–7.5)
ABC-C			
Irritability	1 (0–5)	0.5 (0–3.3)	1 (0–3.5)
Social withdrawal	5 (2.5–10)	4.5 (0.5–8.3)	4 (0.5–7)
Stereotypic behavior	0 (0–4)	0 (0–2.8)	0 (0–2)
Hyperactivity	4 (1.5–4.5)	1.5 (0.3–2)	1 (0–6)
Inappropriate speech	1 (0–2)	1 (0–2.3)	1 (0–3.5)
EQ5D	0.78 (0.68–1)	0.78 (0.73–0.92)	0.78 (0.66–0.92)
GAS*	**37.6 (36.3–37.6)**		**45.4 (37.7–51.4)**

IPAQ, International Physical Activity Questionnaire; CIQ, Community Integration Questionnaire; SE/SS-AID, Self-Efficacy/Social Support Activities for Persons with Intellectual Disability; ABC-C, Aberrant Behavior Checklist-Community.

B1, Self-efficacy in physical activities; B2, Social support from family members; B3, Social support from staff; B4, Social support from friends.

*The bold values are the significant results ($p < 0.10$).

3.3.3. Estimation of possible changes in questionnaires

There was an increase in social support from family members for PA (subscale B2 in the SS-AID) between baseline and the 4-week follow-up ($p = 0.017$), and from baseline to the 12-week follow-up ($p = 0.074$). There was otherwise no statistically significant difference between measures at baseline and follow-up, or between measures from the 4-week follow-up to the 12-week follow-up (**Table 4**). Median MET-minutes from the

TABLE 3 Mean steps per day for each participant at baseline, 4 weeks, and 12 weeks, with minimal clinical important changes.

ID	Mean baseline ($N = 9$)	Mean 4-week ($N = 5$)	Mean 12-week ($N = 6$)	Change baseline—4-week (10% or more)[a]	Change baseline—12-week (10% or more)[b]
1	5,080	8,395	11,083	Increase	Increase
2	4,966	4,015	3,869	Decrease	Decrease
3	6,652	5,527	6,259	Decrease	No change
4	4,507	7,734	4,380	Increase	No change
5	7,851	0	0	–	–
6	5,118	9,956	7,248	Increase	Increase
7	12,228	0	0	–	–
8	1,900	0	1,968	–	No change
9	4,255	0	1,728	–	Decrease
Total mean	5,516	7,126	5,315		
95% confidence interval	3,564–6,387	4,198–10,053	3,278–10,125		
Total median	5,080	7,734	5,057		
IQR	3,269–7,251	4,770–9,176	1,968–7,240		

[a] Change baseline—4-week = mean steps 4-week—mean steps baseline; change is minimum 10%.

[b] Change baseline—12-week = mean steps 12-week—mean steps baseline; change is minimum 10%.

TABLE 5 Results from the different measures of physical activity behavior.

ID	Fitbit Steps/day	IPAQ-s METs	GAS score
1			
Baseline	5,080	4,050	36.3
4-week	8,395	496	52.7
12-weeks	11,083	891	
2			
Baseline	4,966	735	37.58
4-week	4,015	1,072	43.8
12-weeks	3,869	0	
3			
Baseline	6,652	148.5	37.58
4-week	5,527	396	43.8
12-weeks	6,259	505.5	
4			
Baseline	4,507	1,017	37.58
4-week	7,734	–	25.15
12-weeks	4,380	148.5	
5			
Baseline	7,851	946,5	36.3
4-week	–	1,306.5	43.43
12-weeks	–	1,297.5	
6			
Baseline	5,118	1,737	37.58
4-week	9,956	661.1	56.21
12-weeks	7,248	372	
7			
Baseline	12,228	990	36.3
4-week	–	990	45.43
12-weeks	–	3,075	
8			
Baseline	1,900	424	37.58
4-week	–	1,215	50
12-weeks	1,968	660	
9			
Baseline	4,255	0	36.3
4-week	–	198	31.74
12-weeks	1,728	0	

METs, Metabolic Equivalent minutes per week; GAS, Goal Attainment Scaling. Missing data is reported with a line (–).

IPAQ-S were reported as decreasing from baseline to the 4- and the 12-week follow-up, but no statistically significant difference (using non-parametric tests). Table 5 displays the results on only the PA-related measurements.

A decrease in hyperactivity symptoms from the ABC-C was observed from baseline to both the 4-week and 12-week follow-ups (displayed in Table 4), without the changes being statistically or clinically significant.

3.4. Acceptability

Aspects of acceptability were analyzed into two main themes: "positive experiences" and "areas of improvement." In the presentation of the qualitative results, themes and codes from the analysis have been structured so that they corresponded to the study's aim and definition of acceptability, rather than according to the individual themes and codes.

3.4.1. Satisfaction with the applications

Almost all participants achieved one or two goals based on the GAS measurement. All participants had their goals added to the activity planner (Active Leisure) app and had the option to register their accomplished activities.

Everyday structure and fun: The participants, family members, and staff reported that the activity planner (Active Leisure) was easy to use and that it was interesting to receive rewards when registering activities. The activity planner provided a structure for the leisure activities of the participants and reminded them to focus more on physical activities in their daily routines. When using the app, participants had more predictability of the new activities that they were going to perform. Seeing future activities through pictures, symbols, and text in the app also offered predictability of what the week would consist of regarding physical and leisure activities.

Reminder for inclusion: The app also helped the staff remember to include the participants in other activities, such as social and cultural activities. One family member administered the activity planner herself and included all the participants' daily activities, besides PA, in the Active Leisure app.

> *"He found it interesting opening the app and seeing all the things he was supposed to do and what time he should do it. We had not only added physical activities but all other things to do during the day and added things that he is very interested in…sometimes it's hard to make him do things and then it is much better to add them to a plan and then he thinks like okay this is something I must do…"—mother*

Lack of information: Many staff members working in shifts, as well as summer substitutes in the group homes, did not receive information about the project, and therefore did not use the apps. Family members helped the participants with the apps at the beginning of the project, but they found it difficult to add or change activities to the plan when required.

Supplement for daily life: The waste sorting app was used as a supplement when walking from one location to another. This gave the walking activity a goal and greater meaning. They also enjoyed the familiarity of the waste that appeared on the screen and were excited when they received a reward after sorting the waste.

> *"…it (the app) talks a lot. But I found a Zalo bottle (Norwegian dish soap) and a conditioner on the ground!"—participant with ID*

They found the game to be less interesting when the time between waste appearances was too long, and could lose the motivation to continue playing.

Need of support: The results indicated that both apps were primarily used by family members or staff together with the participants. Only one participant used both apps independently (one with high cognitive function).

3.4.2. Satisfaction with activity trackers

As shown in the quantitative data, all participants used the activity trackers during baseline assessments. The participants liked that the activity trackers had different colors and were used as accessories; some were keen on showing the activity trackers to others, in the hope of receiving positive feedback.

Previous experiences: At the 4-week follow-up, there were more missing data from the activity trackers. Two participants had previous experiences using activity trackers and were disappointed when the research-adjusted Fitbit device did not provide the feedback they had previously received. It was also reported that the loss of motivation could be because the information assigned to the participants beforehand was incomprehensible, and they did not know why they were supposed to wear them.

> *"…as we have discussed among staff, we believed that he simply threw both measurement devices in the bin and then took the trash out for recycling. His room is so tidy and organized that there is no way he could have misplaced the devices…"—Staff member*

Adjustments: In several cases, the activity trackers caused skin irritation and adjustments had to be made, such as switching to fabric wristbands or placing sweatbands underneath. However, the skin irritation did not always seem to reduce motivation, as some of those who had skin irritation at baseline continued to wear the device after adjustments were made (at the 4- and 12-week follow-ups).

3.4.3. Satisfaction with study procedures

All participants participated in a goal-setting meeting and qualitative interview, and only one participant had missing questionnaire data at the 4-week follow-up. This indicates a high retention rate and adherence to the study. The qualitative findings have provided supplementary information.

Flexible approach: Participants perceived the study as interesting and important, and most individuals with ID, family members, or staff were pleased with the method of data collection. The method of collecting data was reported to be both flexible and varied, helping family members or staff to maintain motivation and feel satisfied with participation.

> *"This is such an important theme, and I really wanted her to take part in this—even though it was an added everyday effort for us to participate."—father*

Important study focus: All family members and staff were pleased with the focus of the study (PA) and wanted to contribute to the research on this subject. The participants themselves said that they thought it was good to participate in the project and were pleased with the researcher visiting them at home. Family members and staff found distance data sampling (emails and phone calls) an easy way of answering questions and liked that they were given reminders to fill out the questionnaires.

> *"When you come to us, it is very easy. Also, getting the devices delivered has been nice… "—mother*

Lack of information: Some staff requested more information about the study from the group home or daycare center before the study was initiated. They believed that more participants would have wanted to participate if the project had been prioritized by closer leaders at group homes rather than more distant ones at the municipality level.

> *"…if the information about the study and participation came from the group home leaders, this would create a better acceptance for the time and resources spent doing activities with Lisa."—Staff member*

They also mentioned that the time of data collection (4-week follow-up during summer) created problems for participation or the use of the apps. This was due to less staff availability and fewer resources to perform activities with the participants. Some family members and staff also requested more information to the participants that they themselves could understand.

4. Discussion

The purpose of this pilot trial of a 12-week pilot goal-directed PA intervention with mobile application support in adults with ID, was to investigate the feasibility and acceptability of the intervention. The main findings show excellent adherence to the study and data quality for questionnaires, although objective PA measurements were missing for one-third of the participants at follow-up. Eight of nine participants achieved goal attainment for PA, and two individuals exhibited an increase in PA by the end of the study. Furthermore, qualitative results showed positive experiences in using the applications. Participants and family members/staff reported an interest in the study theme and were pleased with the method of data collection, with an estimated statistically significant increase in social support from family members for PAs. However, the recruitment rate was relatively low, which aligns with other studies (26).

Some clinical intervention studies that aim to increase PA show similarly high data quality for questionnaires and retention (43), but many intervention studies on PA report missing data (23, 24). From the activity measurement using Fitbit wrist-worn wearables, missing data were found at the 4-week and 12-week follow-ups, which was also found in other studies, including objective measures of PA using accelerometers or pedometers (70, 71). The quality of the activity data can be questioned, as wear time for the Fitbit device was not retrieved. Qualitative data confirmed that there were issues related to wearing the measurement devices (Fitbit and Axivity) related to skin irritation or loss of motivation, which has been found in other studies (26).

Leung et al.'s (22) systematic review from 2017 showed that 22 studies included accelerometers to objectively measure PA in individuals with ID. In most studies, the accelerometers were placed on the hip. None of the included studies used wrist-worn accelerometers or commercial activity trackers. Wrist-worn accelerometers are not as accurate in providing estimates of energy expenditure but often have better acceptability and higher wear-time (72). Qualitative data from the current pilot study showed satisfaction with using activity trackers at baseline assessments; however, issues regarding skin irritation, size, non-acceptance, and loss of motivation were apparent at follow-up. The absence of missing data from the baseline assessments could imply that wrist-worn accelerometers and/or commercial activity trackers can be useful for high activity data quality in future trials. Increased monitoring during follow-up could potentially be beneficial in avoiding missing data from activity measurements.

Tendencies towards discrepancies between levels of PA objectively measured as steps per day with Fitbit and subjectively as proxy-reported METs from IPAQ-S are seen. This aligns with Moss & Czyz's (73) study, but contradicts the findings of another study (26) that found substantial agreement between the objective and subjective measures in determining active or inactive behaviors. However, none of the measures showed significant changes in total PA from baseline to follow-up. An apparently high median score of METs at baseline is mainly due to a high score from one participant, who may have misunderstood the questionnaire. The IPAQ-S is, as reported earlier (26), more acceptable than an activity tracker, and thereby more suitable for individuals with severe and profound ID. Also, step count at baseline indicate a higher activity level than the inclusion criteria of less than four hours walking per week. It could be that the one-week baseline assessment with activity trackers motivated for a higher activity level than at the timepoint of the screening.

Nearly all participants in this study achieved one or two goals for the PA set using the GAS. Using goal attainment as part of a PA intervention in adults with ID has not been conducted in other studies, to the best of our knowledge. In a study of 92 children with disabilities by Willis et al. (43), GAS was used as one of the outcome measures, and only 32% of participants showed goal attainment for a PA goal at the 12-week follow-up. Combining goal-setting with technology by adding goals to a digital activity planner is promising. The results of the qualitative data showed a positive attitude toward using this specially developed and adjusted digital activity planner that creates structure and predictability. It reminded staff and family members about inclusion and planning for PAs, and may be used together with individuals with ID to increase engagement. Activity measurement data showed a clinically significant increase in PA for only two participants; however, the high rate of goal attainment could have positively influenced the PA of the remaining participants. All types of increases in PA are regarded as positive health outcomes (10).

Few studies have a technological intervention focusing on the structure and predictability of PA. In several studies, predictability is an important facilitator for PA (74–76). In the scoping review by Lancioni et al. (12) of stimulation-regulating technology to increase PA, one group of studies ($n = 15$) used computer video games (77, 78). The majority of the included studies ($n = 27$) used sensors or other stimulation-regulating technology linked to computer systems or mobile technology to increase PA in the form of increased balance, stretching, and arm, leg, and head responses. None of the studies in the last group used wrist-worn activity trackers or accelerometers to measure the steps per day as the outcome (12). Three of the included studies with eight, nine, and six participants used smartphones to increase PA with positive results. However, in contrast to the present study, the participants had severe or profound ID with severe motor or vision impairments and were not ambulatory (19, 20, 79, 80). In the present pilot study, the results indicated satisfaction with the apps used in the present pilot study; the apps were easy to use and sparked interest in the participants with ID. A previous promising study of reminders for PA through a mobile app (13) was performed with four individuals with mild ID and evaluated using the IPAQ. This differs from the current study, in which eight of nine participants had moderate ID, and PA was monitored objectively in addition to using the IPAQ.

Furthermore, this study aimed to develop and evaluate mobile apps for PA (39). One reason that development was necessary was that none of the available apps for PA had inclusive designs intended for adults with ID. An inclusive design includes a simple interface, text alternatives, sufficient contrast, navigational help, and robust systems (81). Communication was also a focus of the apps developed and adjusted for in this pilot trial. None of the studies we read involved increasing PA in adults with ID had the option of using a digital planner for PA, nor did they have an inclusive design as a focus in technological interventions. Using mobile technology for activity planning improves availability and accessibility, as many family members, support persons, and staff own a smartphone (82). Planning also involves engagement from staff and family members, which has been another important predictor of the facilitation of PA for individuals with ID (74, 75). One finding of the qualitative interviews was that the apps were not used independently or over time. Finding ways for these mobile apps to improve the engagement of staff or family members will be crucial for future development.

The present results showed an increase in social support for PA from family members after four and twelve weeks. This indicates that either the study procedures or intervention positively impacted family member engagement in PA. Two individuals who had family members as their support person during the study showed a clinically significant increase in PA. This further emphasizes the importance of creating engagement and interest in PA among persons supporting individuals with ID (74). The estimated effects showed no change in social support for PA among staff members.

4.1. Modifications before a future mHealth PA intervention

Some staff members requested more planning, information, and involvement from leaders and stakeholders of the study to improve its procedures. Future studies should consider ways on improving the support and engagement of staff when developing interventions. Others have been successful with PA interventions, in which either staff or caregivers have been included to conduct or instruct PA interventions (23, 71, 83). The use of family members or staff as mentors in PA interventions may be important to ensure long-term changes in PA behavior (5). Although the research project had a reference group of user representatives and experts, a more formalised inclusive research design could increase the recruitment rate. Goal-directed intervention in combination with an inclusive activity planner is a promising approach that should be investigated in randomized controlled studies. In future trials, a multicenter approach should be used to ensure recruitment from a larger population of adults with ID. In addition, objective measures of how much mHealth apps are used and the wear-time for activity trackers should be included in a future trial.

4.2. Limitations and strengths

This pilot mixed methods feasibility trial has several limitations. The small sample size evidently reduces the generalizability of the findings; however, nine out of ten planned participants were included in this pilot (39). Strengths of the pilot trial include originality as the first mobile-based intervention for PA in ambulatory adults with ID, objectively measuring PA, and the use and evaluation with a mixed methods design, as well as the use of commercially-available activity trackers. Missing data from activity trackers at approximately one-third of the follow-up points was another limitation, a problem also found in other PA intervention studies (24). Furthermore, the activity measurement may not reflect the actual activity of the participants. Typically, a day of 10-hour wear-time is considered a valid day for measurement (84). In this study, at least 500 steps per day (23), were required to be considered a valid measurement, which could overshadow missing step counts. Another possibility is that the achieved activity goals were not measured during the three days of valid measurements (e.g., swimming once a week), but other studies have defined a three-day period with at least 6 h' measurement a day as valid (23). Wear-time for the Fitbit measurement has not been obtained, which is another important limitation that needs to be addressed in future trials.

In this study, no objective measures or back-end recordings of the time spent on the two different apps during the intervention existed. Apps were reported to be used more frequently at the beginning of the study than regularly throughout the study. It is not uncommon for people to lose interest in PA apps after the novelty of the technology has worn off (84), but this has not been extensively investigated for individuals with ID.

Most participants included in the study had moderate ID. Future trials should include more individuals with severe or profound ID to investigate how the use of mobile applications can be adjusted to increase PA. The low recruitment rate may indicate a possible selection bias of participants who are particularly interested in the research topic. Another limitation was that most of the participants were female, which does not provide a balanced view of the gender differences in the general ID population (6). In future trials, a more equal distribution (or more males) in the included participants should be ensured.

5. Conclusion

This is the first study (to the best of our knowledge) to examine the feasibility and acceptability of a pilot PA intervention study using specially developed mobile apps coupled with wrist-worn activity trackers in adults with intellectual disability. The acceptability and feasibility of using goal attainment combined with tailored mobile applications to increase PA are promising. A full study should include participants from a larger area and aim for more engagement from staff and stakeholders.

Data availability statement

The datasets presented in this article are not readily available to protect the anonymity of the participants. Requests to access the datasets should be directed to the authors.

Ethics statement

The studies involving humans were approved by Regional Committees for Medical and Health Research Ethics in Norway. The studies were conducted in accordance with the local legislation and institutional requirements. Written informed consent for participation in this study was provided by the participants' legal guardians/next of kin.

Author contributions

AA, GH, and SW contributed to the conception and design of the study. HM conducted parts of the data collection together with research nurses from the clinical trial unit of the University Hospital of North Norway. AH and GT provided technical help with the activity trackers in the data collection. HM and AA performed the statistical analysis and GP helped with the qualitative analysis. HM wrote the first draft of the manuscript. AA, GP, and AH wrote sections of the manuscript. All authors contributed to the article and approved the submitted version.

Funding

The study has been conducted with grants from the Northern Norway Regional Health Authority (grant number HNF1353-17).

Acknowledgments

We would like to thank the participants, family members, and staff for their cooperation and support. The study has received support from the Department of Clinical Research, University Hospital of North Norway, Tromsø, Norway and we would like to thank the nurses Britt-Ann Winther Eilertsen, Brita Lena Hansen and Annika Gustavsson.

Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

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Paper III

Michalsen, H., Henriksen, A., Hartvigsen, G., Pedersen, E. R., Søndenaa, E., Jahnsen, R., & Anke, A. (2024). Barriers to physical activity participation for adults with intellectual disability: A cross-sectional study. *In review*

Barriers to physical activity participation for adults with intellectual disability: A cross-sectional study

Running Title: barriers for physical activity in intellectual disability

ABSTRACT

Background: Identifying barriers that can be modified to promote physical activity is important for informing health interventions for adults with intellectual disabilities.

Objectives: Exploring participation in physical activity considering age, sex, living conditions, and health conditions. Further, identifying barriers significantly associated with mainly sedentary activity after adjustment for physical activity correlates.

Methods: A cross-sectional study including physical activity and barrier questions from the POMONA-15 health indicators. Multivariate logistic regression analysis with sedentary activity as dependent variable.

Results: Among 213 participants with intellectual disabilities, 36% reported predominately sedentary activities, 53% light and 11% moderate or vigorous physical activity. Barriers related to sedentary activity after adjustment were transportation, health conditions, mobility impairment, and lack of activities at the day activity centre.

Conclusions: The findings highlight the need to enhance physical activity opportunities at day activity centres, tailor programs for wheelchair users, and improve access to physical activity facilities for adults with intellectual disabilities.

Trial registration: ClinicalTrials.gov with the identifier NCT03889002.

Keywords: intellectual disability, physical activity, exercise, barriers, health

Lay Summary

- **Day activity centres for adults with intellectual disability should regularly offer physical activity**
- **There is a need for tailoring exercise programs for wheelchair users**
- **Participation in physical activity could be increased by improved support and transportation to physical activities**

1 Introduction

Extended periods of sedentary behaviour in the general population have been linked to elevated risks of all-cause mortality, heightened metabolic risk factors, and an increased incidence of various health issues, including cardiovascular disease (CVD), type 2 diabetes, and certain types of cancer (Biswas et al., 2015; Patterson et al., 2018). However, a similar body of evidence has yet to be established for individuals with intellectual disabilities, mainly because of a lack of research in the field (Lynch et al., 2022; Melville et al., 2018). Individuals with intellectual disabilities and sedentary lifestyles are highly likely to develop metabolic syndrome (48.6%), be overweight or obese (69-87%), and exhibit elevated osteopenia and osteoporosis risks (30-40%). Moreover, the prevalence of multimorbidity (79%) is high in this population (Lynch et al., 2022; Olsen et al., 2021).

Individuals with intellectual disability spend approximately 12 hours (730 minutes) per day in sedentary pursuits (watching TV, riding in cars, etc.) according to proxy-reported measures (Melville et al., 2017). In objectively measured sedentary levels, the mean time- per-day was 8 hours (Harris et al., 2019). Sedentary levels are similar in the general population, with 8-9 hours of sedentary behaviour per day (Loyen et al., 2017; Patterson et al., 2018). More than

9.5 hours of sedentary time per day has been associated with a greater risk of mortality (Ekelund et al., 2019).

Many individuals with intellectual disability tend to be physically less active than the general population. Only 9% of adults with intellectual disabilities meet the recommended minimum of 150 minutes of moderate-to-vigorous physical activity (MVPA) per week (Dairo et al., 2016), whereas one out of five (22%) individuals in the general population achieve this threshold (Sagelv et al., 2019). Some factors contributing to the barriers for physical activity participation among adults with ID have been explored to a certain extent (Ascondo et al., 2023; Temple, 2007; Vancampfort et al., 2022), but there is a gap in identifying barriers and at the same time adjusting for specific characteristics of individuals that have mainly sedentary activity levels. Some of the identified barriers are intrinsic in nature, such as the presence of a disability, lack of interest in physical activity, and compromised physical and mental health (Ascondo et al., 2023; Stancliffe & Anderson, 2017). The most frequently reported barriers are physical mobility problems and the severity of the intellectual disability (Ascondo et al., 2023; Cartwright et al., 2017; Jacinto et al., 2021; Kreinbucher-Bekerle et al., 2022).

A systematic review by Vancampfort et al. (2022) revealed correlates associated with physical activity participation in adults and older adults with intellectual disability. Among demographic correlates, old age was negatively correlated with physical activity participation, whereas employment status emerged as a positive influence on physical activity participation. Among the biological correlates, physical mobility challenges, obesity, and multimorbidity were identified as negative contributors to physical activity. In addition, individuals with specific physical health conditions such as epilepsy exhibit lower physical activity levels. Regarding psychological, cognitive, or emotional correlates, a more severe level of intellectual disability, the presence of Down´s syndrome (among older adults), cerebral palsy, and depression were associated with reduced physical activity participation. Interestingly, there seems to be a positive trend in physical activity levels for individuals residing in supported accommodations as opposed to those living independently in their own homes (Hilgenkamp et al., 2012; Hsieh et al., 2017). Participating in day activity programs or educational programs was in one study related to low physical activity levels (Hsieh et al., 2017), but higher step count in another (Oviedo et al., 2019). Other reported barriers include insufficient resources or limited engagement from service providers (Laxton et al., 2023; Mahy et al., 2010; Michalsen et al., 2020), communication challenges between family members and paid caregivers (Cartwright et al., 2017), lack of independent access to community exercise facilities, and infrequent engagement in community-based exercise programs (Stancliffe & Anderson, 2017).

However, to date, no prior study has adjusted for physical activity correlates when identifying the barriers to physical activity participation among adults with intellectual disabilities who lead sedentary lifestyles. Thus, our first objective was to explore the physical activity levels by considering associations between mainly sedentary activity levels and factors such as age, degree of intellectual disability, living situation, and health conditions. Additionally, we assessed the barriers that exhibited a significant association with sedentary activity after adjusting for the identified correlates of physical activity.

2 Methods

2.1 Design and setting

The data used in this study were collected in the North Health in Intellectual Disability (NOHID) study—a cross-sectional multi-centre study including five municipalities in the northern and central regions of Norway (Tromsø, Balsfjord, Narvik, Malvik, and parts of

Trondheim). The NOHID study was led by the University Hospital of North Norway (UNN) in Tromsø in close cooperation with St. Olavs Hospital in Trondheim. Data were collected between October 2017 and December 2019.

2.2 Procedure

Potential participants were identified through specialised intellectual disability services at the University Hospital of North Norway (UNN), St. Olavs hospital, and by accessing information concerning individuals with intellectual disability receiving services from the municipalities of Tromsø, Balsfjord, Narvik, Malvik and parts of Trondheim. Invitations were sent to eligible participants, followed by telephone contact with guardians or next of kin. The recruitment and data collection processes were performed by research assistants with backgrounds in healthcare, including research nurses, intellectual disability nurses, and physiotherapists.

Data were gathered through structured interviews using the POMONA-15 (P15) health indicators Questionnaire (Perry et al., 2010). Interviews were conducted with the participants, their caregivers, or support persons. Questionnaires were completed at the hospital's research unit, in participants' homes, at other preferred locations, or via telephone interviews. In seven of the interviews, the person with intellectual disability was the only one present. In 107 interviews, only the support person was present and in 98 interviews both the person with intellectual disability and the support person was present. Information regarding the level of intellectual disability and other health conditions was obtained from the participants' medical records.

The procedures for this study are described in more detail in previous publications from our research project (Olsen et al., 2021; Olsen et al., 2022).

2.3 Ethics

Whenever feasible, we sought informed consent from individuals with intellectual disabilities. In situations where an individual with an intellectual disability was unable to provide consent, a close relative or guardian acted as their authorised representative and provided informed consent on their behalf. The study was approved by the Committee for Medical Research Ethics, Health Region North (2017/811) and the data protection officers at UNN and St. Olavs Hospital. Furthermore, the trial was registered in Clinical Trials under the identification number NCT03889002.

2.4 Participants

All individuals with a verified diagnosis of intellectual disability according to the International Statistical Classification of Diseases and Related Health Problems (ICD-10) 10th revision criteria (WHO, 2019) were eligible to participate in this study. In addition, participants were required to be 16 years of age or older and residing in Norway, in the municipalities of Tromsø, Balsfjord, Narvik, Malvik, or Trondheim.

While there were no predefined exclusion criteria, certain individuals were excluded because of circumstances that hindered the acquisition of reliable information or instances in which the intellectual disability diagnosis was withdrawn. The degree of intellectual disability was categorised as mild (IQ 50–69), moderate (IQ 35–49), severe (IQ 20–34), or profound (IQ < 20) (WHO, 2019). Information regarding eligible nonparticipants was available only for the northern region, where 140 of 266 eligible individuals participated, resulting in a participation rate of 53%. The included participants (mean age 36.1) were younger than the excluded participants and nonparticipants, who had a mean age of 42.3 years (Olsen et al., 2021). In the central part of Norway, participation rates were lower, resulting in a sample of 74 participants with an age and sex distribution comparable to that of northern participants (Olsen et al., 2021). Among the 214 participants initially included in the main study (Olsen et al., 2021; Olsen et al., 2023), one was excluded from our analysis due to missing physical-activity measurements data. A flowchart of the study inclusion is shown in figure 1.

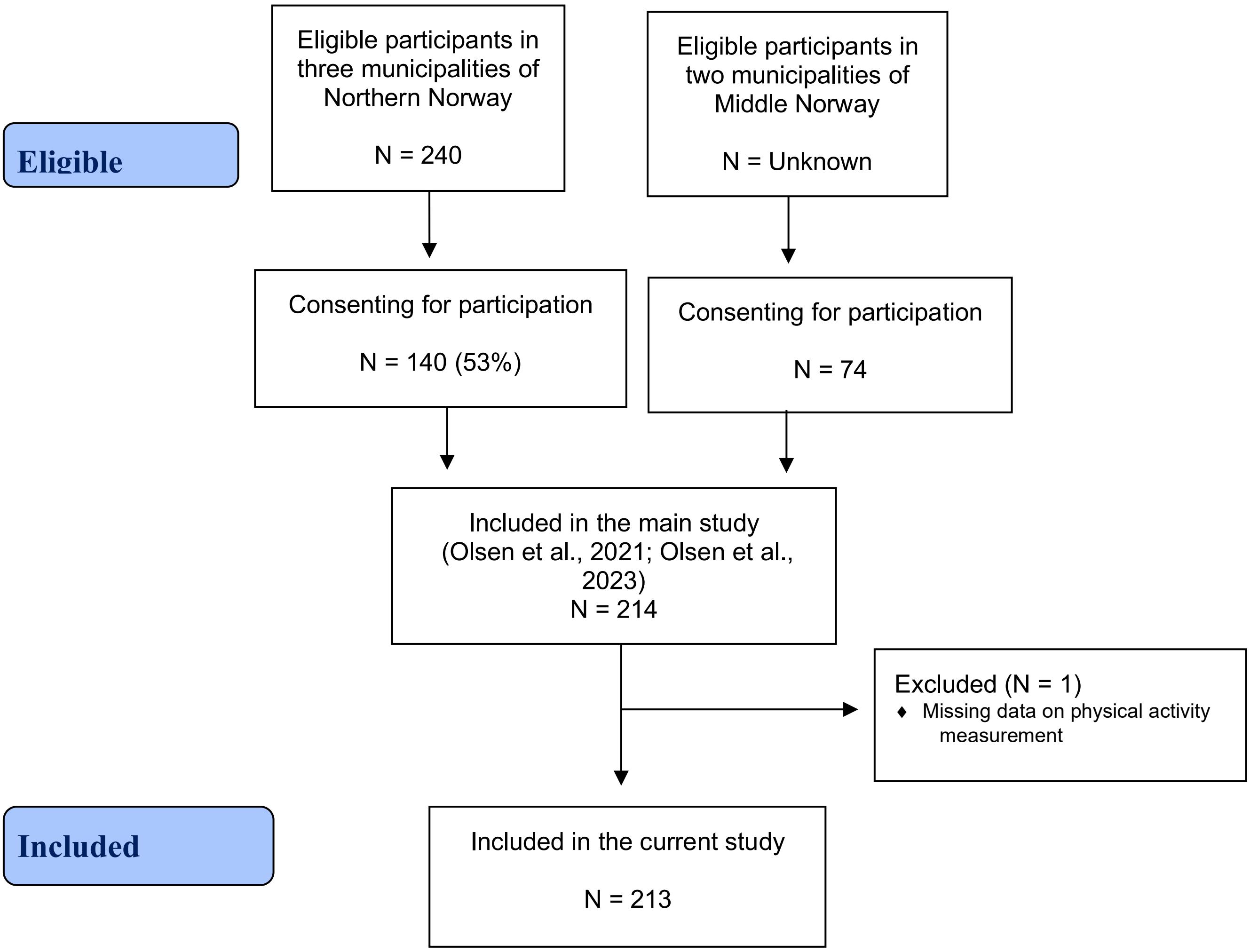

Figure 1: Flow chart of included participants (ref. STROBE).

2.5 Measures

2.5.1 The POMONA-15 survey instrument

The internationally developed POMONA-15 (P15) health indicators (Perry et al., 2010) were developed by a partnership between 13 EU member states with the aim of assessing health disparities among individuals with intellectual disabilities in comparison with the general population (Perry et al., 2010). This comprehensive questionnaire also included questions about physical activity levels, sourced from the Saltin Grimby Physical Activity Questionnaire (SGPALS) (Grimby et al., 2015). The questionnaire also incorporated a list of 15 barriers that impede participation in physical activity among individuals with intellectual disabilities. We used the P15 questionnaire to gather data on demographics, physical activity levels, and health conditions.

The P15 questionnaire includes a comprehensive list of medical conditions, including asthma, allergies, diabetes, cataracts, hypertension, heart attacks, stroke, chronic obstructive pulmonary disease/emphysema, arthritis (both osteoarthritis and rheumatoid arthritis), osteoporosis, peptic ulcers, and various forms of cancer, including leukaemia, migraines or recurrent headaches, constipation, thyroid disorders, and epilepsy. NOHID also documented other frequently occurring conditions, such as skin conditions and musculoskeletal problems. In order to reduce number of variables and avoid small numbers, physical health conditions with prevalence of 25% or greater (Olsen et al., 2021) were included in further analyses in the current study.

Multimorbidity was defined as the presence of one or more physical health conditions in addition to a diagnosis of intellectual disability in accordance with the WHO guidelines (WHO, 2019). Notably, a diagnosis of Down’s syndrome, autism, or cerebral palsy was noted as an underlying diagnosis rather than a physical health condition.

Information about weight from informants was obtained from 194 out of 213 participants, with 9% having missing data. In a subset of participants (n = 50) from the Tromsø region, weight measurements were conducted at the clinical trial unit.

The Aberrant Behavior Checklist-Community (ABC-C) (Aman et al., 1985) is used to assess challenging behaviours and has been validated for use in a Norwegian population with neurodevelopmental disabilities (Halvorsen et al., 2019) The 58-items checklist is divided into five subscales: irritability, social withdrawal, stereotypical behaviour, hyperactivity/noncompliance, and inappropriate speech. It functions as a proxy measure, requiring input from individuals familiar with the person with intellectual disability. Each item is scored on a scale from 0 (least) to 3 (most) severe behaviour.

The Moss Psychiatric Assessment Schedules (Check) (MPAS, previously known as the PAS-ADD Checklist) is a questionnaire developed to identify potential mental illnesses in people with all levels of intellectual disability (Moss, 2012). Three subscale scores were generated: Organic Condition, Affective/Neurotic Disorder, Psychotic Disorder. Each subscale has a specified threshold score; scores equal to or above this threshold indicate that further clinical or mental health assessments are advised. Independent replication of the psychometric properties of the MPAS-Check revealed acceptable internal consistency. The MPAS-Check was found to be sensitive to variations between diagnostic groups and had an overall sensitivity of 66% and a specificity of 70% (Sturmey et al., 2005).

Both ABC-C and MPAS-Check were incorporated into the P15 questionnaire.

2.5.2 Living conditions

Participants' living conditions were classified into three categories: living alone, living with family, or living in apartments attached to services (Molden et al., 2009). In Norway, adults with intellectual disabilities typically reside in individual apartments where they receive municipal support based on their specific requirements. Some individuals lived independently, whereas others lived in clustered apartments with shared housing.

2.5.3 Motor function

The Gross Motor Function Classification System Extended and Revised (GMFCS E&R) categorises gross motor functioning into five levels, with lower levels indicating better function. The GMFCS E&R was developed for persons with cerebral palsy (Palisano et al., 2008) and has high inter-rater reliability (McCormick et al., 2007). The scale assesses gross motor function across five levels.

Level 1: Individuals may exhibit limitations in advanced motor skills (e.g. speed and balance) but can typically walk without constraints.
Level 2: Those at this level often require handrails to navigate the stairs and can walk without assistance, although they may occasionally use devices such as crutches or wheelchairs.
Level 3: Individuals in this category typically rely on mobility aids indoors and require wheelchairs outdoors.
Level 4: People at this level typically depend on wheelchairs for mobility.
Level 5: This signifies the requirement for a wheelchair and additional support for sitting.

Although the GMFCS E&R has been used in studies involving adults with intellectual disabilities (Dijkhuizen et al., 2018; Olsen et al., 2021), it has not been formally validated for use in this population.

2.5.4 Physical activity

As part of the P15 questionnaire, the assessment of physical activity level utilized a modified version of the Saltin Grimby Physical Activity Level Scale (SGPALS) (Grimby et al., 2015). Respondents were asked, ‘ How much of your leisure time have you been physically active in the last year? with four response categories: 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, the questionnaire included a question regarding work activity: ‘If you are in paid or unpaid work, how would you describe your work?’ The response categories for this question were as follows: 1) ‘Mainly sedentary activity (e.g., sitting by a desk),’ 2) ‘Work that involves walking (e.g., salesman, light industrial work, teaching),’ 3) ‘Work that involves heavy lifts (e.g., care worker, builder),’ and 4) ‘Heavy manual labour’ (Sagelv et al., 2019). These questions have been used in the longest-running and most comprehensive population study conducted in Norway, known as the Tromsø study (Hopstock et al., 2022). Furthermore, the P15 questionnaire included the question, ‘Do you work out enough to get sweaty at least once a week?’ with response options “yes”, “no”, “don’t know/unclear”.

To assess the overall physical activity levels of the participants in in their everyday life, the SGPALS question about leisure physical activity, and the question about levels of activity during paid or unpaid work, derived from the Tromsø study, yielded a new composite variable labelled ‘total physical activity’. During the creation of this variable, all participants who had responded ‘reading, TV or other sedentary activities’ (response category 4) as their leisure physical activity level, but had reported ‘work that involves walking, ‘work that involves heavy lifts’, or ‘heavy manual labour’, were changed to the physical activity category ‘walking, cycling or other forms of light exercise at least four hours a week’ (response category 3); i.e. not sedentary activity. This adjustment from response categories 4 to 3, mainly from sedentary to active, was applied to 21 participants.

In our analyses, we used the new variable ‘total physical activity’, which had a four-level scale (encompassing sedentary behaviour, light activity, moderate activity, and vigorous activity). In some analyses, we simplified this scale into a dichotomous classification: ‘active’ (comprising light, moderate, and vigorous activities) and ‘sedentary’.

2.5.4.1 Sedentary behaviour

In many studies, sedentary behaviour is defined as any waking behaviour with an energy expenditure of less than <1.5 metabolic equivalents (METs), during which one is in a seated, reclined, or lying posture (Lynch et al., 2022; Melville et al., 2018; Patterson et al., 2018).

In this study, sedentary behaviour was referred to as “doing mainly sedentary activities” and defined as engaging in activities such as ‘reading, watching TV, or other mainly sedentary activities’ (response category 4, SGPALS) and ‘mainly sedentary activities at work’ (response category 1, work question derived from the Tromsø study). In this article, the term “sedentary activity” is used to describe responses in category 4 fra SGPALS and category 1 from the work question.

2.5.4.2 Barriers

The P15 questionnaire included a single question on barriers to participation in physical activity. The question was framed as follows: ‘Do you have difficulties with physical activity participation for the following reasons?’ It presents 15 different barriers, each with a ‘yes’ or ‘no’ response option. The barriers are presented in table 1. There were two response choices available if the participant could not relate to any of the provided barriers: ‘cannot answer/unclear/don’t know’ and ‘refuse to answer’. Each participant identified several barriers. A “yes” response was categorised as a barrier to participation in physical activity.

Table 1: Presented barriers for physical activity participation in the POMONA-15 questionnaire.

Barriers for physical activity participation
Cannot use public transport
Does not like to exercise
No one to go with
Easily tired
Health related issues (including obesity)
Needs help but no one helps
Severity of intellectual disability
No transport possibilities
No available exercise activities
No available activities at the day care centre
Use of wheelchair/mobility impairment
Not allowed
Not enough time
Not enough money
Age

2.6 Data analysis

Descriptive statistics were used to obtain an overview of data. Continuous variables, such as age, are presented as means with standard deviations (SD) or medians with ranges. Categorical variables are presented as percentages of the defined categories. Associations between the dichotomised physical activity groups were investigated with One-Way ANOVA for the continuous variable age and with the Pearson chi-square test or the non-parametric Fisher exact test for categorical variables.

Barriers that were significantly associated with dichotomised physical activity level (sedentary/active) in cross-tabulation analysis were further analysed in binary logistic regression analyses with dichotomised level of sedentary activity (sedentary/ active) as the dependent variable. Independent adjustment variables were included based on prior knowledge from the literature (level of intellectual disability) or because of a statistically significant association with sedentary activity in the first analysis ($p < .05$). In the multivariate logistic regression analyses of the associations between dichotomised levels of sedentary activity and barriers, we adjusted for the following variables in different combinations: age (continuous), level of intellectual disability (mild, moderate, severe, or profound), gross motor function classification (level 1-2 /level 3-5), epilepsy (yes/no), and Downs' syndrome (yes/no). The diagnosis cerebral palsy was not included because of its small number (n = 24) and its moderate correlation with gross motor function. The entry method was applied. Multicollinearity was assessed. Correlations were made to ensure that none of the variables were highly correlated with each other, with a Spearman's correlation cut-off of 0.7. Model fit was assessed using the Hosmer–Lemeshow goodness-of-fit test. The degree of pseudo-explained variance was reported using Nagelkerke's R square.

3 Results

3.1 Participant characteristics

As shown in Table 2, the study included a sample of 213 individuals with intellectual disabilities, of whom 56% were men. The age of the participants ranged from 16 to 78 years (mean = 36.1 years; SD = 13.8). Additionally, 48 individuals (22%) were diagnosed with autism, 40 (19%) were diagnosed with Down´s syndrome, and 24 (11%) had cerebral palsy. Information regarding the level of intellectual disability was available for 205 participants, with the following distribution: mild, 82 (39%); moderate 56 (26%); severe 49 (23%); profound 17 (8%); and unknown, nine (4%). Multimorbidity, defined as the presence of one or more physical health conditions, was observed in 168 participants (79%). Only 196 participants completed the questionnaires for aberrant behaviour (ABC-C) and mental illness (MPAS). In the ABC-C and MPAS questionnaire data, missing values in the dataset were handled using the imputation methods recommended in the manual for screening instruments (Aman et al., 1995).

Table 2: Participant characteristics

Characteristics	**Total (N = 213)**
Gender, n (%)	
Men	119 (56)
Women	95 (44)
Age (years), mean (SD)	36.1 (14)
Median (range)	32.5 (16-78)
Living condition, n (%)	
Lives independently	25 (12)
Lives with family	41 (19)
Group home with care	147 (9)
Down syndrome, n(%)	40 (19)
Autism diagnosis, n (%)	47 (22)
Cerebral Palsy, n (%)	24 (11)
Level of intellectual disability, n (%) (n = 205)	
Mild	82 (39)
Moderate	56 (26)
Severe	49 (23)
Profound	17 (8)
Unknown	9 (4)
Gross motor function classification scale	
Level 1	122 (57)
Level 2	55 (26)
Level 3-5	36 (17)
Weight, N = 194, n (%)	
Underweight	17 (8)
Normal	62 (29)
Overweight	60 (28)
Obese	55 (26)
Physical health conditions, n (%)	
Epilepsy	55 (26)
Allergies	68 (32)
Visual aids	92 (43)
Musculoskeletal disorders	53 (25)
Multi-morbidity, one physical health condition	168 (79)
Multi-morbidity, two or more physical health conditions	117 (55)
Numbers of physical health conditions, median (IQR)	2 (1-3)
Mental health	
ABC-C[a], mean (SD), n = 196	
Irritability	5.0 (6.6)
Social withdrawal, n = 197	3.3 (4.0)
Stereotypic behaviour, n = 197	1.3 (2.3)
Hyperactivity/noncompliance	4.9 (6.5)
Inappropriate speech	1.5 (2.2)
MPAS[b] (Check), mean (SD), n = 196	
Affective/neurotic	1.8 (3.5)
Organic condition	1.0 (1.8)
Psychotic	0.4 (0.8)

[a]: ABC-C = Aberrant Behaviour Checklist- Community

[b]: MPAS (Check) = Moss Psychiatric Assessment Schedules (Check)

3.2 Levels of physical activity

In response to the Saltin-Grimby questionnaire regarding leisure time physical activity, the reported levels of physical activity were distributed as follows: 46 % mainly engaged in sedentary physical activity, 43% participated in light physical activity, 7% in moderate physical activity, and 4 % in vigorous physical activity. When we considered the total physical activity score, which combines work and leisure activities, 36% had mainly sedentary activity, 53% engaged in light physical activity, 7% had moderate physical activity, and only 4% reported vigorous physical activity. The distribution of the 4-category total score for physical activity in relation to age, sex, degree of intellectual disability, living situation, health conditions, motor function, and weight is shown in Table S1.

For further analysis, the total physical activity variable were categorised into two levels: active (light, moderate, and vigorous activity) and sedentary. As shown in Table 3, participants reporting predominantly sedentary activities had a mean age of 40 years (SD = 15), which was significantly higher than that of participants in the active category (mean 34 years, SD 13; $p < .001$).

Individuals with lower gross motor function (level 3-5) or a diagnosis of cerebral palsy were more likely to report mainly sedentary activity, with 83% falling into this category, in contrast to 23% of individuals with a diagnosis of Down syndrome.

Among those with epilepsy, 52 % reported predominantly sedentary activity, a higher proportion compared to active individuals. Although underweight was statistically associated with being less active ($p < .05$), the underweight variable comprised only 17 participants, potentially leading to unreliable results. Consequently, the “weight” variable was not included in the logistic regression analyses**.** No statistically significant differences were observed in terms of sex, level of intellectual disability, aberrant behaviour, or mental illness between groups with active or mainly sedentary levels.

Table 3: Sedentary vs. active levels of physical activity in association to demographics and health conditions in 213 participants. P-values below 0.05 are in bold.

	Total **N = 213 (100%)**	**Sedentary** **N = 78 (37%)**	**Active** **N = 135 (63%)**	**p-value**
Age Mean (SD)	36.1(13.9)	40.0 (15.1)	33.9 (12.7)	**0.002**
Median (IQR)	33 (24-47)	38 (28-51)	31 (24-44)	
Gender (%)				
men	119 (56)	38 (49)	80 (59)	
women	95 (44)	40 (51)	55 (41)	0.136
Level of intellectual disability (%) n204				
mild	82 (40)	28 (34)	54 (66)	
moderate	56 (28)	19 (34)	37 (66)	
severe/profound	66 (32)	28 (42)	38 (57)	0.510
Gross motor function				
level 1	122 (57)	27 (22)	95 (78)	
level 2	55 (26)	21 (38)	34 (62)	
level 3-5	36 (17)	30 (83)	6 (17)	**<0.001**
BMI, n = 194 mean (SD)	26.9 (6.3)	27.1 (6.1)	26.4 (6.7)	0.449
Living condition, n (%)				
Lives independently	25 (12)	7 (28)	18 (72)	
Lives with family	41 (19)	12 (29)	29 (71)	
Group home with care	147 (69)	59 (40)	88 (60)	0.281
Down syndrome	40 (19)	9 (22)	31 (78)	**0.040**
Autism diagnosis	47 (22)	15 (32)	32 (68)	0.477
Cerebral Palsy	24 (11)	20 (83)	4 (17)	**<0.001**
Weight (%) (n 194)				
Underweight	17 (9)	10 (59)	7 (41)	**0.018**
Normal	62 (32)	18 (29)	44 (71)	0.422
Overweight	60 (31)	18 (30)	42 (70)	0.553
Obese	55 (28)	18 (33)	37 (67)	0.961
Physical health conditions, n (%)				
Epilepsy	55 (25.8)	29 (52)	26 (47)	**0.003**
Allergies	68 (31.9)	22 (32)	46 (68)	0.320
Visual aids	92 (43.2)	34 (37)	58 (63)	0.965
Musculoskeletal disorders	53 (24.9)	20 (38)	33 (62)	0.846
Multi-morbidity, one physical diagnosis, n (%)	95 (44.6)	33 (35)	62 (65)	0.666
Multi-morbidity, two or more physical diagnosis, n (%)	117 (54.9)	44 (38)	73 (62)	0.666
Numbers of physical health conditions, mean (SD)	1.99 (1.7)	2.25 (1.8)	1.84 (1.6)	0.097

ABC-C, mean (SD)				
Irritability	5.02 (6.61)	5.43 (6.54)	4.79 (6.69)	0.360
Social withdrawal	3.34 (3.98)	3.08 (3.41)	3.32 (4.11)	0.745
Stereotypic behaviour	1.32 (2.30)	1.07 (1.84)	1.41 (2.50)	0.372
Hyperactivity/noncompliance	4.87 (6.47)	3.91 (5.37)	5.37 (6.97)	0.188
Inappropriate behaviour	1.53 (2.20)	1.36 (2.22)	1.62 (2.22)	0.334
MPAS-Check, mean (SD)				
Affective/neurotic	1.77 (3.46)	1.59 (3.13)	1.84 (3.63)	0.564
Organic condition	1.00 (1.75)	1.12 (1.68)	0.90 (1.71)	0.245
Psychotic	0.39 (0.84)	0.34 (0.80)	0.42 (0.86)	0.629

ABC-C = Aberrant Behaviour Checklist Community

MPAS (Check) = Moss Psychiatric Assessment Schedules (Check)

3.3 Barriers to physical activity participation

The most prevalent barrier hindering participation in physical activity was “not able to use public transport”, affecting a total of 62 participants (29%) (Table 3). Within this group, significant differences ($p < 0.05$) were noted between active participants (24% could not use public transport) and sedentary participants (39% could not use public transport). ‘No one to go with’ was a barrier for 28% of participants, while ‘Needs help but no one helps’ applied to 25% of them. In addition to ‘cannot use public transport’, the barriers that were statistically significant associations with being in the sedentary group included: ‘easily tired’, ‘health related issues’, ‘severity of the intellectual disability’, ‘no available day care centre activities’, and using a “wheelchair’. Furthermore, “no available exercise activities” was reported by 25% of those with a sedentary activity level, which represented a nearly statistically significantly higher proportion compared to the active group (15%) ($p = .075$). All barriers are presented in table 4 with association to physical activity participation and p-values.

Table 4: Sedentary versus active levels of physical activity in association to fifteen barriers for physical activity participation in 213 participants. Pearsons Chi Square test. P-values below 0.05 are in bold.

Barriers with decreasing prevalence	**Total**	**Sedentary (col%) (row%)**	**Active (col%) (row%)**	**p-value**
	N = 213 (100%)	**N = 78 (100%)**	**N = 135 (100%)**	
Cannot use public transport (n = 212)	62 (29)	30 (39)	32 (24)	**0.019**

Does not like to exercise (n = 210)	60 (28)	26 (35)	34 (25)	0.145
No one to go with (n = 211)	59 (28)	22 (29)	37 (27)	0.881
Easily tired (n = 212)	60 (28)	29 (38)	31 (23)	**0.022**
Health related issues (including obesity) (n = 212)	56 (26)	29 (38)	27 (20)	**0.005**
Needs help but no one helps (n = 211)	53 (25)	20 (26)	32 (24)	0.673
Severity of intellectual disability (n = 212)	45 (21)	25 (33)	20 (15)	**0.003**
No transport possibilities (n = 212)	36 (17)	9 (12)	27 (20)	0.121
No available exercise activities (n = 212)	40 (19)	19 (25)	20 (15)	0.075
No available activities at the day care centre (n = 212)	37 (17)	21 (27)	15 (11)	**0.003**
Wheelchair (n = 212)	36 (17)	31 (40)	5 (4)	**<0.001**
Not allowed (n = 211)	15 (7)	3 (4)	11 (8)	0.239
Not enough time (n = 212)	11 (5)	1 (1)	10 (7)	0.054
Not enough money (n = 212)	10 (4.7)	5 (7)	5 (4)	0.357
Age (n = 212)	9 (4.2)	2 (3)	7 (5)	0.369

In the multivariate logistic regression analyses exploring the associations between mainly sedentary activity and barriers, we incorporated adjustments for variables that were significantly associated with sedentary activity level ($p < 0.05$), in addition to level of intellectual disability. The variables included age, level of intellectual disability, gross motor function, epilepsy, and Down syndrome (Table 3).

Table 5 presents the association between the six barriers (selected based on statistical significance in cross-tabulation) and the sedentary activity level in both univariate (unadjusted) and multivariate analyses. Various combinations of covariates including age, level of intellectual disability, gross motor function, epilepsy, and Down syndrome, were included in the analyses. All six barriers remained significantly associated with sedentary activity level when adjusted for age and level of intellectual disability. Moreover, incorporating epilepsy or Down syndrome as additional control variables did not disrupt the significant associations. However, when adjusting for low gross motor function, the association between barriers and sedentary activity became non-significant in three out of the six analyses. An important exception was observed with the barrier ‘No available activities at the day care centre’, which maintained a robust association with physical activity levels (unadjusted OR 3.0, 95% CI 1.44-6.25). In addition, the use of a wheelchair had the highest odds ratio, 17.5 (95% CI 6.43-47.76), with minimal changes observed when introducing the adjustment variables.

Table 5: Binary logistic regression analyses of sedentary activity level as dependent variable in association to barriers for participation in physical activity. Barriers significantly associated with sedentary/active in crosstab analysis were included. Results are shown unadjusted and with different combinations of adjusted variables.

Barriers and adjustment variables	**p-value for the barrier**	**Odds ratio Exp(B)**	**95% confidence intervals**	**Nagelkerke R squared**
Cannot use public transport (n = 212)	**0.020**	2.06	1.12-3.77	0.04
Age, ID, and epilepsy	**0.031**	2.08	1.07-4.04	0.15
Age, ID, and Down syndrome	**0.046**	1.93	1.01-3.68	0.11
Age, ID and GMFCS	0.122	1.75	0.86-3.54	0.27
Easily tired (n = 212)	**0.023**	2.03	1.10-3.70	
Age, ID, and epilepsy	**0.036**	2.06	1.05-4.05	0.15
Age, ID, and Dows syndrome	**0.032**	2.06	1.06-3.98	0.11
Age, ID and GMFCS	0.203	1.59	0.78-3.23	0.26
Health related issues (including obesity) (n = 212)	**0.006**	2.42	1.29-4.51	0.05
Age, ID, and epilepsy	**0.018**	2.31	1.16-4.61	0.16
Age, ID, and Down syndrome	**0.015**	2.29	1.18-4.47	0.12
Age, ID and GMFCS	0.339	1.44	0.68-3.03	0.26
Severity of the intellectual disability (n = 212)	**0.003**	2.76	1.41-5.42	0.06
Age, ID, and epilepsy	**0.007**	2.94	1.34-6.48	0.17
Age, ID, and Down syndrome	**0.012**	2.72	1.25-5.90	0.12
Age, ID and GMFCS	**0.008**	3.13	1.35-7.25	0.29

No available activities at the day care centre (n = 212)	**0.003**	3.00	1.44-6.25	
Age, ID, and epilepsy	**0.008**	3.12	1.35-7.20	0.17
Age, ID, and Down syndrome	**0.018**	2.68	1.19-6.05	0.12
Age, ID and GMFCS	**0.011**	3.20	1.30-7.61	0.29
Wheelchair/mobility impairment (n = 212)	**<0.001**	17.52	6.43-47.76	0.27
Age, ID, and epilepsy	**<0.001**	15.65	5.52-44.42	0.33
Age, ID, and Down syndrome	**<0.001**	16.02	5.54-46.34	0.30
Age, ID and GMFCS	**0.002**	8.07	2.18-29.96	0.31

ID = intellectual disability

4 Discussion

The primary objective of this study was to investigate the associations between mainly sedentary activity and barriers to physical activity participation while considering factors such as age, sex, living situation, and health condition. Specifically, we aimed to identify barriers significantly associated with sedentary activity within the population with intellectual disability, adjusted for physical activity correlates. Our study findings revealed that approximately one third of the study population primarily engaged in sedentary activities in both daytime and leisure settings. In multivariable analyses, the three barriers hindering physical activity participation was related to wheelchair use, absence of available activities at day activity centres and severity of the intellectual disability. Importantly, these barriers were significantly associated with a higher level of sedentary activity, even after adjusting for age, intellectual disability, health conditions and gross motor function.

The absence of available activities at day activity centres was a barrier that was significantly associated with sedentary activities. This finding has been reported in other studies that investigated physical activity participation in group homes or day activity centres (Laxton et al., 2023). In a study measuring the levels of sedentary behaviour in a population with intellectual disability, longer periods of sedentary time were observed during the daytime (Harris et al., 2019). As many individuals with intellectual disabilities spend most of their time during the day in day-activity centres, developing community-based interventions for physical activity in day-activity centres can provide an opportunity to reduce sedentary behaviour.

Another frequently reported barrier to participation in physical activity was the inability to use public transportation. Park and Chowdhury (2022) investigated the use of public transportation by disabled individuals in New Zealand. In this study, 2% of the participants had an intellectual disability, which can be interpreted as if those with intellectual disabilities being less frequent users of public transport in a disabled population. Transport difficulties have been identified as a barrier in several other studies as well (Dixon-Ibarra et al., 2017; Mahy et al., 2010; Michalsen et al., 2020). Thus, there may be a need to organise specially arranged transport systems. Furthermore, governments must ensure accessibility and that public transport meets inclusive design guidelines and standards (Park & Chowdhury, 2022).

Article 30 of the 2006 Convention on the Rights of Persons with Disabilities (CRPD) states that people with disabilities have the right to be included in all cultural life, recreation, leisure, and sports activities. They have the right to be encouraged to participate and opportunities to organise, develop, and participate in disability-specific sports and recreational activities. They should ensure access to all services provided within the community. Nevertheless, many individuals with intellectual disabilities in Norway are not offered these adjustments, as they are not part of Norwegian legislation on human rights. In the current study, the barrier ‘wheelchair’ was significantly related to doing mainly sedentary activities, indicating that having mobility problems and using a wheelchair are hindrances to physical activity participation, which would be a direct contradiction to CRPD. Physical mobility problems have consistently emerged as the primary barrier to participation in physical activity (Ascondo et al., 2023; Cartwright et al., 2017; Jacinto et al., 2021; Vancampfort et al., 2022). There is a noticeable scarcity of physical activity interventions tailored to individuals with intellectual disabilities who use wheelchairs (Hassan et al., 2019) compared with those with intellectual disabilities but without mobility problems.

The findings indicate a reported sedentary behaviour in 35% of the study population, which is lower than the level reported by other cross-sectional studies using self-reported physical activity measurements for individuals with intellectual disabilities (Melville et al., 2018). Furthermore, our results indicate that individuals with intellectual disabilities have sedentary behaviour comparable to those observed in the general population, where approximately 36% engage in mainly sedentary activities (Loyen et al., 2017).

However, when comparing levels of moderate-to-vigorous physical activity between the study and the general population, there is a possible discrepancy between the two populations. In the current study, 11% of the study population reported engaging in regular moderate or vigorous physical activity. In a representative urban Norwegian population, 28% of participants reported this level of physical activity in 2016, referred to as the proportion engaging in exercise (Morseth & Hopstock, 2020). The study participants were young with a median age of 33 years. Increasing the levels of physical activity with higher intensities yield numerous health benefits, such as increased cardiovascular and muscular capacity (Sun et al., 2022), and a reduction in the burden of chronic diseases (Dodd & Shields, 2005).

The health benefits, development of physical activity interventions and surveillance of physical activity levels are well documented in the general population but lacking for the population with disability (Martin Ginis et al., 2021). This study adds to the knowledge gap regarding reported physical activity levels in the northern population of individuals with intellectual disabilities. Further research on physical activity levels, benefits, and facilitators needs to be conducted to develop effective interventions and secure long-term changes in physical activity levels.

The analysis did not find any correlation between sedentary behaviour and mental health problems as measured by the MPAS or ABC-C. Previous research has shown a strong relationship between sedentary behaviour and impaired mental health (Hamer et al., 2014; Harris et al., 2018), arguing that sedentary behaviour causes reduced metabolic activity, which can lead to an increased risk of mental health problems. In addition, sedentary behaviour may hinder the development of social interactions and networks. The findings of the present study do not support those of previous studies, although mental health screening (MPAS) may have underestimated the social components of mental health.

3.5 Strength and limitations

The current study had several limitations. First, the study does not include an objective physical activity measurement. In most studies conducted on sedentary behaviour, recommendations for future research focus on obtaining precise estimates of sedentary behaviour and recognising specific groups in need of intervention. However, the current study employed a well-known questionnaire presented in an interview setting, also used in both previous studies in adults with intellectual disability (ref), and repeatedly in Norwegian population studies (Morseth, Hopstock). There is a lack of evidence of physical activity behaviour in the intellectually disabled population, specifically in the Nordic region. Proxy-reported measures are more readily available and provide accurate information on physical activity behaviour when investigating whether individuals with intellectual disabilities are active or inactive (Dairo et al., 2017). Although more challenging (Michalsen et al., 2023), future population-based studies of adults with intellectual disability should aim to use objective methods in addition to proxy reports. Another possible limitation is the multiple comparisons without Bonferroni correction to control for the overall probability of a Type 1 error (false-positive result). However, this may not be an objection as the final analysis was a multivariate logistic regression analysis with adjustment for other possible predictors. Others argue that not adjusting for multiple comparisons is preferable (Rothman, 1990).

The study population was limited as it included a selected number of municipalities in the northern and middle regions of Norway. In the current study, the included participants were younger than the excluded participants and nonparticipants. This is due to a selection bias in the recruitment of participants. Thus, the study population is not representative of individuals with intellectual disabilities in the study region, and other barriers may be more relevant in older populations. Also, living conditions and the organisation of services varies between countries and future studies in other regions may yield different results.

A strength of this study is the community- based design. An additional strength is the availability of information on health conditions and levels of intellectual disability, with the possibility of adjusting for the association between barriers and activity levels.

5 Conclusions

This study highlights various barriers to participation in physical activity among individuals with intellectual disabilities. Identifying these barriers is important to inform future health interventions for this population. Specifically, there is a growing need to enhance physical activity opportunities within day-activity centres, tailor programs for wheelchair users, and improve access to physical activity facilities.

6 References

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Supplementary file 1

Table S1: Levels of physical activity and participants characteristics in 213 participants

	TOTAL N = 213	Sedentary (%) N = 78 (36.4)	Light activity (%) N = 112 (52.6)	Moderate activity (%) N = 15 (7)	Vigorous activity (%) N = 8 (3.7)	Total p
Age Mean (SD)	**36.1**	**40.0 (15.1)**	**35.2 (13)**	**27.2 (9)**	**28.5 (7.9)**	
Median (IQR)		**38 (28-51)**	**31 (24-45)**	**24 (20-32)**	**26.5 (24-32)**	<0.001
Gender (%)						
Men	119 (56)	38 (32)	64 (54)	11 (9)	5 (4)	
Women	95 (44)	40 (42)	48 (51)	4 (4)	3 (3)	0.210
Level of intellectual disability (%)						
Mild	82 (38)	28 (34)	42 (51)	7 (8.5)	5 (6)	
Moderate	56 (26)	19 (34)	30 (54)	5 (9)	2 (3)	
Severe/profound	26 (12)	28 (42)	34 (52)	3 (5)	1 (1)	0.736
Gross motor function						
level 1	123 (57)	27 (22)	76 (62)	11 (9)	8 (6.6)	
level 2	55 (26)	21 (38)	31 (56)	3 (6)	0 (0)	
level 3-5	36 (18)	30 (83)	5 (14)	1 (3)	0 (0)	**<0.001**
BMI mean (SD)	26.9	26.4 (6.8)	27.1 (5.8)	27.3 (6.9)	27.5 (9)	
median (IQR)		25.9 (21-32)	26.6 (23-30)	25.7 (24-30)	24.7 (23-29)	0.952
Living condition, n (%)						
Lives independently	25 (12)	7 (28)	12 (48)	3 (12)	3 (12)	
Lives with family	43 (20)	12 (29)	23 (56)	5 (20)	1 (2)	
Group home with care	146 (68)	59 (40)	77 (52)	7 (5)	4 (3)	0.107
Down syndrome	40 (19)	9 (23)	25 (63)	3 (7)	3 (7)	0.141
Autism diagnosis	48 (22)	15 (32)	26 (55)	5 (11)	1 (2)	0.591
Cerebral Palsy	24 (11)	20 (83)	4 (17)	0 (0)	0 (0)	**<0.001**
Weight, n (%)						
Underweight	18 (8)	10 (59)	6 (35)	1 (6)	0 (0)	
Normal	62 (29)	18 (29)	34 (55)	5 (8)	5 (8)	
Overweight	60 (28)	18 (30)	36 (60)	5 (8)	1 (2)	
Obese	55 (26)	19 (33)	31 (56)	4 (7)	2 (4)	0.396
Physical health conditions, n (%)						
Epilepsy	55 (26)	29 (52)	22 (40)	2 (4)	2 (4)	**0.028**
Allergies	69 (32)	22 (32)	40 (59)	4 (6)	2 (3)	0.578
Visual aids	92 (43)	34 (37)	46 (50)	7 (8)	5 (5)	0.699
Musculoskeletal disorders	53 (25)	20 (38)	28 (53)	4(7)	1 (2)	0.872
Multimorbidity, one physical diagnosis, n (%)	95 (44)	33 (35)	49 (52)	8 (8)	5 (5)	0.654

Multimorbidity, two or more physical diagnosis, n (%)	118 (55)	44 (38)	63 (54)	7 (6)	3 (3)	0.654
Numbers of physical health conditions, median (IQR or range)		2.25 (1.8)	1.93 (1.6)	1.53 (1.4)	1.25 (1.2)	0.210
Aberrant Behavior Checklist - Community	5 (6.5)	5.5 (6)	5 (7)	2.6 (4)	3.3 (3.6)	0.429
Irritability	3 (4)	3 (3)	3.5 (4)	3 (3.5)	1.4 (1.5)	0.676
Social withdrawal	1 (2)	1 (2)	1.5 (2.5)	1.2 (2)	-	0.123
Stereotypic behavior	5 (6)	4 (5)	5.5 (7)	3.5 (4)	4 (5)	0.603
Hyperactivity	1.5 (2)	1.2 ()	1.5 (2)	2 (3)	1 (1)	0.646
Inappropriate behavior						

Appendix

Appendix I – Interview guides for the focus groups and individual interviews in paper I

Appendix II – The interview guide used in the qualitative interviews from the pilot study of paper II

Overview over formal documents

Formal documents are not included in the appendices. They can be sent to the evaluation committee if required.

The formal document include:

1. Decision from the Reginal Committee for Heath Ethics for studies in paper I and II
2. Information and consent form for the qualitative study of paper I
3. Information and consent form for the mixed methods pilot study of paper II
4. Decision from data protection officer at the University Hospital of North Norway for the studies of paper I and II
5. Decision from the Reginal Committee for Heath Ethics for the NOHID-study of paper III
6. Information and consent form for the NOHID-study of paper III

Appendix I

Interview guides for the focus groups and individual interviews in paper I

Theme	**Question**	**Comments/reflections**
Introduction to focus group interview with parents or guardians	• *Present the framework for the interview. Tell about the project and what the purpose of the interview is.* • Can you tell us a little bit about who you are? • Can you tell us a little about why you want to participate in this study? • Can you tell us a little about your son/daughter/sibling?	Overview of the group
Physical activity	• Can you describe a normal day for your son/daughter/sibling? • How much physical activity does your daughter/son/sibling do on a daily basis? (number of hours per week) • What kind of physical activity is she/he involved in?	Mapping the level of physical activity
Barriers/Resources	• What do you think may be the reason why your son/daughter is little involved in physical activity? • *If a lot* – What do you think has been important for your son/daughter being so physically active? • What can be an obstacle to participation in physical activity?	Identify barriers to participation in physical activity Map resources and sustaining factors for participation in physical activity
Preferences	• What does your daughter/son/sibling like to do when he/she is physically active? • What do your son/daughter/sibling like to do? Why is this particularly fun, engaging, pleasurable? • Can this activity/these activities in some way contribute to promoting a more active everyday life? If so, in what way?	Identify preferences. Obtain fields of interest that can influence/influence the level of physical activity.
Perception of mastery and motivation for participation in physical activity	• What is your son/daughter/sibling good at? • How does your son/daughter/sibling experience participation in physical activity? • What do you think is good motivation for participation in physical activities for your son/daughter/sibling?	Bring out experiences of mastery in physical activity. What can give a sense of mastery for participation in physical activities and what can impair mastery. What is motivation to be physically active.

	• When do you experience that your son/daughter/sibling feels a sense of mastery in connection with physical activity? • What do you think can increase the mastery of physical activity in your son/daughter/sibling? • In what context do you think that mastery is not achieved in connection with physical activity?	
Using technology in everyday life	• How are technological tools (iPad, PC, mobile) used in everyday life in your home/together with your son/daughter/sibling? • How do you or your son/daughter/sibling relate to using mobile phones in everyday life? • How do you think the use of technological tools (mobile) will work in the context of physical activity?	
Ending	• Is there anything we haven't touched on, but that you think is important to highlight when it comes to facilitating physical activity for this group?	Inform and invite further participation in workshops

Theme	**Question**	**Comments/reflections**
Introduction to focus group interviews with service providers	• Can you tell us a little about who you are and why you want to participate in this study? • What role do you have in relation to people with intellectual disabilities?	Present a framework for interviews. Get an overview of the group and their connection to people with intellectual disabilities.
Physical activity	• How would you describe a normal day for the users (individuals with intellectual disability)? • What physical activities are they involved in and how much of the day/week are they physically active?	Map the level of physical activity in everyday life
Barriers to participation in physical activity	• What do you think is the reason why physical activity levels are low? (If high – why is the activity level high?) • What do you perceive as barriers (and opportunities) to participation in physical activity?	Identify barriers to participation in physical activity in everyday life
Sustaining factors for low levels of physical activity and possible factors that may contribute to change	• What can you and others do to overcome these barriers? • Are there leisure physical activities you miss?	Identify factors of change
Promote resources for physical activity	• What do you think is needed to increase the level of physical activity?	Bring out resources in the person/user and in the municipal services
Motivation for participation and ways service providers can influence motivation	• What offers for participation in physical activity do you think would be ideal for users? • How do you think motivation for physical activity can be promoted? • In what way can you, as healthcare personnel, help increase motivation for physical activity? How can you help change their level of physical activity?	Identify motivating factors for participation in physical activity
Use of technological tools	• How are technological tools used in collaboration with person/user? • How is mobile phones used for persons/users in everyday life? • Do you see any challenges/barriers with using technology to promote physical activity?	Mapping the use of technological tools in everyday life

Appendix II

The interview guide used in the qualitative interviews from the pilot study of paper II

Interview Guide Part 1

Theme	Question	Comments/reflections
Introduction to interview	• *Brief introduction about the focus of the study and what the interview will be about:* *Experiences from participation, use of apps and activity trackers* • *Tell the subject a little about why we want to learn more about this*	Lessons learned from the pilot
Active Leisure app	• How have you experienced using the Active Leisure app? • What has been great about the app and what can make it even better? • How do you think the use of Active Leisure has worked over a long period of time (did you use the calendar as much at the beginning as towards the end of the pilot)? • Can you say something about whether you managed to complete the planned activities in the Active Leisure app?	Mapping experiences with the Active Leisure app
Student app	• What has it been like using the Sorterius app? • What has been great about the app and what can make it even better? • Can you say something about whether Sorterius affected the level of physical activity?	Mapping experiences from student apps
Fitbit and Axivity	• What has it been like for (participant) to use the Fitbit watch? • What has been great about the activity tracker and what can make it even better? • What has it been like using the Axivity? • What has been great about using the activity tracker and what can make it even better? • What motivated you to wear your watch(es) over several weeks? • Is there anything about the watches you wish were different (some may want to see their steps, for example)? • Can you say something about whether the clock made you more motivated to be active (some motivated by being measured)?	Feedback on the use of activity trackers from the pilot
Experience	• What do you think it has been like to participate in this study?	Experience of participating in the study. Opportunities

	• Do you have any input on how we can make it better for (participant) or you to participate in a new study later?	for improvement to a possible later RCT.

Interview Guide Part 2

Theme	**Question**	**Comments/reflections**
Use of technology	• *Introduction: in this part of the interview we want to investigate how (participant) and you / you have experienced the use of technology in connection with physical activity. We want to learn more about how we can use technology to motivate, facilitate, inspire the surrounding environment and ultimately increase the level of physical activity.* • Can you tell us how the technology has been used in specific physical activities?	Investigate how the apps in the study have affected the level of physical activity. Obtain individual characteristics that can affect your level of physical activity
Motivation	• Can you say something about whether the use of technology has had an impact on the participants' motivation for physical activity? • Or are there completely different factors that promote motivation in the participants, and if so, what is it all about?	Reflection on motivating factors for physical activity and how they can be affected
Barriers	• Can you give examples of barriers to physical activity among participants? • Can technology or other measures help break down these barriers? • What could be the reason why (participant) has not participated in the activities that have been in the calendar of the (participant)?	The interviewee's thoughts on the challenges that have arisen along the way and suggestions for how they can be solved
The surrounding environment	• What has it been like for you as employees/parents to follow up participants in this study? • What do you think are the biggest challenges with the environment around (participant) to be able to use such tools (apps) in connection with physical activity?	Get a handle on how the environment affects participation in physical activity, use of the technology and participation in the research project