Physical activity and fitness in older adults with intellectual disabilities

Lichamelijke activiteit en fitheid bij ouderen met een verstandelijke beperking

Thessa Hilgenkamp

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Chapter 1

General Introduction

WHY STUDY THE POPULATION WITH AN INTELLECTUAL DISABILITY?

Intellectual disability is "a disability characterized by significant limitations both in intellectual functioning and in adaptive behavior, which covers many everyday social and practical skills", according to the American Association of Intellectual and Developmental Disabilities. In the Netherlands in 2009, around 160,000 people in the Netherlands had an intellectual disability (ID) and were registered nationally to receive extra support or care in some form [1]. Although this is only 1 percent of the total Dutch population, health care costs for this group were 6.8 billion euro in 2009 [1], which is around 11 percent of the total Dutch health care costs of that year. This means not only that this group is the most expensive diagnosis group of about 100 distinctly described diagnosis groups in the Netherlands [2], it also underlines the importance of more insight into the underlying causes of these high health care costs, as well as into future developments.

INCREASE OF THE OLDER POPULATION WITH INTELLECTUAL DISABILITIES

Both the numbers of registered people with ID and their health care costs are still growing, due to larger absolute numbers of the Dutch population, an increased registration of adolescents and younger adults with mild and borderline ID and behavioral problems, and the longer life expectancy of adults with ID due to improved health care [3]. Furthermore, the percentage of adults aged 55 years and over increased from 20.2% of the total registered population with ID in 2007 to 21.1% in 2008, while the largest age category of 26-54 years decreased from 44.9 to 42.8% in the same period. The people in this largest age category will shift towards the oldest age category in the next few decades, which suggests an ongoing ageing effect in the population with ID [1]. For these reasons, the number of older adults with ID is likely to grow further in the next decades. The increased life expectancy represents the success of improved care, as well as a new challenge for care services [4]. Although there always has been a group of older adults with mild and borderline ID, the increasing older population with moderate and severe ID is relatively new, and much is unknown about their health and needs in health care and support.

HEALTH IN OLDER ADULTS WITH INTELLECTUAL DISABILITIES

In the general population, ageing goes hand in hand with a higher risk of chronic diseases, loss of functioning and increased need for support and care, but these effects can be prevented or delayed by a healthy lifestyle [5]. As adults with ID age, they experience the same physical changes and age-related chronic diseases as the general population. But in older adults with ID, this ageing process seems to be complicated by several reasons. First of all, older adults with ID often already have multiple health problems, sensory impairments and motor impairments [6-9]. Secondly, frequent use of anti-epileptic and psychotropic drugs in this population can cause a range of side-effects, posing a threat to healthy ageing [10]. These complex health issues are also hampered by difficulties in identifying and managing disease and physical disabilities in this group [11]. Furthermore, syndrome-specific ageing processes, such as those in Down syndrome or Prader Willi syndrome[12-13], pose an additional barrier to appropriate health care for older adults with ID.

All together this calls for "robust epidemiological and population-level observational data, to identify the prevalence of ageing adults with ID, to characterize their health status, and to determine their unique disease risks and trajectories" [14].

PHYSICAL ACTIVITY PROMOTION TO ENHANCE HEALTH

In the general older population, one way of preventing or delaying age-related physical changes and chronic diseases is by adhering to a healthy lifestyle, with physical activity as a major component [5,15]. The effects of physical activity on functioning, health and well-being have been demonstrated extensively in the general population [16], and being physically active continues to sort into old age [17]. As in other countries, promoting physical activity is one of the important themes in Dutch health promotion for the general older population, together with other activity-related themes, such as fall prevention [18].

Adults with intellectual disabilities however, are often reluctant or unable to participate in health promotion for the general population [19]. The body of literature on physical activity and fitness levels in adults with ID includes mainly younger adults, mostly with mild to moderate levels of ID, and has consistently shown low levels of physical activity and fitness [20-24]. This has led to initiatives to adapt health promotion to adults with intellectual disabilities [25]. The ageing population with ID has not been part of this focus yet.

To effectively deploy health promotion in older adults with ID, it is necessary to first investigate the current state of health in this population. Arguments to suspect health risks in this group have been summarised above, but previously, no study has objectively addressed health in a large and representative sample of older adults with ID. This first step can provide the much sought-after information about health risks, risk groups and possible gain of physical activity promotion.

NATIONAL DEVELOPMENTS AS INSTIGATORS OF THIS STUDY

In the Netherlands, the Advisory Committee on Health Research concluded in 2005 that research in the field of people with ID was scarce and that a research infrastructure had to be set up. This advice led to a call for grant proposals in 2006 under the theme 'Course and stages of life'. An additional demand was to form a consort, thus stimulating the set up of a research infrastructure including academic institutes as well as care services for people with ID. Considering the previously described worldwide developments regarding health issues in people with ID, and experiences with the new group of ageing adults in ID care services, a consort was founded, titled 'Healthy ageing and intellectual disabilities (HA-ID)'. Inspired by questions of the care organizations themselves (formulated by client panels and staff panels), three themes were chosen: 1. Physical activity and fitness, 2. Nutrition and nutritional state and 3. Mood and anxiety. The scientific aims of this project were:

a. To perform baseline assessments of prevalence rates and secondary health effects for each theme and to identify risk groups.

b. To assess mutual relationships between the themes and their underlying concepts.

c. To select and evaluate diagnostic tools to assess each theme.

To meet these aims, an observational cross-sectional design was chosen for this multi-centre research project. Also part of this project was an intervention study, aimed at improving physical activity in older adults with ID and investigating the effects of these improvements on physical fitness and health. The outcomes are currently being analysed and results will be published in another thesis.

In the current thesis, first results of the theme 'Physical activity and fitness' will be presented.

CONCEPTUAL FRAMEWORK

The conceptual model which served as an underlying framework for this study was a combination of the model of Bouchard et al. (1994) and of the ICF-model (2010) (Figure 1). Bouchard described the positive influence of physical activity on physical fitness and health, and vice versa [26], while the ICF model describes health and disability in terms of impact [27]. This study focused on the concepts of physical activity, fitness and activities of daily living, and the model illustrates the wider perspective in which these concepts operate.

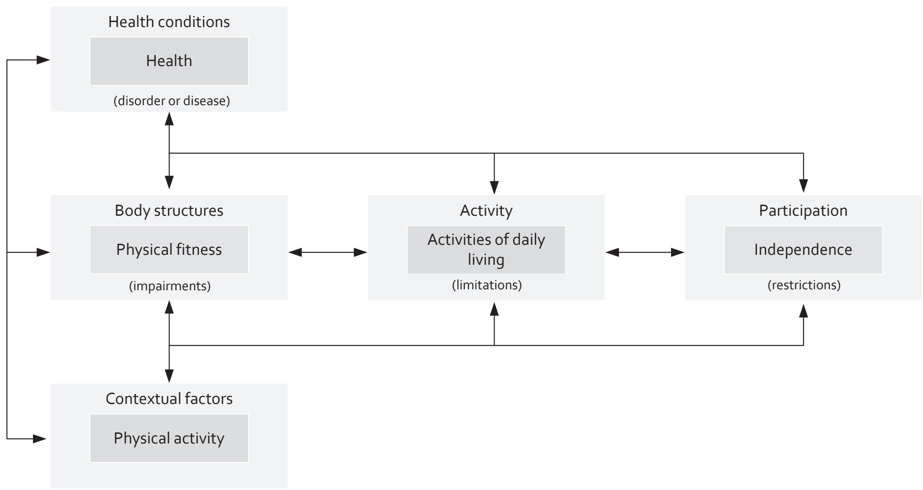

Figure 1 Model of Bouchard and the ICF model combined

CONTENTS OF THIS THESIS

This thesis starts with a description of the design of the total study, the informed consent procedure and a description of the HA-ID study population in Chapter 2.

The first concept which will be addressed is Physical activity. Physical activity has never been measured objectively before in older adults with ID. Chapter 3 describes how to apply and interpret measurements with pedometers in this group. Chapter 4 presents the results of these measurements: physical activity levels in older adults with ID in comparison with the general population, and describes factors associated with low physical activity.

The second concept is Physical fitness, which consists of multiple, interrelated fitness components, selected on the basis of relevance for the population of focus. Since physical fitness has not been measured in older adults with ID before, this study had to start by operationalizing the concept for this specific population. Secondly, available measures had to be searched for in the literature, and a structured selection was made of possibly suitable tests for this population. These steps are described in Chapter 5. Chapter 6 describes a pilot study in which we investigated the feasibility and reliability of this selection of tests in older adults with ID. After confirmation of both feasibility and reliability of all tests, they were deployed in the large study population of HA-ID. Feasibility for use in clinical practice could be studied in more detail with this large sample, and is described in Chapter 7. The results of four components of physical fitness are compared to those of the general population in Chapter 8. An assessment of factors associated with low physical fitness levels within the population of older adults with ID is presented in Chapter 9.

As described in the model above, physical activity and fitness are associated with daily functioning. The level of daily functioning and the impact of mobility, together with the level of ID, on specific activities of daily living are described in Chapter 10. The general discussion (Chapter 11) reflects on the results presented in this thesis, comment on the applicability of these results in clinical practice, and provide recommendations for future research.

REFERENCES

1. van der Kwartel A.J.J., *Brancherapport Gehandicaptenzorg VGN*, V.V.G. Nederland, Editor. 2011, Kiwa Prismant: Utrecht.
2. Poos M.J.J.C., Smit J.M., Groen J., et al., *Kosten van Ziekten in Nederland 2005: Zorg voor euro's – 8*. 2008, RIVM: Bilthoven.
3. Ras M., Woittiez I., van Kempen H., et al., *Steeds meer verstandelijk gehandicapten. Ontwikkelingen in vraag en gebruik van zorg voor verstandelijk gehandicapten 1998-2008*. 2010, SCP Sociaal Cultureel Planbureau: Den Haag.
4. McCallion P. and McCarron M., *Ageing and intellectual disabilities: a review of recent literature.* Current opinion in Psychiatry, 2004. **17**: p. 349-352.
5. de Groot L.C., Verheijden M.W., de Henauw S., et al., *Lifestyle, nutritional status, health, and mortality in elderly people across Europe: a review of the longitudinal results of the SENECA study.* J Gerontol A Biol Sci Med Sci, 2004. **59**(12): p. 1277-84.
6. van Schrojenstein Lantman-De Valk H.M., Metsemakers J.F., Haveman M.J., et al., *Health problems in people with intellectual disability in general practice: a comparative study.* Fam Pract, 2000. **17**(5): p. 405-7.
7. van Splunder J., Stilma J.S., Bernsen R.M., et al., *Prevalence of visual impairment in adults with intellectual disabilities in the Netherlands: cross-sectional study.* Eye, 2006. **20**(9): p. 1004-10.
8. Meuwese-Jongejeugd A., Vink M., van Zanten B., et al., *Prevalence of hearing loss in 1598 adults with an intellectual disability: cross-sectional population based study.* Int J Audiol, 2006. **45**(11): p. 660-9.
9. Cleaver S., Hunter D., and Ouellette-Kuntz H., *Physical mobility limitations in adults with intellectual disabilities: a systematic review.* J Intellect Disabil Res, 2009. **53**(2): p. 93-105.
10. Robertson J., Emerson E., Gregory N., et al., *Receipt of psychotropic medication by people with intellectual disability in residential settings.* J Intellect Disabil Res, 2000. **44 (Pt 6)**: p. 666-76.
11. Fisher K., *Health disparities and mental retardation.* J Nurs Scholarsh, 2004. **36**(1): p. 48-53.
12. Barnhart R.C. and Connolly B., *Aging and Down syndrome: implications for physical therapy.* Phys Ther, 2007. **87**(10): p. 1399-406.
13. Sinnema M., Maaskant M.A., van Schrojenstein Lantman-de Valk H.M., et al., *Physical health problems in adults with Prader-Willi syndrome.* Am J Med Genet A, 2011. **155A**(9): p. 2112-24.
14. Perkins E.A. and Moran J.A., *Aging adults with intellectual disabilities.* JAMA, 2010. **304**(1): p. 91-2.
15. Paterson D.H. and Warburton D.E., *Physical activity and functional limitations in older adults: a systematic review related to Canada's Physical Activity Guidelines.* Int J Behav Nutr Phys Act, 2010. **7**: p. 38.
16. DHHS, *Physical Activity Guidelines Advisory Committee Report*. 2008, U.S. Department of Health and Human Services, : Rockville (MD).

17. Chodzko-Zajko W.J., Proctor D.N., Fiatarone Singh M.A., et al., *American College of Sports Medicine position stand. Exercise and physical activity for older adults.* Med Sci Sports Exerc, 2009. **41**(7): p. 1510-30.
18. Harbers M.M. *Preventie gericht op ouderen samengevat.* Nationaal Kompas Volksgezondheid\Preventie\Gericht op doelgroepen\Ouderen 2009; Available from: http://www.nationaalkompas.nl/algemeen/menu-rechts/english/.
19. US Surgeon General, *Report: Closing the gap: A national blueprint for Improving the Health of Individuals with Mental Retardation.* 2002, Surgeon General's Conference on Health Disparities an Mental Retardation.
20. Temple V.A., Frey G.C., and Stanish H.I., *Physical activity of adults with mental retardation: review and research needs.* Am J Health Promot, 2006. **21**(1): p. 2-12.
21. Graham A. and Reid G., *Physical fitness of adults with an intellectual disability: a 13-year follow-up study.* Res Q Exerc Sport, 2000. **71**(2): p. 152-61.
22. Lahtinen U., Rintala P., and Malin A., *Physical performance of individuals with intellectual disability: a 30 year follow up.* Adapt Phys Activ Q, 2007. **24**(2): p. 125-43.
23. Carmeli E., Ayalon M., Barchad S., et al., *Isokinetic leg strength of institutionalized older adults with mental retardation with and without Down's syndrome.* J Strength Cond Res, 2002. **16**(2): p. 316-20.
24. Fernhall B., *Physical fitness and exercise training of individuals with mental retardation.* Med Sci Sports Exerc, 1993. **25**(4): p. 442-50.
25. Heller T., McCubbin J.A., Drum C., et al., *Physical Activity and Nutrition Health Promotion Interventions: What is Working for People With Intellectual Disabilities?* Intellect Dev Disabil, 2011. **49**(1): p. 26-36.
26. Bouchard C. and Shephard R.J., *Physical Activity, Fitness, and Health: The model and key concepts*, in *Physical Activity, Fitness and Health. International Proceedings and Consensus Statement*. 1994, Human Kinetics Publishers: Champaign.
27. *Towards a common language for functioning, disability and health: ICF The International Classification of Functioning, Disability and Health*. 2002, World Health Organization: Geneva, Switzerland.

Chapter 2

Study healthy ageing and intellectual disabilities: Recruitment and design

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ABSTRACT

Questions encountered in epidemiologic health research in older adults with intellectual disabilities (ID) are how to recruit a large-scale sample of participants and how to measure a range of health variables in such a group. This cross-sectional study into healthy ageing started with founding a consort of three large care providers with a total client population of 2322 clients of 50 years and over, and two academic institutes. This consort made formal agreements about a research infrastructure and chose three research themes: 1. Physical activity and fitness, 2. Nutrition and nutritional state, and 3. Mood and anxiety. Subsequently, preparation was started by carefully reviewing and selecting instruments to measure a wide set of health variables to answer the research questions. Specific demands of these instruments were that they could be executed efficiently and accurately on-site in a large sample of participants and that the burden of these measurements for participants as well as their caregivers was as minimal as possible. Then, preparation was continued by designing and executing a thorough communication plan for clients, legal representatives and staff of the care providers, preceding the informed consent procedure. In this plan, which had a top-down structure, specific attention was given to personally informing and motivating of key stakeholders: the professional caregivers. This preparation led to a recruitment of 1050 participants (45.2%) and to high participation rates in key parts of the assessment.
A detailed description is provided about the recruitment and organization and the selected instruments.

INTRODUCTION

Life expectancy of adults with intellectual disabilities (ID) is lengthening towards that of adults without intellectual disabilities, but daily practice indicates that this ageing is relatively often not a healthy ageing. With a higher risk of motor impairments, sensory impairments and epilepsy since earlier in life, these people are prone to develop multiple physical and mental comorbidities at older age [1-3]. 'Frail patients' (multiple diagnoses, complex medical routines, frequent hospitalisation, functional impairment) [4], requiring individualised managed care, are expected to be highly prevalent in this population. Furthermore, functional deterioration is frequent [5], leading to diagnostic and therapeutic uncertainty, transfers from community-based to central residential settings, and high costs.

With these risks in mind, three Dutch care organizations (Abrona, Huis ter Heide; Amarant,Tilburg; Ipse de Bruggen, Zwammerdam) and two academic departments (Intellectual Disability Medicine, Department of General Practice, Erasmus MC in Rotterdam; Center for Human Movement Sciences, UMCG, Groningen) intended to start a large-scale project to study health in older adults with intellectual disabilities in 2006. Inspired by questions of the care organizations themselves (formulated by client panels and staff panels), three themes were chosen: 1. Physical activity and fitness, 2. Nutrition and nutritional state, and 3. Mood and anxiety. These themes cover a substantial impact on health and quality of life and are supposed to have strong mutual relationships, but have hardly been studied in ageing people with ID. The scientific aims of this project were: a. To perform baseline assessments of prevalence rates and secondary health effects for each theme and to identify risk groups. b. To assess mutual relationships between the themes and their underlying concepts. c. To select and evaluate diagnostic tools to assess each theme.

To meet these aims, an observational cross-sectional design was chosen for this multi-centre research project. However, before such a study in this particular and complex target population could be executed, two major obstacles needed to be dealt with.

The first obstacle in the execution of such a study is caused by the specific living circumstances of older adults with ID. Many older adults with ID depend on a care system, involving family and professional caregivers. Lack of involvement, commitment and ultimately support by the care system can be an obstacle to the recruitment of a large, representative sample, as well as to participation in the assessments which would be a part of the study.

The second obstacle is how to measure a range of health characteristics in older adults with ID. In the general population, preventive health checks are used to collect data about certain health characteristics or risk factors, like the Canadian Study of Health and Aging [6], or the Cardiovascular Health Study [7]. This kind of screening is not applicable to the population of older adults with ID because self-report questionnaires, neuropsychological tests and often physical tests may require a certain level of cognitive and physical abilities which may not be compatible with that of older adults with ID.

Because of such barriers, most published epidemiological research in adults with ID is based on existing (medical) records or registries, or observations of professional caregivers [8-13]. With this method, underrecognition of certain health problems or risk factors is to be expected [14], due to communication difficulties of the participants and lack of suitable diagnostic instruments. Another solution is to limit the number of participants, [15]. With this solution, extrapolation of the results is hampered since the number of participants is often limited or narrowed by strict exclusion criteria, thus often underestimating the actual problems in this group [16].

This gives rise to the following research question: How to successfully measure health in older adults with intellectual disabilities in a large, representative sample?

MATERIALS AND METHODS

Before starting the actual study, measures were taken to ensure optimal circumstances for executing a large-scale study. Therefore, the formation of a consort and description of the base population will be presented first. The method section then proceeds with a detailed description of the selection of instruments and organization of measurements, after which the standard informed consent procedure is described. Subsequently, extra activities undertaken to optimize recruitment will be described, such as extra activities in communication and consent procedures. Inclusion, representativeness and participation are described as main outcome measures.

Founding a consort

Former research has shown the importance of cooperation and commitment of different management levels to provide the necessary conditions for a successful execution of a large-scale study in the field [17-19]. For this reason, three large care providers and two academic departments joined together in a consort, and preparation of a first large-scale study was started at CEO level in 2006. Formal agreements were made about financing and grant acquisition, responsibilities, communication, project management and infrastructure, involvement of clients and client representatives. Agreement was reached on the following aims of the consort: 1. to increase knowledge on healthy ageing in intellectual disability by means of scientific research,

2. to increase the scientific attitude of staff of care providers by means of participation in research and continuous education, 3. innovation of care by means of implementation of research outcomes. In the preparatory phase and during the execution of the study, the consort discussed about policy, practical issues, results and future directions on three management levels: CEO-level, level of the boards of directors, and middle-management level, to ensure embedding of and commitment to this project.

The members of this consort cooperated in obtaining a governmental grant for this first research project (granted by the Netherlands Organisation for Health Research and Development, 2007, nr. 57000003).

Base population

The three involved care providers in the consort mentioned above provided financial and organizational support and gave access to a large population of older adults with intellectual disabilities receiving any type of care or support from these care organizations.

The care organizations are geographically located in different regions of the Netherlands, both in urban and rural areas and all provide care to a broad spectrum of clients, varying in level of intellectual disability, mobility and living arrangements and all including different care settings: central residential settings, community-based homes, day activity centers and supported living. Together they provide care for 8550 persons with intellectual disabilities, which is approximately 10% of the total Dutch client population of specialized care providers [20]. The distribution of clients primarily receiving care (35%) and clients primarily receiving support (65%) is similar as that in the total Dutch client population with ID [20]. Furthermore, the percentage of older adults (50 years and over) in their client population (10%) is similar to that in the total Dutch population with ID [20]. We therefore consider this base population to be representative for the total Dutch client population of older adults with intellectual disabilities.

Materials

The selection of diagnostic methods had to be performed with great care. A detailed description of the selection process of instruments within each subtheme stretches too far for this paper, but has been published elsewhere [21-22].

In general, reliability, validity and feasibility in this specific population were important criteria in the selection of instruments.

As far as feasibility is concerned, the instruments had to be applicable in large-scale research, which means they had to be not too time-consuming and suitable for a large part of this heterogeneous population. Where possible, instruments which were also used in the general (older) population were chosen. This enables comparison between this specific population of older adults with intellectual disabilities and the general population. Furthermore, they had to be executable by a large group of professionals, without high risks of differences between test observers. Due to the on-site nature of the assessments, instruments had to be ambulatory available, and if possible, non-invasive. The costs of the instruments were also an important factor, considering future use in clinical practice.

For the physical fitness tests and the instruments measuring anxiety and depression, a literature search and evaluation of the retrieved instruments did not result in a definite evidence-based choice for an instrument. Expert meetings were used to incorporate the clinical experience of scientific and care professionals in the final choice. In some cases English instruments had to be translated into Dutch and tested for feasibility and reliability, for example the questionnaires for anxiety and for eating disorders. A pilot study in November 2008 was used to evaluate those instruments, as well as the feasibility of the entire set of instruments.

The definite selection of instruments is presented in the Appendix, with a distinction between measurements requiring active involvement of the participant and measurements without active involvement of the participant.

Procedure

The large-scale nature of an epidemiological study puts three specific demands on the organization of measurements. The organization needs to be efficient, the measures need to be executed accurately and the burden of these measurements for participants as well as their caregivers needs to be as minimal as possible. The burden for participants and their caregivers was considered a central factor in designing the organization of measurements. The feasibility of this organization was also tested in the pilot study and led to minor adjustments in the instruments and organization.

To complete all assessments efficiently, and to comply with one of the aims of the consort as well, the measurements needed to be executed by groups of test administrators, consisting of professionals of the involved care providers. To enhance their commitment and to optimise the organization, they were informed and consulted in an early stage of the study. Their preferences considering planning and location were followed as much as possible, and interference with existing (medical) routines was avoided as much as possible. To enhance efficiency even further, the particularly time-consuming diagnostic process of psychiatric disorders (through expert interviews) was replaced by a two-step model, with a screening for all participants by self-report or informant-report questionnaires, and only a diagnostic interview for those participants who scored above cut-off points on the questionnaires. Cognitive, social and emotional capabilities determined if a participant could be assessed by self-report questionnaires, administered by a trained test assistant in a screening interview. To ensure accurate administration of the assessments in this large group of test administrators, they were all trained by the researchers themselves or external experts and regularly checked on correct test assessment and scoring during the entire duration of the study.

Professional caregivers of the clients were informed in an early stage of the study, even before the consent procedure had been started. After consent, involved caregivers were consulted about their preferences and suggestions for the organization of the measurement, to increase their collaboration during the assessments. These preferences were used as input for the final schedule of measurements for individual participants. Involvement and cooperation was thus managed by careful communication and organization.

In order to enhance participation during the assessments, we needed to keep the impact for participants and caregivers as low as possible. All diagnostic assessments needed to be organised at settings nearby participants, preferably locations they were familiar with. Furthermore, all assessments needed to be carried out by trained professionals of the health care organizations themselves, who were familiar to most of the participants. We decided that to decrease the burden of participation even further, all assessments needed to be concentrated in a period of two weeks for a participant, and all participants of the same living facility needed to be clustered together in the same two weeks, to decrease the impact for the involved professional caregivers too. The assessment consisted of parts where active involvement of the participant was necessary (i.e. physical examination) and of parts with no need of active involvement of the participant (i.e. questionnaires for professional caregivers), and the advice of the professional caregiver was followed concerning what parts were too stressful for a specific client.

In these two weeks, the emphasis of the assessment was on the first day, with a physical examination and a physical fitness test for the participants, and questionnaires to be completed by the professional caregivers. In the following two weeks the participants carried a pedometer and an accelerometer, and had appointments for a mealtime observation of swallowing and a short interview structured by self-report questionnaires about anxiety and mood and, if consented to, a venipuncture. Only when a participant scored above cut-off points in this screening for anxiety and/or depression, an in-depth diagnostic interview by trained behavioral therapists with client and/or a professional caregiver took place (all assessments described in more detail in the Appendix).

After the assessment on the first day, the participant received a medal, and after the whole two weeks, each participant received a certificate of participation. The professional caregiver received a report with a summary of the results of the assessment, with advice whether to consult a physician or behavioral therapist or not.

Standard informed consent procedure

We aimed to include all clients aged 50 years or older receiving care or support by one of the three health care organizations (at the 1st of September 2008). No other exclusion criteria were applied. This selection method is likely to result in a very heterogeneous cohort with regard to etiology and disabilities, reflecting the heterogeneity in the actual population of older adults with intellectual disabilities. All eligible clients were invited to participate from November 2008 to July 2010.

Separate consent procedures were followed for clients who were capable of understanding the available information and deciding themselves to participate or not in this research project, and clients who were not capable of doing so. In some health care organizations this distinction was already available from their databases, in others we sought advice from the involved behavioral therapists in this matter, following the guidelines of WGBO [23], the Dutch law that provides in rights and obligations between patient and health care professionals.

For clients who could make their own decision regarding consent for participation, information consisted of an introductory letter, an information booklet and a consent form, all with adjusted texts and pictograms to be easily readable. For clients who were not able to make this decision themselves, their legal representatives were approached, again with an introductory letter, an information booklet and a consent form. In case of doubt or unavailable information about the capability of the clients to decide for themselves, we first approached the legal representatives, giving them the possibility to forward this decision to the clients.

The study would not interfere with routine medical practice. Ethical approval was obtained (number 2008-234) from the Ethics Committee of the Erasmus University Medical Center. The study followed the guidelines of the Declaration of Helsinki [24].

Optimizing recruitment

- Extra feature in the organizational structure is that this study was executed by PhD students, who were each employed by one of the health care organizations. This resulted in further strengthening of the connection between research and daily practice and at the same time complying with one of the requirements of the grant organization.
- A time period of around six months was reserved for the communication and practical preparation of the measurements. Extra efforts were made to design a detailed communication plan. Previous projects have shown that the success of a study in ID care depends on the commitment of the professionals in the participat-

ing health care organization [25]. Informing and motivating all involved professionals as well as different management levels is essential. Furthermore, information should be adapted to the particular professionals who are informed, for example management versus professional caregivers. Within the three health care organizations, a top-down information route was applied, from top management to the teams of professional caregivers, and this route was extended horizontally to the local ethical committees and client councils. Preceding the study, routine meetings of these groups were used to provide oral and written information. Only after this information route was fully completed, including the level of the professional caregivers, the consent procedure was started.

- Local ethical committees and boards of clients and client representatives of the three involved care organizations were informed as well and they formally consented to this research project. This created support on different levels of the involved care organizations.
- The invitations to the participants were sent in sequential batches, to limit the time between consent and assessment and therewith minimize the loss of participants due to lack of motivation.
- Extra efforts were made to receive responses of all invited participants. Telephone calls were made to announce the sending of the consent materials, and if not returned in time, telephone reminders were made to obtain the missing consent forms. This offered the opportunity to clients and/or their caregiver to ask remaining questions about the study.
- The consent procedure was accompanied by extra information about the possibility to exclude measurements which were too stressful for a specific participant. This took away expected concerns of legal representatives and/or professional caregivers and was therefore an important extra activity in the consent procedure: After consent, intellectual or physical disabilities of various levels were taken into consideration in the actual participation in different parts of the assessment. Furthermore, the advice of the professional caregiver was to be followed concerning which parts of the assessment would be too stressful or not possible to execute for a specific client and thus be omitted. At all times unusual resistance to (parts of) the assessment by the client was leading [26].

Outcomes

Inclusion

Numbers of clients in the different phases in the consent procedure will be presented, with a detailed description of non-participants.

Table 1: ZZP Classifications ID care [27]

ZZP score	Content of ZZP
1 VG	Residence with minimal support
2 VG	Residence with support
3 VG	Residence with support and care
4 VG	Residence with support and intensive care
5 VG	Residence with support and very intensive care
6 VG	Residence with intensive support, care and regulation of behavior
7 VG	(Enclosed) Residence with very intensive support, care and regulation of behavior
Functional indication	Support with no residence (only day care or ambulatory support)

Representativeness

To determine if the resulting sample would be representative for the base population, we collected administrative data of all clients aged 50 year and over (gender, age, type of living facility and ZZP-score). ZZP (ZorgZwaartePakket) is the Dutch classification of levels of support, care and/or treatment as a basis for long-term financing [27] (Table 1). ID care and mental health care (MHC) have different ZZP-classifications. A small number of clients may be indicated according to the ZZP classification for mental health care, although having an intellectual disability as well. For clients who participate in day activities within the consort and obtained residential care from other care providers, the ZZP score needed to be collected elsewhere.

To determine representativeness of the included sample, we used Pearson's Chi-square test for independence, with null hypothesis that the participants and non-participants are similar (i.e. that characteristics are not depending on group).

Participation

To evaluate whether health was successfully measured in this sample of older adults with intellectual disabilities, participation rates are given for four key measurements of the complete health assessment (physical examination, physical fitness test, questionnaires completed by caregivers, interviews). Data on all other measurements will be provided in separate papers concerning those measurements.

RESULTS

Inclusion

In figure 1 the results of the recruitment procedure are shown. Although the consent rate (consent/invited) was 1069/2150 (49.7%), the total rate of participants of the total cohort (total number/participants) was 1050/2322 (45.2%).

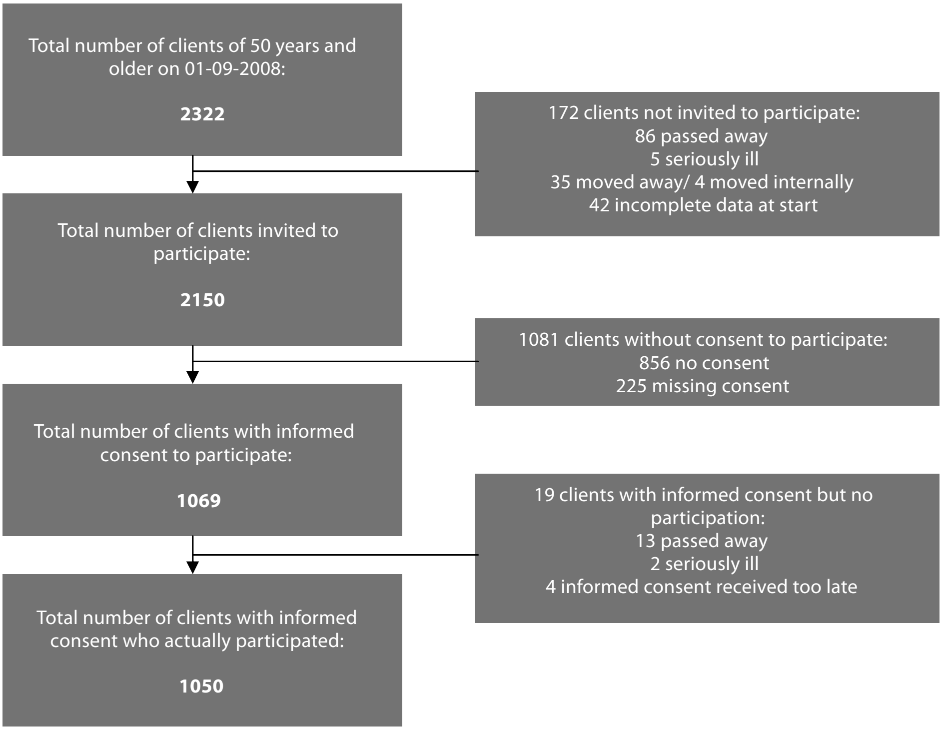

Figure 1 Flow chart inclusion of the HA-ID study

Representativeness

In Table 2 the numbers are presented for the total population of older adults in all three care organizations, for participants and for non-participants, including the contributing Chi-square terms per category. The categories with the largest deviation from the expected numbers are bold, to show which categories cause the significant differences between both groups. Overall Chi-square statistics are presented in Table 3.

Participation

Participation to parts of the health assessment is presented in Table 4.

CONCLUSION AND DISCUSSION

This paper describes how to successfully include a large sample of older adults with ID and to measure their health. A selection of instruments suitable for large-scale health assessment in this group is presented. Involvement of top and middle management in the entire process and a thorough communication plan (with a focus on key groups

Table 2 Representativeness of the study population

	Total population	Participants		Non-participants	
	N	N	$(X_o-X_e)^2/X_e$	N	$(X_o-X_e)^2/X_e$
Total	2322	1050		1272	
Gender					
Male	1253	539	1.34	714	1.11
Female	1069	511	**1.58**	558	1.30
Age					
50 – 54 years	638	304	0.83	334	0.69
55 – 59 years	605	246	2.78	359	2.14
60 – 64 years	471	224	0.57	247	0.47
65 – 69 years	235	118	1.29	117	1.06
70 – 74 years	181	90	0.82	91	0.68
75 – 79 years	110	47	0.15	63	0.12
80 – 84 years	56	11	**8.08**	45	**6.66**
85 – 89 years	19	8	0.04	11	0.03
90 – 94 years	7	2	0.45	5	0.38
Residential status					
Central setting	1159	557	0.65	602	0.56
Community-based	867	432	2.13	435	1.85
Independently living with ambulatory support	192	43	**23.93**	149	**20.76**
With relatives	19	7	0.37	12	0.32
Unknown	85	11		74	
Level of care (ZZP-scores)					
Only day care indication	21	6	1.54	15	1.37
Only indication ambulant care	125	37	**8.26**	88	**7.41**
1 VG	23	12	0.11	11	0.10
2 VG	95	39	0.78	56	0.69
3 VG	308	138	0.41	170	0.37
4 VG	366	207	**6.64**	159	**5.86**
5 VG	690	325	0.01	365	0.01
6 VG	202	93	0.07	109	0.06
7 VG	278	142	0.84	136	0.75
MHC ZZP scores	8	2	0.85	6	0.77
Unknown	206	49		157	

Table 3 Chi-square statistics

Characteristic	Chi-square (df)	p
Gender	5.3 (1)	0.028
Age	27.41 (8)	0.001
Type of living facility	50.55 (3)	<0.001
Level of care	41.06(9)	<0.001

Table 4 Participation to parts of the health assessment

Measurement	Participation
Physical examination (or part of it)	90%
Physical fitness test (or part of it)	87%
Questionnaires by the caregivers	94%
Interviews participants themselves	20%

such as professional caregivers) proved of paramount importance to effectively organize this kind of large-scale research projects.

Not documented in this study, but an important factor in recruitment and measurements, was the actual involvement and cooperation of professional caregivers. Feedback from management of all levels in the care organizations, combined with our personal experiences in this process, suggest that the professional caregivers reacted positively to the personal communication and cooperativeness of the researcher to follow their preferences in the organization of measurements, leading to widespread cooperation during the consent procedure as well as the measurements themselves.

The actual percentage of clients with informed consent was 49.7%. This percentage seems low, but considering the extensive health screening, which could be seen as a burden for the participant, it might be relatively good. In a multi-center study with only an assessment of visual and hearing function, the consent percentage was 61% [19].

The absence of exclusion criteria (except for age) led to a very heterogeneous population. The study population showed significant differences in all categories between participants and non-participants, so it is not a completely representative sample for the total Dutch client population. The significant difference for the category 'gender' was caused by a small overrepresentation of women. For age, the significant difference was caused by an underrepresentation of 80-84 year-olds. This could be explained by the small numbers in the higher age groups, with large consequences for representativeness by small deviations in absolute numbers. Older adults with supported living and often with an indication of ambulant care only, proved hard to reach or to motivate to participate in this study, resulting in an underrepresentation of this group in both the categories 'residential status' and 'ZZP-scores'. One possible explanation might be that they do not recognise themselves as clients of services for people with ID or do not want to be labelled as 'intellectually disabled'. On the other hand, clients with an indication of residence with support and intensive care are overrepresented. Weighting will have to be applied for the results to be generalised to the complete older adult client population with ID in the Netherlands.

Researchers of earlier large-scale studies in populations with intellectual disabilities have reported a number of obstacles, which were avoided in this study by the carefully prepared communication routes and set-up of assessments [25]. Already in 2004, Evenhuis et al concluded that local coordination, sufficiently supported by the management, was the key factor in a successful organization of an epidemiological study in ID services [19]. Meuwese et al (2005) concluded that it is not possible to organize a large-scale intervention study without the active cooperation of the management to provide sufficient resources and support [17]. Sjoukes et al (2006) studied concept-mapping as a method to effectively introduce complex interventions, but concluded this method alone was not sufficient. This method resulted in actions which were primarily operational and ad hoc, instead of changing strategic policies of the care organizations. This resulted in a lack of motivation of the professional caregivers and the middle management [18]. In our study, involvement of top and middle management was secured in the research infrastructure. Next to management involvement in decision-making and policy strategies, they provided necessary conditions and solutions for problems in the execution of this study.

Next to the involvement of top and middle management, this paper provides a few other take home messages for the infrastructure of a large-scale multi-center study for adults with ID. First of all, good preparation of the organization of measurements is as important as designing the research protocol, and requires just as much effort and time. This preparation consists mainly of writing and executing a thorough communication plan, with specific attention for key stakeholders (i.e. professional caregivers). Involved professionals of any kind within the care organizations need to be informed and trained timely and to enhance cooperation they need to have a say in the organization and planning of the assessments. A more detailed description of the research infrastructure and management of involvement and cooperation will be published elsewhere.

REFERENCES

1. Janicki M.P. and Jacobson J.W., *Generational trends in sensory, physical, and behavioral abilities among older mentally retarded persons.* Am J Ment Defic, 1986. **90**(5): p. 490-500.
2. Davidson P.W., Janicki M.P., Ladrigan P., et al., *Associations between behavior disorders and health status among older adults with intellectual disability.* Aging Ment Health, 2003. **7**(6): p. 424-30.
3. Fisher K. and Kettl P., *Aging with mental retardation: increasing population of older adults with MR require health interventions and prevention strategies.* Geriatrics, 2005. **60**(4): p. 26-9.
4. Chess D., Krentzman M., and Charde J., *Creating a wellness program/safety net for the medically complex and frail patient.* J Ambul Care Manage, 2007. **30**(1): p. 30-8.
5. Evenhuis H., *Medical aspects of ageing in a population with intellectual disability: III. Mobility, internal conditions and cancer.* J Intellect Disabil Res, 1997. **41 (Pt 1)**: p. 8-18.
6. Eastwood R., Nobbs H., Lindsay J., et al., *Canadian Study of Health and Aging.* Dement Geriatr Cogn Disord, 1992. **3**(4): p. 209-212.
7. Fried L.P., Borhani N.O., Enright P., et al., *The Cardiovascular Health Study: design and rationale.* Ann Epidemiol, 1991. **1**(3): p. 263-76.
8. Perry J., Linehan C., Kerr M., et al., *The P15 - a multinational assessment battery for collecting data on health indicators relevant to adults with intellectual disabilities.* J Intellect Disabil Res, 2010. **54**(11): p. 981-91.
9. Whitfield M., Langan J., and Russell O., *Assessing general practitioners' care of adult patients with learning disability: case-control study.* Qual Health Care, 1996. **5**(1): p. 31-5.
10. van Schrojenstein Lantman-de Valk H.M., van den Akker M., Maaskant M.A., et al., *Prevalence and incidence of health problems in people with intellectual disability.* J Intellect Disabil Res, 1997. **41 (Pt 1)**: p. 42-51.
11. van Schrojenstein Lantman-De Valk H.M., Metsemakers J.F., Haveman M.J., et al., *Health problems in people with intellectual disability in general practice: a comparative study.* Fam Pract, 2000. **17**(5): p. 405-7.
12. Minihan P.M. and Dean D.H., *Meeting the needs for health services of persons with mental retardation living in the community.* Am J Public Health, 1990. **80**(9): p. 1043-8.
13. Cooper S.A., *Clinical study of the effects of age on the physical health of adults with mental retardation.* Am J Ment Retard, 1998. **102**(6): p. 582-9.
14. Janicki M.P., Davidson P.W., Henderson C.M., et al., *Health characteristics and health services utilization in older adults with intellectual disability living in community residences.* J Intellect Disabil Res, 2002. **46**(Pt 4): p. 287-98.
15. Wilson D.N. and Haire A., *Health care screening for people with mental handicap living in the community.* BMJ, 1990. **301**(6765): p. 1379-81.
16. Prasher V.P.J., M.P., *Physical health of adults with intellectual disabilities*. 2002, Oxford, United Kingdom: Blackwell Publishing Ltd.

17. Meuwese-Jongejeugd A., Harteloh P., Verschuure H., et al., *Brief research report: Audiological rehabilitation in adults with intellectual disability: why does it fail?* Journal of Policy and Practice in Intellectual Disabilities, 2005. **2**(1): p. 66-67.
18. Sjoukes L., Harteloh P., and Evenhuis H., *Brief Research Report: Is Concept-Mapping an effective method of introducing complex interventions into intellectual disability services?* Journal of Policy and Practice in Intellectual Disabilities, 2006. **3**(2): p. 133-135.
19. Evenhuis H., van Splunder J., Vink M., et al., *Obstacles in large-scale epidemiological assessment of sensory impairments in a Dutch population with intellectual disabilities.* J Intellect Disabil Res, 2004. **48**(Pt 8): p. 708-18.
20. Woittiez and Crone, *Zorg voor verstandelijk gehandicapten. Ontwikkelingen in de vraag.* 2005, CPB Centraal Cultureel Planbureau: The Hague, the Netherlands.
21. Hilgenkamp T.I., van Wijck R., and Evenhuis H.M., *Physical fitness in older people with ID-Concept and measuring instruments: a review.* Res Dev Disabil, 2010. **31**(5): p. 1027-38.
22. Hermans H., van der Pas F.H., and Evenhuis H.M., *Instruments assessing anxiety in adults with intellectual disabilities: A systematic review* Res Dev Disabil, 2011. **32**(3): p. 861-70.
23. WGBO, *WGBO (Wet op de geneeskundige behandelovereenkomst)*. 1995, Ministry of Health Welfare and Sport of the Netherlands.
24. Helsinki. *World Medical Associaton Declaration of Helsinki, Ethical Principles for Medical Research Involving Human Subjects*. 2008; Available from: http://www.wma.net/en/30publications/10policies/b3/.
25. Veugelers R., Calis E.A., Penning C., et al., *A population-based nested case control study on recurrent pneumonias in children with severe generalized cerebral palsy: ethical considerations of the design and representativeness of the study sample.* BMC Pediatr, 2005. **5**: p. 25.
26. WMO, *Medical Research Involving Human Subjects Act*. 1999: http://www.ccmo-online.nl/main.asp.
27. CVZ, *Gebruikersgids Zorgzwaartepakketten 2010: Verstandelijke beperking*, CVZ (College voor Zorgverzekeringen), Editor. 2010.
28. Chumlea W.C., Roche A.F., and Steinbaugh M.L., *Estimating stature from knee height for persons 60 to 90 years of age.* J Am Geriatr Soc, 1985. **33**(2): p. 116-20.
29. Durnin J.V. and Rahaman M.M., *The assessment of the amount of fat in the human body from measurements of skinfold thickness.* Br J Nutr, 1967. **21**(3): p. 681-9.
30. Mathiowetz V., Volland G., Kashman N., et al., *Adult norms for the Box and Block Test of manual dexterity.* Am J Occup Ther, 1985. **39**(6): p. 386-91.
31. Berg K., Wood-Dauphinee S., and Williams J.I., *The Balance Scale: reliability assessment with elderly residents and patients with an acute stroke.* Scand J Rehabil Med, 1995. **27**(1): p. 27-36.
32. Mathiowetz V., Kashman N., Volland G., et al., *Grip and pinch strength: normative data for adults.* Arch Phys Med Rehabil, 1985. **66**(2): p. 69-74.
33. Rikli R.E. and Jones C.J., *Senior fitness test manual*. 2001: Human Kinetics Europe Ltd

34. Singh S.J., Morgan M.D., Scott S., et al., *Development of a shuttle walking test of disability in patients with chronic airways obstruction*. Thorax, 1992. **47**(12): p. 1019-24.
35. Singh S.J., Morgan M.D., Hardman A.E., et al., *Comparison of oxygen uptake during a conventional treadmill test and the shuttle walking test in chronic airflow limitation.* Eur Respir J, 1994. **7**(11): p. 2016-20.
36. Hui S.S. and Yuen P.Y., *Validity of the modified back-saver sit-and-reach test: a comparison with other protocols.* Med Sci Sports Exerc, 2000. **32**(9): p. 1655-9.
37. Sheppard J.J., *Managing dysphagia in mentally retarded adults.* Dysphagia, 1991. **6**(2): p. 83-7.
38. Rush A.J., Giles D.E., Schlesser M.A., et al., *The Inventory for Depressive Symptomatology (IDS): preliminary findings.* Psychiatry Res, 1986. **18**(1): p. 65-87.
39. Mindham J. and Espie C.A., *Glasgow Anxiety Scale for people with an Intellectual Disability (GAS-ID): development and psychometric properties of a new measure for use with people with mild intellectual disability.* J Intellect Disabil Res, 2003. **47**(Pt 1): p. 22-30.
40. Zigmond A.S. and Snaith R.P., *The hospital anxiety and depression scale.* Acta Psychiatr Scand, 1983. **67**(6): p. 361-70.
41. Hoekman J., Douma J.C.H., Kersten M.C.O., et al., *IDQOL - Intellectual Disability Quality of Life.* NTZ : Nederlands tijdschrift voor zwakzinnigenzorg, 2001. **4**: p. 207-224.
42. Moss S., Patel P., Prosser H., et al., *Psychiatric morbidity in older people with moderate and severe learning disability. I: Development and reliability of the patient interview (PAS-ADD).* Br J Psychiatry, 1993. **163**: p. 471-80.
43. Guigoz Y., Vellas B., and Garry P.J., *Mini Nutritional Assessment: a practical assessment tool for grading the nutritional state of elderly patients.* . Facts and research in gerontology., 1994(Supplement: nutrition): p. 15-60.
44. Matson J.L. and Kuhn D.E., *Identifying feeding problems in mentally retarded persons: development and reliability of the screening tool of feeding problems (STEP).* Res Dev Disabil, 2001. **22**(2): p. 165-72.
45. Esbensen A.J., Rojahn J., Aman M.G., et al., *Reliability and validity of an assessment instrument for anxiety, depression, and mood among individuals with mental retardation.* J Autism Dev Disord, 2003. **33**(6): p. 617-29.
46. Arrindel W. and Ettema J., *Handleiding bij een multidimensionele psychopathologie indicator*. 1986, Lisse: Swets & Zeitlinger.
47. Evenhuis H., *Manual of the Dementia Questionnaire for Persons with Mental Retardation (DMR)*. 1995, Amsterdam: Harcourt Assessment BV.
48. Mahoney F.I. and Barthel D.W., *Functional Evaluation: the Barthel Index.* Md State Med J, 1965. **14**: p. 61-5.
49. Lawton M.P. and Brody E.M., *Assessment of older people: self-maintaining and instrumental activities of daily living.* Gerontologist, 1969. **9**(3): p. 179-86.

50. Kempen G.I., Miedema I., Ormel J., et al., *The assessment of disability with the Groningen Activity Restriction Scale. Conceptual framework and psychometric properties.* Soc Sci Med, 1996. **43**(11): p. 1601-10.
51. Suurmeijer T.P., Doeglas D.M., Moum T., et al., *The Groningen Activity Restriction Scale for measuring disability: its utility in international comparisons.* Am J Public Health, 1994. **84**(8): p. 1270-3.
52. Hauser S.L., Dawson D.M., Lehrich J.R., et al., *Intensive immunosuppression in progressive multiple sclerosis. A randomized, three-arm study of high-dose intravenous cyclophosphamide, plasma exchange, and ACTH.* N Engl J Med, 1983. **308**(4): p. 173-80.
53. Palisano R., Rosenbaum P., Walter S., et al., *Development and reliability of a system to classify gross motor function in children with cerebral palsy.* Dev Med Child Neurol, 1997. **39**(4): p. 214-23.

Appendix

Measurements with active involvement of the participant		
Type	**Outcome**	**Details**
Physical assessment	Height	Seca stadiometer, type 214. Body Mass Index calculated: weight divided by squared height.
	Knee height	Formulas Chumlea et al. [28] for calculating body height.
	Weight	Digital floor scale (Seca robusta type 813). Body Mass Index calculated: weight divided by squared height.
	Fat percentage	Formulas Durnin and Womersly [29] for calculating fat percentage from the sum of four skinfolds: triceps, biceps, subscapular and suprailiacal. Thickness of skinfolds measured with skinfold caliper (Harpenden).
	Body circumferences	Flexible tape for hip, waist, calf and upper arm circumference. Waist-to-hip ratio calculated: waist circumferences divided by hip circumference.
	Blood pressure	Omron M7.
	Ankle-Arm-Index	Omron M7 (arm). Boso classico and 8-MHz Doppler probe (Huntleigh MD II) (ankle). Ankle-arm-index calculated: systolic blood pressure ankle divided by systolic blood pressure arm..
	Bone Quality	Ultrasonometer (Lunar Achilles Insight) for measuring bone stiffness calcaneus.
Fitness Assessment	Manual dexterity	Box and block test [30].
	Response time	Response time test.
	Balance	Berg Balance Scale [31].
		5 m walking speed (comfortable and fast).
	Muscle strength	Grip strength [32] with Jamar Hand Dynamometer (#5030J1, Sammons Preston Rolyan, USA).
	Muscle endurance	30s Chair stand [33].
	Cardiorespiratory endurance	10m Incremental shuttle walking test [34]. Results of this test recalculated to VO2max [35].
	Flexibility	Extended version of Modified back saver sit and reach test [21,36]
Diary	Food intake	3-day food intake diary
Two weeks at home	Rest-activity rhythm	Actiwatch AW 7 (Cambridge Neurotechnologies)
	Physical activity	Pedometer (NL-1000, New Lifestyles, Missouri USA)
Meal time observation	Swallowing problems	Dysphagia Disorders Survey [37].
Interview (if possible)	Self-report depression	Inventory of Depressive Symptomatology Self Report (IDS-SR) [38]. Phrasing of the questions adapted to people with ID.
	Self-report anxiety	Glasgow Anxiety Scale for people with an Intellectual Disability (GAS-ID) [39]. Translated version of the GAS-ID into Dutch.
	Self-report anxiety	Hospital Anxiety and Depression Scale (HADS) [40] -anxiety subscale. Phrasing of the questions adapted to people with ID
	Social contacts	Checklist about number of contacts with family, friends and peers and visiting leisure-clubs.
	Quality of life	Intellectual Disability Quality of Life (IDQOL-16) [41]

Interview	Diagnostic interview depression and/or anxiety	Participants with scores above the preset cut-off scores on one of the depression or anxiety questionnaires further examined by behavioral scientists trained in assessing the PAS-ADD-10 interview with participant or his/her caregiver [42]
Venipuncture	Biochemical markers	Fasting plasma levels: glucose, cholesterol, HDL-cholesterol, triglycerides, CRP, Hb and albumin.
Measurements without active involvement of the participant		
History	Medical files	Checklist for general practitioners or ID-physicians
	Psychological files	Checklist for psychologists or behavioral therapists
	Dental files	Checklist for dentists
Questionnaires professional caregiver	Malnutrition	Mini Nutritional Assessment (MNA) [43].
	Eating disorders	Screening Tool of fEeding Problems (STEP) [44]. Translated version in Dutch.
	Gastro-oesophageal reflux disease (GORD).	GORD Questionnaire: a newly developed questionnaire consisting of 50 items involving risk factors and symptoms of gastro-oesophageal reflux disease.
	Informant-report depression and anxiety	Anxiety, Depression, And Mood Scale (ADAMS) [45]. Translated version of the ADAMS into Dutch.
	Somatic complaints	Somatic complaints subscale of the Symptom Checklist-90 (SCL-90) [46]
	Life-events	Checklist Life Events. Newly developed checklist based on other checklists, earlier life event-studies and experience from professionals working with people with ID.
	Social outcome	Checklist about number of contacts with family, friends and peers and visiting leisure-clubs.
	Cognitive functioning	Dementia questionnaire for people with intellectual disabilities (DMR) [47]
	Activities of daily life and mobility	Barthel Index [48]
	Instrumental activities of daily Life	Questionnaire based on the Instrumental Activities of Daily Living of Lawton and Brody [49] and the Groningen Activities Restriction Scale [50-51].
	Mobility	Questionnaire based on the Hauser Ambulation Index [52] and the characteristics of the Gross Motor Function Classification Scale [53].
	Physical activity	Questionnaire about the participants' habitual physical activity.
Interview	Diagnostic interview depression and/or anxiety	Participants with scores above the preset cut-off scores on one of the depression or anxiety questionnaires further examined by behavioral scientists trained in assessing the PAS-ADD-10 interview with the caregiver [42].

Chapter 3

Measuring physical activity with pedometers in older adults with ID: reactivity and number of days

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ABSTRACT

The minimum number of days of pedometer monitoring, needed to estimate valid average weekly step counts, and reactivity was investigated for older adults with intellectual disabilities (ID). Participants (n=268) with borderline to severe ID aged 50 years and older were instructed to wear a pedometer for 14 days. Outcome measure was steps/day. Reactivity was investigated with repeated-measures ANOVA, the monitoring frame was investigated by comparing combinations of days with average weekly step counts (with intraclass correlation coefficients (ICCs) and regression analyses). No reactivity was present. Any combination of four days resulted in ICCs of 0.96 or higher and 90% of explained variance. Conclusion: any four days of wearing a pedometer is sufficient to validly measure physical activity in older adults with ID.

INTRODUCTION

Epidemiological research has demonstrated that physically active adults without disabilities, when compared to their sedentary counterparts, demonstrate reduced risk for several chronic diseases, including coronary heart disease (CHD), hypertension, and type 2 diabetes [1]. These findings can also be applied to adults with intellectual disabilities (ID) [2]. Methods of measuring physical activity include interviews and questionnaires, heart rate monitors, accelerometers and pedometers [2-3]. Interviews and questionnaires are often administered by the participants themselves with caregiver assistance, or by proxy respondents, such as parents or professional caregivers. Methodological limitations of these methods are the accuracy of the instrument and the accuracy of the respondents, which are both insufficiently described in most studies in adults with ID [2]. More reliable instruments to assess physical activity are accelerometers and pedometers, of which the pedometer is the most widely-used and cost-effective [4].

Daily walking distance or walking time is often underestimated in questionnaires [5-6], but is, at the same time, the most commonly reported physical activity by individuals with ID [7]. A pedometer is a movement sensor worn at the ankle or waist, and measures physical activity by means of the number of steps taken by the participant, which enables a reliable measurement of walking [4]. Although the pedometer is easily applicable, some measurement issues are to be considered when using it for research purposes, such as the choice of metric (raw measure like step count, or calculated measures like total distance or caloric expenditure), the monitoring frame (number of days measured), data recording and collection procedures (missing data in the absence of a memory function of a pedometer, or added data when returning the pedometer by mail), or other sources of error such as movement during travel by car, slower walking speed and obesity [4,8-9].

The focus of this study concerns the monitoring frame when measuring activity with pedometers. Specifically, the number of days required to obtain a reliable estimate of habitual physical activity. This subject was investigated by Tudor-Locke et al. (2005), to reduce participant burden and study costs. They concluded that any 3 days of measuring is sufficient to get a reliable estimate for weekly physical activity [10]. However, the length of the monitoring frame depends on the population in question [4]. Differences between physical activity patterns of the general population and adults with ID could contribute to variability between days. They have lower activity levels than the general population [2], and walking is the primary type of physical activity in adults with ID [7]. Therefore, the issue of the monitoring frame was re-addressed for the population of adults with ID by Temple & Stanish (2009). From a large pooled data set (n=154), they concluded that 3 days of monitoring steps/day predict average weekly physical activity sufficiently in this population, too [11].

Although Temple and Stanish used a relatively large data set, the study population consisted mainly of adults younger than 50 years (men: mean=35.5, SD=11.4, women: mean=37.9, SD=9.4). Seventeen participants were aged 50 years or older and only one participant was older than 65 years. Differences in activity patterns between younger and older adults have been described for the general population [12] and are likely to be present in ageing adults with ID as well. Retirement from work or day activities may cause differences in activity patterns, since these activities (and commuting to and from these activities) are suggested to contribute to the level of physical activity in this group [11]. Furthermore, the population assessed by Temple and Stanish consisted of adults with mild and moderate levels of ID, but differences between those subgroups were not investigated. The activity patterns of participants with borderline and severe ID have not been studied at all. It is therefore necessary to analyse the minimal time frame needed to reliably predict weekly step counts for the population of older adults with different levels of ID.

Recently, another issue in measuring physical activity in short-term pedometer studies has emerged, called reactivity, which is the positive influence of wearing the pedometer on ambulatory activity [13]. In studies with adults with normal cognitive capabilities, reactivity was present in the first 3-4 days of the measurement period and caused validity problems for short-term pedometer studies [13-15]. This could be of influence in older adults with ID as well, but this has never been a topic of research before, to the best knowledge of the authors.

The research questions of this paper are: 1. How many days of measuring step counts are necessary to predict weekly physical activity in older adults with different levels of ID? and 2. Does reactivity influence daily step counts in older adults (aged 50 years and over) with ID?

METHODS

Participants

This study was part of a large cross-sectional study to measure health in older adults with intellectual disabilities (ID). All clients aged 50 years and over of three care providers in the Netherlands (Abrona, Amarant, Ipse de Bruggen) were invited to participate, of which 1050 clients did. Ethical approval was provided by the Ethical Committee of the Erasmus Medical Centre (number 2008-234) and by the ethical committees of the participating care providers. Informed consent was obtained for all participants, and unusual resistance was reason for aborting measurements at all times [16]. Details about design, recruitment, representativeness of the sample and communication procedures have been presented elsewhere [17].

Materials

The accuracy and reliability of pedometers has been widely studied and differences have been presented across different walking speeds, ground surfaces, body composition and location of wearing. Two of these issues, slow walking speed and overweight/obesity, are likely to be present in older adults with ID [18-19]. The Yamax digiwalker is the pedometer most frequently used in research, but can only measure reliably at minimal walking speeds of around 5 km/h [20-23]. The NL-2000 is able to measure reliably at minimal walking speeds of 3.2 km/h (0.9 m/s) and has the advantage to be able to reliably measure steps in overweight/obese participants as well [21,24-25]. The other pedometers in this series (NL-1000 and NL-800) have the same piezo-electric measurement mechanism, and therefore the same psychometric properties. The NL-1000 and NL-800 only differ in additional information they provide (distance, moderate-to-vigorous physical activity time or calories). In this study the NL-1000 (New Lifestyles, Missouri, USA) was used, which provides steps, distance and minutes of physical activity of moderate intensity.

Procedure

As part of a physical fitness assessment, stride length and comfortable walking speed of participants were measured by administering number of steps and the time necessary to cover a distance of five metres. This was repeated three times [26].

Inclusion criteria to participate in this study were: no resistance of the participant (or their professional caregiver) to wear the pedometer, a comfortable walking speed of 3.2 km/h or more in at least one of the three attempts.

Instructions concerning the use of the pedometer were given to the professional caregiver and the participant. The pedometer was attached to the belt of the participant, midway between the iliac crest and the umbilicus. During the monitoring period, participants wore the pedometers from morning to bedtime. Pedometers were removed during water-related activities (e.g., swimming, bathing, showering). The monitoring period of two weeks was chosen to compensate for missing days and therefore, insuring that a full week of monitoring (i.e., 7 consecutive days) took place. The professional caregiver was instructed to record the number of steps, distance and activity minutes in a diary every evening. After 14 days, the pedometers were retrieved by the research team and the diaries were checked for completeness. If data of any of the last seven days was missing in the diary, while a participant did wear the pedometer, the 7-day memory of the pedometer was checked to retrieve missing results.

Analyses

Descriptive characteristics of participants are computed. If the first days of the measurement period were influenced by reactivity, they needed to be deleted in the analyses for determining the monitoring frame, so reactivity was analysed first.

Reactivity was analysed by comparing the results of the consecutive days with a repeated-measures ANOVA, with gender and level of ID as a between-subjects factor, following the analysis methods of previous research [14]. The Greenhouse-Geisser epsilon F was interpreted in the case of violation of the assumption of sphericity. If an overall significant F level was indicated, differences between days were examined with pair wise analyses with Bonferroni correction, for the complete group and for subgroups of gender and different levels of ID. Only participants with a complete set of data were included in this part of the analyses, because the consecutiveness of the measuring days was the point of interest. The day at which the pedometer measurement started, was determined by the day of the physical fitness assessment, which could be any weekday. Because of this mix of days, this dataset was suitable to assess the differences between the consecutive days. Days with steps/day which were significantly different from other days of the consecutive measurement period, so which were influenced by reactivity, were omitted from further analyses.

To determine the necessary monitoring frame, the data of the consecutive 14 days were reorganised according to the days of the week. The measurement period was 14 days, resulting in two step counts per day of the week.

An extensive analysis method was used, similar to previous research about this subject [10-11]. This method consisted of an analysis of the intra-individual variability compared with the inter-individual variability and of three statistical analyses: ANOVA, intraclass correlation coefficients (ICC) and regression analysis to determine the suitable monitoring frame.

First, coefficient of variation (CoV = SD/mean*100) was calculated. The coefficient of the intra-individual variability (variability within an individual, CoVw) was calculated by dividing the individual standard deviation of the steps/day by the individual mean steps/day of the complete dataset times 100. The interindividual variability (variability between individuals) was calculated by dividing the standard deviation of the steps/day of the complete study population by the mean steps/day of the complete study population times 100. The assumption of the coefficient of variation was a linear relationship between the mean and the standard deviation, which was checked graphically and with Pearson correlation.

To determine if patterns were present in physical activity across the days of the week, the average steps/day (and SDs) of both weeks was calculated for every day of the week. This provided a dataset which incorporated both weeks of data.

A repeated-measures ANOVA was used to determine if the days of the week had different mean steps/day. To investigate if these patterns were different for males or females, participants with different levels of ID, participants with or without Down syndrome, or participants with age below 65 years or 65 years and over, these variables were added as between-subjects factors to study their interaction effects with the within-subjects factor days of the week. The Greenhouse-Geisser epsilon F was interpreted in the case of violation of the assumption of sphericity. If an overall significant F level was indicated, differences between days were examined with pair wise analyses with Bonferroni correction. Intraclass correlation coefficients were used to analyse how combinations of days compare to the criterion score.

To determine how many days of wearing the pedometer is necessary to predict weekly step counts, intraclass correlation coefficients (ICCs) were calculated. For the analysis of these ICCs, mean steps/day (and SDs) were calculated for each day separately and for any combination of any number of days of the first week of measuring, resulting in 119 combinations of 2, 3, 4, 5 and 6 days. These unique combinations were examined to enable conclusions about combining data from non-consecutive days, as is the case in data sets characterized by missing data patterns [10]. The mean steps/day of the first week and the mean steps/day of the complete measuring period were computed and used as the two criterion scores. For comparison with the mean of the first week, only participants with a complete first week of data were included, for comparison with the mean of the complete measuring period, only participants with a complete measuring period of data were included. Then, all computed combinations were compared with these criterion scores with ICCs for mixed effects, looking at absolute agreement between single measures (which are the mean scores of the combinations). According to the minimum level of consistency needed for multiple day observation of physical activity, an ICC of 0.80 was considered sufficient [27].

Thirdly, stepwise regression analysis was used to determine both how many and what types of days were necessary to predict both the criterion scores. The total predictive value of the model was evaluated by the adjusted R^2, which represents the explained variance in outcome by the model. First, only one single day mean was entered in a model, secondly the consecutive day was entered, thirdly the next consecutive day was entered, until the model explains 90% of the variance or over. SPSS version 15.0 was used for all analyses and the significance level was set at $p = 0.05$.

RESULTS

Descriptives

Descriptive characteristics of participants are presented in Table 1. Of the 1050 older adults who participated in the large epidemiological study, 268 complied with the inclusion criteria for the assessment of physical activity with a pedometer.

Reactivity

A complete dataset of 14 consecutive days of measuring was available for 135 participants, and these were included in this part of the analyses. The assumption of sphericity was violated, so Greenhouse-Geisser's F was used en proved to be significant ($F=8.031$, $p< 0.001$). Pairwise comparisons revealed that only the first day was significantly different from all other days, which was due to the time the participant was given the pedometer and starting wearing (somewhere during the day). The data of this day was omitted in further analyses. No other differences between the means of

Table 1 Descriptives of the study population

		N	% of category
Total		268	100.0
Gender	Male	138	51.5
	Female	130	48.5
Age	50-54	70	26.1
(years)	55-59	81	30.2
	60-64	52	19.4
	65-69	36	13.4
	70-74	17	6.3
	75-79	8	3.0
	80-84	4	1.5
Level of ID	Borderline	11	4.1
	Mild	90	33.6
	Moderate	152	56.7
	Severe	10	3.7
	Profound	0	0.0
	Unknown	5	1.9
Down Syndrome	Down syndrome	22	8.2
	No Down syndrome	190	70.9
	Unknown	56	20.9

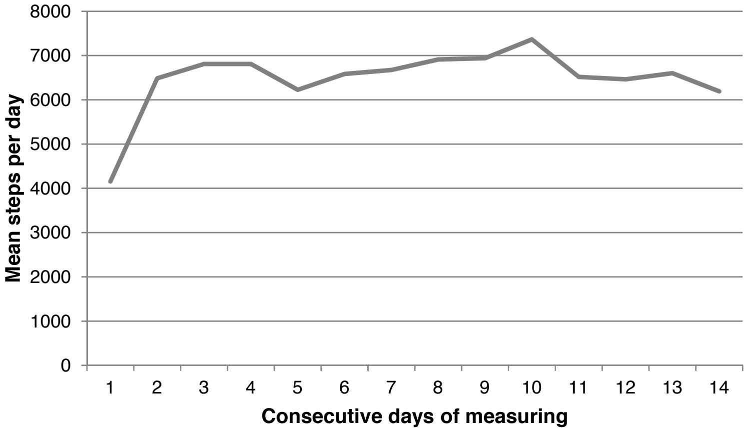

Figure 1: Activity pattern across the consecutive days of wearing the pedometer

Table 2 Mean steps/day with standard deviation of the seven days of the week

Week 1				Week 2				Mean both weeks			
Day	Mean	SD	N	Day	Mean	SD	N	Day	Mean	SD	N
Monday	6981	5016	234	Monday	6755	4819	155	Monday	6946	4599	248
Tuesday	6897	4656	239	Tuesday	7020	4566	204	Tuesday	7050	4532	254
Wednesday	6880	4440	241	Wednesday	7335	6022	149	Wednesday	6977	4342	251
Thursday	6980	4691	243	Thursday	7027	4479	191	Thursday	7099	4561	253
Friday	6800	4257	243	Friday	7126	4982	223	Friday	6937	4227	257
Saturday	6419	5062	227	Saturday	5739	3614	217	Saturday	6098	4026	246
Sunday	5372	4621	234	Sunday	5404	4787	214	Sunday	5293	4261	250

the days of measuring were noticed (see figure 1), neither for the complete group nor for subgroups of gender or different levels of ID.

Monitoring frame

A linear relationship between the mean and standard deviation of steps/days was confirmed graphically (Pearson r=.69, p<0.001). CoVw (intra-individual variability) is 42.76%, CoVb (inter-individual variability) is 54.49%.

Steps/day of every weekday of the measurement period and the mean per day of both weeks are presented in Table 2. When performing the repeated-measures ANOVA, the assumption of sphericity was violated. Therefore, Greenhouse-Geisser's F was used. The results of this analysis revealed a significant effect for the within-subjects factor days of the week (F=15.413, p<0.001). All weekdays did not differ significantly from the other weekdays, but Sunday had significantly lower step counts than any other day of the week, and Saturday had significantly different lower counts than Tuesday and

Table 3 Intraclass correlation coefficients for all single days and combination of days of the week

Any combination of	N of combinations	ICCs compared with 1 week mean			ICCs compared with total dataset (13 days) mean		
		Mean	Median	Range	Mean	Median	Range
Single day	7	0.78	0.79	0.74-0.83	0.75	0.77	0.69-0.80
Two days	21	0.90	0.90	0.86-0.92	0.87	0.87	0.81-0.90
Three days	35	0.94	0.94	0.93-0.95	0.92	0.92	0.89-0.94
Four days	35	0.97	0.97	0.96-0.97	0.94	0.94	0.92-0.96
Five days	21	0.98	0.98	0.97-0.99	0.96	0.96	0.94-0.97
Six days	7	0.99	0.99	0.99-0.99	0.97	0.97	0.96-0.98

Thursday. No interaction effects were found between days of the week with gender, level of ID, Down syndrome or aged younger than 65 years, which means that the patterns of physical activity across the days of the week were not different for any of these groups. Consequently, data of all participants were combined for subsequent analyses.

The mean, median and range of ICCs for any single and any combination of days with both the criterion scores (1 week mean and mean of total dataset) is presented in Table 3, including the number of used combinations and the range of the numbers of participants used to calculate the ICC for every combination. Data of the complete first week were available for 183 participants, whereas 136 participants had data of the complete measuring period (13 days).

The adjusted R^2's of models with all possible consecutive combinations of 1, 2, 3 and 4 days are presented in Table 4. Explained variance of 90% (adjusted R^2 =0.90) is reached in four of the models with three consecutive days (if starting at Monday, Tuesday, Saturday or Sunday), whereas if starting on Wednesday, Thursday or Friday, four consecutive days of wearing the pedometer are necessary to reach 90% variance explained.

DISCUSSION

Reactivity was not present in the pedometer-data of older adults with intellectual disabilities (ID). The number of steps/day in the weekend was lower than during the week: Sunday has significantly lower steps/day than any other day of the week, and Saturday also has significantly lower steps/day than Tuesday and Thursday. A monitoring frame

Table 4 Adjusted R^2 of regression-analysis with 1, 2, 3 or 4 consecutive days of measuring

Model 1 day			Model 2 days			Model 3 days			Model 4 days		
Model	Adj. R^2 7 days	Adj. R^2 13 days	Model	Adj. R^2 7 days	Adj. R^2 13 days	Model	Adj. R^2 7 days	Adj. R^2 13 days	Model	Adj. R^2 7 days	Adj. R^2 13 days
Mon	0.70	0.67	Mon-Tue	0.85	0.83	Mon-Wed	0.90	0.86	Mon-Thu	0.93	0.91
Tue	0.74	0.69	Tue-Wed	0.83	0.77	Tue-Thu	0.90	0.88	Tue-Fri	0.92	0.88
Wed	0.64	0.63	Wed-Thu	0.80	0.80	Wed- Fri	0.86	0.83	Wed-Sat	0.93	0.90
Thu	0.61	0.62	Thu-Fri	0.78	0.75	Thu-Sat	0.88	0.84	Thu-Sun	0.94	0.89
Fri	0.62	0.53	Fri-Sat	0.82	0.73	Fri-Sun	0.89	0.81	Fri-Mon	0.95	0.90
Sat	0.62	0.57	Sat-Sun	0.77	0.70	Sat-Mon	0.90	0.86	Sat-Tue	0.94	0.90
Sun	0.62	0.56	Sun-Mon	0.83	0.80	Sun-Tue	0.90	0.87	Sun-Wed	0.93	0.90

of any four days is sufficient to predict weekly step counts, with both an agreement of 0.8 or higher and explained variance of 90%.

This conclusion is somewhat different from conclusions drawn in previous research [10-11]. They concluded that three days of measuring is sufficient to predict weekly step counts in adults with and without ID, based on ICCs and regression analyses. The difference in the current paper is that regression analysis was performed not only for models with consecutive days starting with the single day which explained the most of the variance (such as in previous research), but for models with consecutive days which could start on any one of the seven days of the week. In the current study, three days were also sufficient to explain 90% of the variance in the best models, but in three out of seven starting days, 90% of the variance was only explained when four consecutive days were included.

This short monitoring frame, which is valid for consecutive days as well as randomly distributed days, is useful in case of missing data. For the population studied in this paper, it means that data of 11 participants can be included in further analyses, who had successfully worn the pedometer during 4-6 days and would have been excluded if using a monitoring frame of 7 days.

The intra-individual variability was smaller than the inter-individual variability (42.76% vs. 54.49%), but still very large. In such heterogeneous study populations, the ICC tends to be higher because it is a ratio of the true variance between subjects divided by the sum of the true variance and other causes of variance (variance due to measurement error, interaction or random error). When the true variance is high, the relative contribution of the other causes of variance is automatically lower, resulting in high ICCs. In heterogeneous populations, such as the current study population, the ICC is therefore not the recommended method of analysing agreement, and the conclusion of a monitoring frame of four days in this paper was based on the regression analyses.

Other potential threats to an accurate, reliable and valid measurement of physical activity with a pedometer were mentioned by Tudor-Locke et al (2001), such as the used metric, procedures for data recording and collecting, slower walking speeds and automobile travel.

This study followed the recommendations of these authors regarding the used metric and used raw step counts, in contrast with calculated metrics like the total distance covered, which could introduce possible error, for example for individuals with smaller stride lengths.

Procedures for data recording and collecting were set up to minimize missing data (memory function in the pedometer) and error through transportation (pedometer was picked up by the research team).

Slower walking speeds can cause an error in the estimated number of steps because pedometers have a minimum speed at which they can measure steps reliably. To minimize the influence of this error, the comfortable walking speed was measured in advance during the physical fitness assessment and only participants with sufficiently fast comfortable walking speeds were included. The authors realize that these included participants might in reality sometimes walk too slowly as well (as in the general population), but most of their walking will be at or above their own comfortable walking speed and therefore reliably recorded.

Obesity was mentioned as a possible source of error too, but the pedometer used in this study was tested reliable in measuring overweight and obese participants as well [24].

A limitation of this study is the lack of information on the amount of automobile travel, which could have influenced the step counts [4].

The large number of participants is a strength of this study, which enabled a detailed analysis of patterns across the days of the week and the minimal monitoring frame. Although the study population of 268 participants out of a total 1050 participants is a small, selected group, this bias does not interfere with the results in this article because no interaction effects were present for gender, level of ID, Down syndrome or aged younger than 65 years based on the repeated-measures analyses. In further analyses about the actual results of physical activity, this bias should be reckoned with when drawing conclusions.

Another advantage in this study is the initial monitoring frame of 14 days. Patterns across days of the week were analysed with means of the days of both these weeks, which is more stable than data of one week only. Furthermore, the predictive value of different monitoring frames could be compared not only to the one-week average, but also to the average of the complete set of days, which gives more insight into the validity of the monitoring frame.

In conclusion, if measuring physical activity in older adults with ID, it is important to use an appropriate pedometer, which can measure steps reliably at slow walking speeds and in overweight participants. To predict average weekly step counts, participants need to wear the pedometer four days successfully (not necessarily consecutively). This reduces the burden for participants as well as for caregivers when participating in research or intervention projects, and the costs and duration of research will be further minimised.

REFERENCES

1. DHHS, *Physical Activity Guidelines Advisory Committee Report*. 2008, U.S. Department of Health and Human Services, : Rockville (MD).
2. Temple V.A., Frey G.C., and Stanish H.I., *Physical activity of adults with mental retardation: review and research needs.* Am J Health Promot, 2006. 21(1): p. 2-12.
3. Frey G.C., Stanish H.I., and Temple V.A., *Physical activity of youth with intellectual disability: review and research agenda.* Adapt Phys Activ Q, 2008. 25(2): p. 95-117.
4. Tudor-Locke C.E. and Myers A.M., *Methodological considerations for researchers and practitioners using pedometers to measure physical (ambulatory) activity.* Res Q Exerc Sport, 2001. 72(1): p. 1-12.
5. Bassett D.R., Jr., Cureton A.L., and Ainsworth B.E., *Measurement of daily walking distance-questionnaire versus pedometer.* Med Sci Sports Exerc, 2000. 32(5): p. 1018-23.
6. Richardson M.T., Leon A.S., Jacobs D.R., Jr., et al., *Comprehensive evaluation of the Minnesota Leisure Time Physical Activity Questionnaire.* J Clin Epidemiol, 1994. 47(3): p. 271-81.
7. Draheim C.C., Williams D.P., and McCubbin J.A., *Prevalence of physical inactivity and recommended physical activity in community-based adults with mental retardation.* Ment Retard, 2002. 40(6): p. 436-44.
8. Tudor-Locke C., Williams J.E., Reis J.P., et al., *Utility of pedometers for assessing physical activity: convergent validity.* Sports Med, 2002. 32(12): p. 795-808.
9. Tudor-Locke C., Williams J.E., Reis J.P., et al., *Utility of pedometers for assessing physical activity: construct validity.* Sports Med, 2004. 34(5): p. 281-91.
10. Tudor-Locke C., Burkett L., Reis J.P., et al., *How many days of pedometer monitoring predict weekly physical activity in adults?* Prev Med, 2005. 40(3): p. 293-8.
11. Temple V.A. and Stanish H.I., *Pedometer-measured physical activity of adults with intellectual disability: predicting weekly step counts.* Am J Intellect Dev Disabil, 2009. 114(1): p. 15-22.
12. DiPietro L., *Physical activity in aging: changes in patterns and their relationship to health and function.* J Gerontol A Biol Sci Med Sci, 2001. 56 Spec No 2: p. 13-22.
13. Clemes S.A., Matchett N., and Wane S.L., *Reactivity: an issue for short-term pedometer studies?* Br J Sports Med, 2008. 42(1): p. 68-70.
14. Clemes S.A. and Parker R.A., *Increasing our understanding of reactivity to pedometers in adults.* Med Sci Sports Exerc, 2009. 41(3): p. 674-80.
15. Marshall A.L., *Should all steps count when using a pedometer as a measure of physical activity in older adults?* J Phys Act Health, 2007. 4(3): p. 305-14.
16. WMO, *Medical Research Involving Human Subjects Act*. 1999: http://www.ccmo-online.nl/main.asp.
17. Hilgenkamp T.I., Bastiaanse L.P., Hermans H., et al., *Study healthy ageing and intellectual disabilities: Recruitment and design.* Res Dev Disabil, 2011. 32(3): p. 1097–1106.

18. Bohannon R.W., *Comfortable and maximum walking speed of adults aged 20-79 years: reference values and determinants.* Age Ageing, 1997. 26(1): p. 15-9.
19. Lahtinen U., Rintala P., and Malin A., *Physical performance of individuals with intellectual disability: a 30 year follow up.* Adapt Phys Activ Q, 2007. 24(2): p. 125-43.
20. Cyarto E.V., Myers A.M., and Tudor-Locke C., *Pedometer accuracy in nursing home and community-dwelling older adults.* Med Sci Sports Exerc, 2004. 36(2): p. 205-9.
21. Grant P.M., Dall P.M., Mitchell S.L., et al., *Activity-monitor accuracy in measuring step number and cadence in community-dwelling older adults.* J Aging Phys Act, 2008. 16(2): p. 201-14.
22. Le Masurier G.C. and Tudor-Locke C., *Comparison of pedometer and accelerometer accuracy under controlled conditions.* Med Sci Sports Exerc, 2003. 35(5): p. 867-71.
23. Pitchford E.A. and Yun J., *The accuracy of pedometers for adults with Down syndrome.* Adapt Phys Activ Q, 2010. 27(4): p. 321-36.
24. Crouter S.E., Schneider P.L., and Bassett D.R., Jr., *Spring-levered versus piezo-electric pedometer accuracy in overweight and obese adults.* Med Sci Sports Exerc, 2005. 37(10): p. 1673-9.
25. Marsh A.P., Vance R.M., Frederick T.L., et al., *Objective assessment of activity in older adults at risk for mobility disability.* Med Sci Sports Exerc, 2007. 39(6): p. 1020-1026.
26. Hilgenkamp T.I., van Wijck R., and Evenhuis H.M., *Physical fitness in older people with ID-Concept and measuring instruments: a review.* Res Dev Disabil, 2010. 31(5): p. 1027-38.
27. Baranowski T. and de Moor C., *How many days was that? Intra-individual variability and physical activity assessment.* Res Q Exerc Sport, 2000. 71(2 Suppl): p. S74-8.

Chapter 4

Physical activity levels in older adults with intellectual disabilities are extremely low

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ABSTRACT

This study measures physical activity levels in a representative population-based sample of older adults (aged ≥ 50 years) with intellectual disabilities. The physical activity levels of all 1,050 participants of the Healthy Ageing and Intellectual Disabilities study (HA-ID; a study conducted among three Dutch healthcare providers in 2009-2010) were attempted to be assessed with a pedometer.

Largely due to physical limitations (n=103), walking speed < 3.2 km/h (n=252), limited understanding or non-cooperation (n=233), only 257 participants of the total group were able to participate in valid measurements with pedometers. Of these 257 participants, only 16.7% (95% CI 12.2-21.3) complied with the guideline of 10,000 steps/day, 36.2% (95% CI 30.3-42.1) took 7,500 steps/day or more, and 39% (95% CI 32.6-44.5) was sedentary (< 5,000 steps/day). Because the measured sample was the more functionally able part of the total sample, this result is likely to be a considerable overestimation of the actual physical activity levels in this population.

This realistic study shows that physical activity levels are extremely low in adults aged 50 years and over with intellectual disabilities. Focus on lifetime promotion of physical activity in this specific, but rapidly growing population, is recommended.

INTRODUCTION

Although the life expectancy of people with intellectual disabilities (ID) is increasing due to improved health care [1], it is unknown whether these extra years are healthy or unhealthy years, and prevention in this group has received little attention. Low levels of physical activity have been consistently demonstrated in adolescents and adults with ID [2]. Prevention research has shown the positive effects of physical activity on physical and psychological health [3-5] and such effects are also seen in the ageing population [6-7]. Considering these health benefits, the World Health Organization's (WHO) recommendation concerning physical activity is equally as important to vulnerable populations with chronic illnesses and disabilities, such as intellectual disability (ID) [8]. Because older populations are generally less active than younger adults [6,9], we expect older adults with ID to be at particular risk for low levels of physical activity.
In addition to the personal health and wellbeing of older adults with ID, the consequences of inactivity may increasingly influence required levels of support and future health care costs of this population. Therefore, more insight into their physical activity levels is urgently required; this is the first aim of the present study.

Relevant subgroups at risk for low levels of physical activity have been identified in the general population, based on demographic and biological factors. A positive relationship was shown between physical activity and education level, heredity and income; and a negative relationship between physical activity and older age, female gender and race (non-white) [10]. In the population with ID, negative relationships have repeatedly been found for older age [11-12], more severe level of ID [11]_ENREF_14, epilepsy [12], and living in more supported settings [12-13] or, contradictorily, living in a group home [14]. In contrast with the general population, no difference in physical activity levels was found between men and women [11,15-16], with the exception of one study [17]. Because of such inconsistencies, together with the small number of factors investigated and the inclusion of young/healthy participants with only mild to moderate ID, the second aim of this study is to examine which subgroups are at higher risk of physical inactivity among the older population with ID.

Methods

Study design and participants

This study was part of the large cross-sectional study 'Healthy ageing and intellectual disabilities' (HA-ID), conducted by a Dutch consortium of three ID care providers (Abrona at Huis ter Heide; Amarant at Tilburg; and Ipse de Bruggen at Zwammerdam), in collaboration with two university institutes (Intellectual Disability Medicine, Erasmus

Medical Center at Rotterdam; and the Center for Human Movement Sciences, University Medical Center at Groningen).

All 2,150 clients with ID (aged ≥ 50 years) in the three organizations providing care were invited to participate, resulting in a near-representative sample of 1,050 clients (specifically, an underrepresentation of the most independent living clients). Details on recruitment, consent procedures and representativeness of the sample, as well as diagnostic methods, have been published elsewhere [18]. Data collection took place in 2009 and 2010. Part of the HA-ID study was the measurement of physical activity with pedometers.

The study was approved by the Medical Ethical Committee of Erasmus Medical Center (MEC 2008-234) and by the ethical committees of the participating care providers. Informed consent was obtained from all participants; however, unusual resistance was a reason for aborting measurements at all times [19].

Materials

General characteristics

Gender and age were collected from the records of the care providers. Professional caregivers provided information about residential status (facility with intensive care and support, community-based, independent with ambulatory support or with relatives) and mobility impairment (independent, with walking aid, or wheelchair-bound). Level of ID was categorized by psychologists or behavioral therapists as: borderline (IQ=70-84), mild (IQ=50-69), moderate (IQ=35-49), severe (IQ=20-34) or profound (IQ <20) (according to ICD-10 criteria). The presence of Down syndrome was collected through the medical files.

Physical activity measurement

Physical activity was measured with the NL-1000 pedometer (New Lifestyles, Missouri, USA), which has the same piezo-electric mechanism as the widely studied NL-2000 pedometer, and takes reliable measurements at a minimal walking speed of 3.2 km/h and in overweight/obese participants [20-23].

Risk group assessment

In the HA-ID study, characteristics with a significant association with low physical activity levels in the ID population (gender, age, residential status, level of ID, Down syndrome and epilepsy), and characteristics with a higher prevalence in the ID population than in the general population which could be associated with physical activity levels, were collected through the medical files (hearing impairment, vision impairment, spasticity and scoliosis), through physical assessment (body mass index; BMI), and the files of the psychologist or behavioral therapist (behavioral disorder, autism, depression, anxiety and dementia).

Procedure

Inclusion criteria for the study were: no resistance of the participant (or his/her professional caregiver) to wearing the pedometer, and a comfortable walking speed of 3.2 km/h or more in at least one of three recordings.

As part of a physical fitness assessment (including height/weight to calculate BMI), participants were asked to walk a marked distance of 8 m three times, to assess their comfortable walking speed [24].

The pedometer was attached to the belt worn by the participant, halfway between the umbilicus and the side of the body. The professional caregiver was instructed to record the number of steps, distance and activity in minutes in a diary every evening. After 14 days, the pedometers were retrieved by the research team and the diaries checked for completeness. If data of any of the previous 7 days were missing in the diary, even though a participant had worn the pedometer, the 7-day memory of the pedometer was checked to retrieve the missing data.

Data analysis

Primary analyses of the complete dataset revealed that a monitoring frame of at least 4 days, (not necessarily consecutively) is sufficiently long to correctly estimate physical activity levels in older adults with ID [25]. All participants with at least 4 days of complete pedometer data were included in the analyses. Drop-out from the study was analysed, and participants were compared with non-participants on baseline characteristics (gender, age, level of ID, presence of Down syndrome, residential status and mobility impairment) using Pearson's chi-square tests.

Although the recommendation in steps per day is usually formulated as 10,000 steps/day [26] there is evidence that health benefits can be realized in the range of 7,500 to 9,999 steps/day (called: 'somewhat active') [27-28]. Taking into account the discussion about which guideline is most effective [29], the present study provides data on the prevalence of sufficient physical activity according to the guideline of 10,000 steps/day and 7,500 steps/day.

Next, a multiple linear regression analysis was performed to define risk groups. Variables known to be relevant in adults with ID were entered into the first block (gender, age, residential status, level of ID, Down syndrome and epilepsy). Other comorbidities with a high prevalence in the population with ID were placed in the second block with the forward method, i.e. behavioral disorder, autism, depression, dementia, overweight (BMI $\geq$ 25), hearing impairment, vision impairment, spasticity, scoliosis and mobility

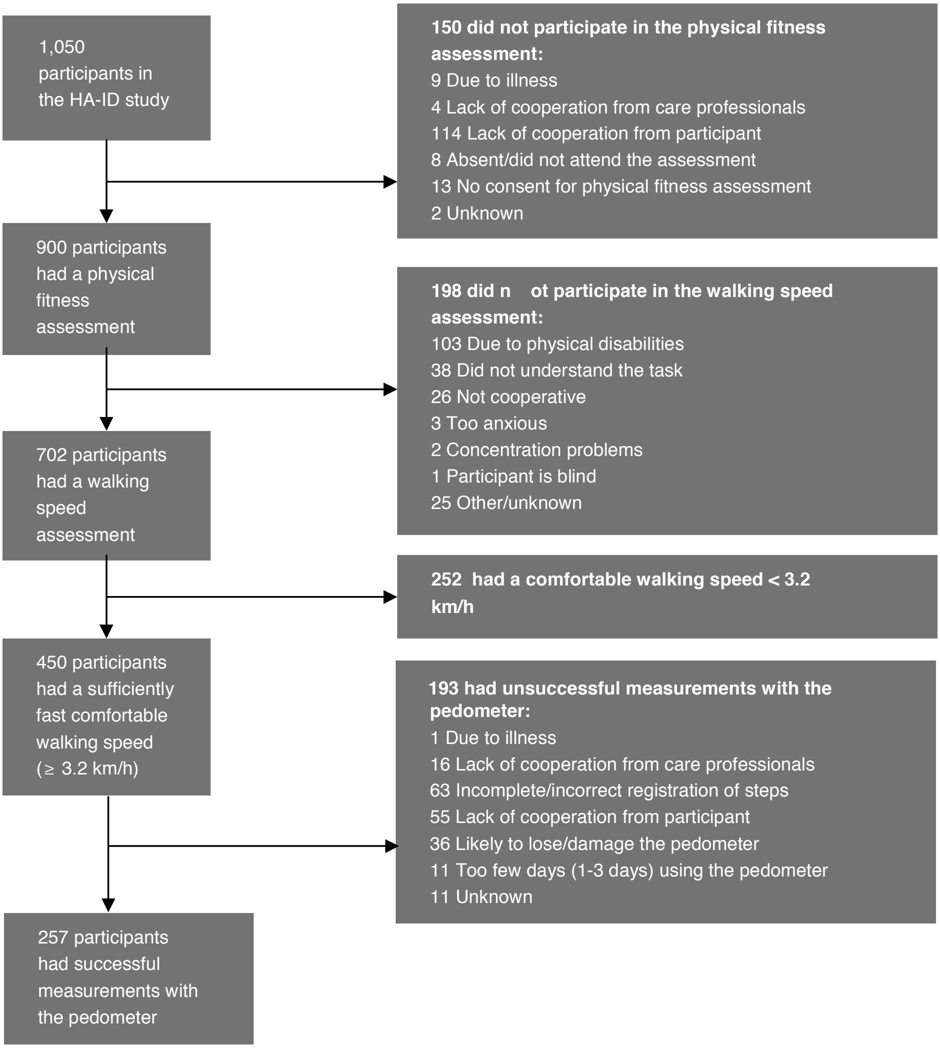

Figure 1 Flow chart of the participants and drop-outs for the pedometer measurement during the HA-ID study

impairment (use of walking aids). Only participants with a complete dataset for all variables were included in the regression analysis.

According to the results of the regression analysis, physical activity data are presented for the relevant subgroups.

All analyses were performed with SPSS version 17; a p-level ≤ 0.05 was considered statistically significant.

RESULTS

Participation

Of the 1,050 participants in the HA-ID study [18], only 257 (24.5%) had a successful measurement with the pedometer. Figure 1 shows a flow chart of the participants and drop-outs during the study. The main reasons for drop-out were physical disability (n=103), walking speed < 3.2 km/h (n=252), and limited understanding (n=38) or non-cooperation of participants (n=195).

Characteristics of the study population

Chi-square tests revealed significant differences between participants (n=257) and non-participants (n=793) in distribution across the age categories (chi-square=17.40, df=4, p=0.002), level of ID (chi-square=93.68, df=4, p<0.001), presence of Down syndrome (chi-square=11.55, df=1, p<0.001), residential status (chi-square=75.28, df=3, p<0.001) and mobility level (chi-square=79.33, df=2, p<0.001), but not in gender. In the study sample the following categories are overrepresented: age group 50-59 years, mild ID, causes of ID other than Down syndrome, community-based living, and walking independently. Groups which are underrepresented are: age group 70-79 years, severe and profound ID, Down syndrome, living in a facility with intensive care and support, walking with support, and wheelchair users (Table 1).

Levels of physical activity

Table 2 presents data on levels of physical activity: 83.3% (95% CI 78.7-87.8) did not comply with the guideline of 10,000 steps/day, and 63.8% (95% CI 57.9- 69.7) walked less than 7,500 steps/day.

Risk group analysis

A complete dataset with all variables included in the regression analysis was available for 169 participants. Table 3 presents the results of the regression analysis. Female gender, older age, more severe ID and mobility impairment are all significant predictors of low physical activity. Anxiety disorder was not included in the regression analysis, because this condition was present in only four participants. The regression model accounts for 13.4% of the variance in steps/day.

Table 4 presents data on the numbers of steps, and the cumulative percentages of participants with ≥ 10,000 steps/day and ≥ 7,500 steps/day, for all relevant risk groups (n=257).

Table 1 Characteristics of the study population

		Study population pedometer		Non-participants pedometer	
		n	%	n	%
Total		257	100.0	793	100.0
Gender	Male	133	51.8	406	51.2
	Female	124	48.2	387	48.8
Age (years)	50-59	146	56.8	347	43.8
	60-69	83	32.3	287	36.2
	70-79	25	9.7	137	17.3
	80-89	3	1.2	19	2.4
	90-94	0	0.0	3	0.4
Level of ID	Borderline	11	4.4	20	2.5
	Mild	88	34.9	136	17.2
	Moderate	143	56.7	363	45.8
	Severe	10	4.0	161	20.3
	Profound	0	0.0	91	11.5
	Unknown	5	1.9	22	2.7
Down syndrome	Down syndrome	19	7.4	130	16.4
	No Down syndrome	184	71.6	540	68.1
	Unknown	54	21.0	123	15.5
Residential status	Facility with intensive care and support	76	29.6	481	60.7
	Community-based living	161	62.6	276	34.8
	Independent with ambulatory support	17	6.6	30	3.8
	With relatives	3	1.2	6	0.8
Mobility	Independent	239	93.0	492	62.0
	With walking aid	13	5.1	138	17.4
	Wheelchair	0	0.0	107	13.5
	Unknown	5	1.9	56	7.0

Table 2 Levels of physical activity in the study population (n=257)

Category	Steps/day	n	Percentage (95% CI)	Cumulative percentage(95% CI)
Sedentary	< 5,000	99	38.5 (32.6 – 44.5)	38.5 (32.6 – 44.5)
Low active	5,000-7,499	65	25.3 (20.0 – 30.6)	63.8 (57.9 – 69.7)
Somewhat active	7,500-9,999	50	19.5 (14.6 – 24.3)	83.3 (78.7 – 87.8)
Active	10,000-12,500	29	11.3 (7.4 – 15.2)	94.6 (91.8 – 97.3)
Highly active	>12,500	14	5.4 (2.7 – 8.2)	100.0
Total		257	100.0	

Table 3 Results of the regression analysis (n=169)

	Standardised β coefficient	Sig.	Adjusted R square	F change	Sig. F change
Female gender	-0.158*	0.031	0.134*	3.977	0.048
Older age	-0.270*	0.001			
Residential status	0.084	0.250			
More severe level of ID	-0.201*	0.008			
Presence of Down syndrome	-0.152	0.050			
Epilepsy	-0.030	0.681			
Mobility impairment	-0.146*	0.048			

* significant at p <0.05

Table 4 Data on physical activity in the subgroups

Variable	Categories	n	Mean	SD	Percentage ≥10,000 steps/day	Percentage ≥7,500 steps/day
Total		257	6601	3610	16.7	36.2
Gender	Male	133	7193	4063	21.8	42.9
	Female	124	5966	2937	11.3	29.0
Age (years)	50-59	146	7038	3565	17.8	41.1
	60-69	83	6578	3699	18.1	34.9
	70-79	25	4616	2818	8.0	16.0
	80-89	3	2511	1336	0.0	0.0
Level of ID	Borderline	11	8321	3368	27.3	63.6
	Mild	88	7018	3291	22.7	44.3
	Moderate	143	6347	3816	12.6	29.4
	Severe	10	5487	2428	10.0	30.0
	Unknown	5	4993	4398	20.0	40.0
Mobility	Independent	239	6745	3609	17.2	37.7
	With walking aid	13	3775	2712	7.7	7.7
	Unknown	5	7041	3095	20.0	40.0

DISCUSSION

This first study of objectively measured physical activity levels in a near-representative sample of 1,050 older adults with ID, shows that only 257 of the group were able to participate in valid measurements with pedometers. This low number is largely due to physical limitations (n=103), walking speed < 3.2 km/h (n=252), and limited understanding or non-cooperation (n=233). Only 16.7% (95% CI 12.2-21.3) of the participants complied with the guideline of 10,000 steps/day, 36.2% (95% CI 30.3-42.1) took ≤ 7,500 steps/day, and 39% (95% CI 32.6-44.5) was sedentary (< 5,000 steps/day). Because the study sample comprised the more functionally able part of the total sample, this result is likely to be a considerable overestimation of the actual physical activity levels in this population.

Although some of the variables make a significant contribution in explaining steps/day (female gender, older age, more severe level of ID and mobility impairment), they explain only 13.4% of the variance. This indicates that low physical activity levels are not confined to one or more subgroups, but are seen across the entire population of older adults with ID; this suggests that other determinants (e.g. motivation and opportunity), may be important for physical activity in this population.

A strength of this study is the large and near-representative study population, objective measurement of physical activity, and the extensive analysis of non-participants. Based on the considerable investment in information, communication and motivation strategies at the start of the HA-ID study [18], together with support from the management of the care organizations involved, in our opinion this is the best obtainable result. Only the use of equipment that can reliably measure walking speeds of less than 3.2 km/h, such as the Stepwatch [30], might provide even more complete information.

A limitation of the present study is that pedometers measure ambulatory activity only, and not physical activity in all its forms. However, we consider the impact of this limitation to be relatively small, because walking is the most important form of physical activity in this population with ID [16].

A review on physical activity in younger adults with ID showed that 17.5%-33.0% meet the WHO criterion of 30 min of moderate-intensity physical activity per day, and that 20%-45% meet the criterion of 10,000 steps/day [2,31-32], whereas a more recent study found that 14% of 131 adults with mild to moderate ID met the criterion of 10,000 steps/day [11]. A methodological issue in these studies is the use of pedometers with a relatively high threshold for a minimal walking speed which can be measured reliably (± 5 km/h) [21,23,33-34]. Based on outcomes of our walking speed assessments, together with the fact that no walking speed assessment was mentioned in the protocols of previous studies, it is likely that participants with slower walking speeds were included in those studies, resulting in an underestimation of actual physical activity levels. The present study aimed to avoid this issue by only including participants with a sufficient walking speed; nevertheless, only 16.7% met the criterion of 10,000 steps/day.

A review of studies measuring physical activity with pedometers in different samples of community-dwelling older adults in the general population (numbers of participants ranging from 15 to 344) showed that the mean number of steps/day ranges from 2,000 to 9,000 steps/day [35]; however, differences in pedometer type, inclusion criteria, recruitment procedure and sealed/unsealed condition of the pedometers hinder accurate comparison. Two large-scale studies in the Dutch general population, based on self-report questionnaires, reported percentages of participants who are physically active for 30 minutes on at least 5 days of the week of, respectively, 65 and 52% (35-54 years), 59 and 73% (55-64 years), 58 and 70% (65-74 years), and 44 and 40% (75+ years) [36-37]_ENREF_40. The present study shows that physical activity levels are markedly lower in the older population with ID than in the general older population, even according to the mildest criterion of 7,500 steps/day or more: 41% (50-59 years), 35% (60-69 years) and 16% (70-79 years).

In conclusion, the group of even more functionally able older adults with ID are less active than both younger adults with ID and older adults in the general population. Outcomes of qualitative research on specific factors hampering an active lifestyle, as well as on factors motivating participation in movement programs, will support such policy and practice [38]. Prevention of a sedentary lifestyle and promotion of physical activity needs to become a priority for formal services and health care, and should be routinely incorporated in the daily support and care of this group.

REFERENCES

1. Patja K., Iivanainen M., Vesala H., et al., *Life expectancy of people with intellectual disability: a 35-year follow-up study.* J Intellect Disabil Res, 2000. **44 (Pt 5)**: p. 591-9.
2. Temple V.A., Frey G.C., and Stanish H.I., *Physical activity of adults with mental retardation: review and research needs.* Am J Health Promot, 2006. **21**(1): p. 2-12.
3. WHO, *Health and development through physical activity and sport*. 2003, World Health Organization, : Geneva, Switzerland.
4. WHO, *Global health risks: mortality and burden of disease attributable to selected major risks.* 2009, World Health Organization, : Geneva, Switzerland.
5. DHHS, *Physical Activity Guidelines Advisory Committee Report*. 2008, U.S. Department of Health and Human Services, : Rockville (MD).
6. Chodzko-Zajko W.J., Proctor D.N., Fiatarone Singh M.A., et al., *American College of Sports Medicine position stand. Exercise and physical activity for older adults.* Med Sci Sports Exerc, 2009. **41**(7): p. 1510-30.
7. DiPietro L., *Physical activity in aging: changes in patterns and their relationship to health and function.* J Gerontol A Biol Sci Med Sci, 2001. **56 Spec No 2**: p. 13-22.
8. Tudor-Locke C., Washington T.L., and Hart T.L., *Expected values for steps/day in special populations.* Prev Med, 2009. **49**(1): p. 3-11.
9. Caspersen C.J. and Merritt R.K., *Physical activity trends among 26 states, 1986-1990.* Med Sci Sports Exerc, 1995. **27**(5): p. 713-20.
10. Trost S.G., Owen N., Bauman A.E., et al., *Correlates of adults' participation in physical activity: review and update.* Med Sci Sports Exerc, 2002. **34**(12): p. 1996-2001.
11. Peterson J.J., Janz K.F., and Lowe J.B., *Physical activity among adults with intellectual disabilities living in community settings.* Prev Med, 2008. **47**(1): p. 101-6.
12. Finlayson J., Jackson A., Cooper S.A., et al., *Understanding predictors of low physical activity in adults with intellectual disabilities.* Journal of applied research in intellectual disabilities, 2009. **22**: p. 236-247.
13. Robertson J., Emerson E., Gregory N., et al., *Lifestyle related risk factors for poor health in residential settings for people with intellectual disabilities.* Res Dev Disabil, 2000. **21**(6): p. 469-86.
14. Rimmer J.H., Braddock D., and Marks B., *Health characteristics and behaviors of adults with mental retardation residing in three living arrangements.* Res Dev Disabil, 1995. **16**(6): p. 489-99.
15. Stanish H.I. and Draheim C.C., *Walking habits of adults with mental retardation.* Ment Retard, 2005. **43**(6): p. 421-7.
16. Draheim C.C., Williams D.P., and McCubbin J.A., *Prevalence of physical inactivity and recommended physical activity in community-based adults with mental retardation.* Ment Retard, 2002. **40**(6): p. 436-44.
17. Emerson E., *Underweight, obesity and exercise among adults with intellectual disabilities in supported accommodation in Northern England.* J Intellect Disabil Res, 2005. **49**: p. 134-143.

18. Hilgenkamp T.I., Bastiaanse L.P., Hermans H., et al., *Study healthy ageing and intellectual disabilities: Recruitment and design*. Res Dev Disabil, 2011. **32**(3): p. 1097–1106.
19. WMO, *Medical Research Involving Human Subjects Act*. 1999: http://www.ccmo-online.nl/main.asp.
20. Crouter S.E., Schneider P.L., and Bassett D.R., Jr., *Spring-levered versus piezo-electric pedometer accuracy in overweight and obese adults.* Med Sci Sports Exerc, 2005. **37**(10): p. 1673-9.
21. Grant P.M., Dall P.M., Mitchell S.L., et al., *Activity-monitor accuracy in measuring step number and cadence in community-dwelling older adults.* J Aging Phys Act, 2008. **16**(2): p. 201-14.
22. Marsh A.P., Vance R.M., Frederick T.L., et al., *Objective assessment of activity in older adults at risk for mobility disability.* Med Sci Sports Exerc, 2007. **39**(6): p. 1020-1026.
23. Pitchford E.A. and Yun J., *The accuracy of pedometers for adults with Down syndrome.* Adapt Phys Activ Q, 2010. **27**(4): p. 321-36.
24. Hilgenkamp T.I., van Wijck R., and Evenhuis H.M., *Physical fitness in older people with ID-Concept and measuring instruments: a review.* Res Dev Disabil, 2010. **31**(5): p. 1027-38.
25. Hilgenkamp T.I.M., van Wijck R., and Evenhuis H.M., *Measuring physical activity with pedometers in older adults with intellectual disabilities: reactivity and number of days.* Intellect Dev Disabil, 2011. **In press**.
26. Tudor-Locke C. and Bassett D.R., Jr., *How many steps/day are enough? Preliminary pedometer indices for public health.* Sports Med, 2004. **34**(1): p. 1-8.
27. Marshall S.J., Levy S.S., Tudor-Locke C.E., et al., *Translating physical activity recommendations into a pedometer-based step goal: 3000 steps in 30 minutes.* Am J Prev Med, 2009. **36**(5): p. 410-5.
28. Rowe D.A., Kemble C.D., Robinson T.S., et al., *Daily walking in older adults: day-to-day variability and criterion-referenced validity of total daily step counts.* J Phys Act Health, 2007. **4**(4): p. 434-46.
29. Haskell W.L., *J.B. Wolffe Memorial Lecture. Health consequences of physical activity: understanding and challenges regarding dose-response.* Med Sci Sports Exerc, 1994. **26**(6): p. 649-60.
30. Foster R.C., Lanningham-Foster L.M., Manohar C., et al., *Precision and accuracy of an ankle-worn accelerometer-based pedometer in step counting and energy expenditure.* Prev Med, 2005. **41**(3-4): p. 778-83.
31. Stanish H.I., *Accuracy of pedometers and walking activity in adults with mental retardation.* Adapt Phys Activ Q, 2004. **21**: p. 167-179.
32. Stanish H.I. and Draheim C.C., *Assessment of walking activity using a pedometer and survey in adults with mental retardation.* Adapt Phys Activ Q, 2005. **22**: p. 136-145.
33. Cyarto E.V., Myers A.M., and Tudor-Locke C., *Pedometer accuracy in nursing home and community-dwelling older adults.* Med Sci Sports Exerc, 2004. **36**(2): p. 205-9.
34. Le Masurier G.C. and Tudor-Locke C., *Comparison of pedometer and accelerometer accuracy under controlled conditions.* Med Sci Sports Exerc, 2003. **35**(5): p. 867-71.
35. Tudor-Locke C., Hart T.L., and Washington T.L., *Expected values for pedometer-determined physical activity in older populations.* Int J Behav Nutr Phys Act, 2009. **6**: p. 59.

36. Hildebrandt V.H., Chorus A.M.J., and Stubbe J.H., *Trend report Physical activity and Health 2008/2009 [available only in Dutch: TNO Trendrapport Bewegen en Gezondheid 2008/2009]*. 2010, TNO Quality of life, : Leiden.

37. Wendel-Vos G.C. and Frenken F., *Physical activity in the Netherlands based on the 2001-2009 data from POLS of Statistics Netherlands (CBS) (Chapter 10)*, in *Trendrapport Bewegen en Gezondheid 2008/2009*. 2010, TNO, : Leiden.

38. Bartlo P. and Klein P.J., *Physical activity benefits and needs in adults with intellectual disabilities: systematic review of the literature.* Am J Intellect Dev Disabil, 2011. **116**(3): p. 220-32.

Chapter 5

Physical fitness in older people with ID - Concept and measuring instruments: A review

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ABSTRACT

A certain level of physical fitness is a prerequisite for independent functioning and self-care, but the level of physical fitness declines with ageing. This applies to older adult with intellectual disabilities too, but very little is known about their actual level of physical fitness. This lack of knowledge is partly caused by a lack of suitable instruments to measure physical fitness in this group, but the search for and choice of instruments depends on the operationalisation of the concept physical fitness for specific this target population. In this article the advantages of two known definitions of physical fitness are combined, leading to a combination of seven components to describe physical fitness in older adults with intellectual disabilities: coordination, reaction time, balance, muscular strength, muscular endurance, flexibility and cardio-respiratory endurance.

A literature search for all instruments to measure any of these components resulted in a large number of available instruments. These instruments were evaluated according criteria of functionality, reliability and feasibility in this target population. The aim of this article was to propose a selection of instruments which complied with these criteria and creates possibilities for widespread use and sharing and/or pooling of data.

The proposed selection of tests to measure physical fitness in older adults with intellectual disabilities is: Box and block test, Reaction time test with an auditive and visual signal, Berg balance scale, Walking speed comfortable and fast, Grip strength with a hand dynamometer, 30 sec Chair stand, Modified back saver sit and reach and the 10 m Incremental shuttle walking test.

INTRODUCTION

Background

Physical fitness describes how 'fit' a person physically is to cope with the demands set by his/her environment. For older adults to continue living independently, these demands include Activities of Daily Life (ADL) and Instrumental Activities of Daily Life (IADL) [1]. ADL are activities necessary for self-care, like eating or bathing. IADL cover activities necessary for independent living, like cleaning, cooking or doing groceries [2]. These demands are not different for older people without or with intellectual disabilities. To execute these activities, and maintain living independently, a certain level of physical fitness is required [1,3]. For people with physical fitness levels below this required level, it is often necessary to relocate to a care-facility.

The level of fitness declines with ageing [4,5]. The natural ageing process in the body itself is called primary ageing, and this process causes physical fitness to decline directly. Secondary ageing includes all changes influenced by the primary ageing process, such as age-related health conditions and lower activity levels. These changes further reduce physical fitness [6].

Older adults with intellectual disabilities (ID) experience a similar primary and secondary ageing process as older adults without ID [7], but this group has some additional risk factors for low levels of physical fitness. Low levels of physical activity in younger adults with ID suggest a low level of physical fitness at a young age, probably at older age as well [8]. Secondly, this group has high prevalence rates of sensory conditions and motor conditions, often leading to secondary arthritis, which influence physical fitness negatively [9,10]. With these differences in the secondary ageing process, older adults with ID are probably at an even higher risk of not meeting the physical demands set by the environment to live as independently as possible than older adults without ID. Because their intellectual disability already causes some degree of dependence on others, one could argue that the role of physical fitness in living as independently as possible, is even more important than in older people without ID.

Research of the last decade has shown that the secondary ageing process can be partly slowed down or reversed by physical activity [11], but more information about the actual physical fitness levels of older people with ID is necessary to apply this knowledge usefully to this group. However, to our best knowledge, there is no information available concerning reliable and feasible instruments to measure physical fitness in older adults with ID. The aim of this article is to propose a selection of instruments to measure physical fitness in older adults with ID which is functional, reliable and feasible, to create possibilities for widespread use and comparing, sharing and/or pooling of data.

Theoretical framework

First, we need to describe what physical fitness for older people is. In this paper, physical fitness is related to ADL and IADL, since these activities are a prerequisite for self-care and independent living.

Despite different opinions on the exact dimensions and components of the concept physical fitness, there is consensus about its multidimensional nature [12].

The American College of Sports Medicine uses the definition of physical fitness of the U.S. Centers for Disease Control and Prevention [13]: "Physical fitness is a set of attributes that people have or achieve that relates to the ability to perform physical activity." Furthermore the U.S. Centers for Disease Control and Prevention offer a distinction between health-related components and athletic ability (or performance-related) components: "The health-related components are more important to public health than the athletic ability components" but "operational definitions of physical fitness vary with the interest and need of the investigators" (U.S. Centers for Disease Control and Prevention).

The health-related and performance-related components of physical fitness according to the U.S. Centers for Disease Control and Prevention are shown in Table 1.

For independent functioning, looking only at health-related components is too limited to describe physical fitness. Activities of daily life can be as much as a performance for one person as a sports match for another person. This is why performance-related components also play a role in independent functioning in older adults, although not all of the components mentioned in Table 1 are equally relevant. Speed is not necessary to perform activities of daily life, and neither is power (maximal strength output in one short interval). Balance encompasses a static and dynamic component and therefore agility (ability to turn quickly) as a separate component is less relevant. Thus, the operation of physical fitness of the U.S. Centers for Disease Control and Prevention is constructive, specific and measurable, but lacks any clustering of related components.

To achieve clustering of the remaining relevant components, Bouchard et al. (1994) provide a useful classification. According to these authors, health-related fitness refers to those components of fitness that are affected favorably or unfavorably by habitual physical activity and which are related to health status [1].

The authors defined it as "a state characterized by (a) an ability to perform daily activities with vigor and (b) demonstration of traits and capacities that are associated with a low risk of premature development of hypokinetic diseases and conditions" and presented a list of factors of health-related fitness, clustered in components (Table 2)

Table 1: Health-related and performance-related components of physical fitness according to U.S. Centers for Disease Control and Prevention.

Health- related components	Performance-related components
Cardiorespiratory Fitness	Balance
Body Composition	Reaction Time
Flexibility	Coordination
Muscular Strength	Agility
Muscular Endurance	Speed
	Power

Table 2: Components of health-related fitness according to Bouchard et al. (1994)

Components of health-related fitness				
Morphological	**Muscular**	**Motor**	**Cardiorespiratory**	**Metabolic**
- Body mass for height - Body composition - Subcutaneous fat distribution - Abdominal visceral fat - Bone density - Flexibility	- Power - Strength - Endurance	- Agility - Balance - Coordination - Speed of movement	- Submaximal exercise capacity - Maximal aerobic power - Heart functions - Lung functions - Blood pressure	-Glucose tolerance -Insulin sensitivity - Lipid and lipoprotein metabolism - Substrate oxidation characteristics

Table 3: Combining components of physical fitness

Components according to Bouchard et al. (1994)	Components according to U.S. Centers of Disease Control and Prevention	New suggested combination of components
Motor	Coordination	**Physical fitness of older adults**
	Reaction time	
	Balance	
Muscular	Muscular strength	
	Muscular endurance	
	Flexibility	
Cardiorespiratory	Cardiorespiratory fitness	
Morphological	Body composition	Morphological fitness
Metabolic		Metabolic fitness

[12]. The components in this model are grouped at a different level than the components in the definition of the U.S. Centers for Disease Control and Prevention.

All mentioned components are distinguished theoretically, but are intertwined in their functioning practically. Morphological and metabolic components have an indirect influence on the execution of activities [14], they provide conditions in which activities can be performed. The muscular, motor and cardiorespiratory component have a crucial, active role in the actual execution of activities. In Table 3, the remaining relevant components of physical fitness (health- and performance related) from the model of the U.S. Centers of Disease Control and Prevention are combined with the components from Bouchard et al., to achieve a clustering in the components of the U.S. Centers of Disease Control and Prevention.

As said, the muscular, motor and cardiorespiratory component are crucial in the actual execution of activities, and therefore physical fitness of older people in this article is based on these three components according to Bouchard, operationalised in the seven components of the U.S. Centers of Disease control and prevention (third column in Table 3).

METHODS

Literature search

A literature search in Pubmed, Embase and Web of Science was performed in April 2008 for all instruments used to measure any of the selected components of physical fitness (Table 3). The used search terms for the selected components are shown in Table 4. Muscular strength and muscular endurance are combined in one set of search terms and discussed together because they share the search term 'muscular' and therefore will result for a large part in the same selection of articles.

To identify which instruments were already in use for specific populations, we combined these search terms with synonyms for older people, with synonyms for intellectual disability and with a combination of these two.

Google Scholar was also used to search for instruments. A website with an extensive overview of all kinds of instruments used by physiotherapists, was used to complement the search with missing instruments (Centre of Evidence-Based Physiotherapy: www.cebp.nl), together with expert consultation of physiotherapists. All instruments mentioned in these articles, reports and website were collected without further inclusion or exclusion criteria.

Evaluation of instruments

All instruments collected from the different sources were evaluated according to the following criteria.

Criterion 1: The instrument needed to use a functional task to measure the specific component. Functional in this context means a task that is equal to or resembles a task executed in Activities of Daily Life, but which is executable in a standardized environment. A performance on an everyday task gives more useful information diagnostically,

Table 4 Search terms for all fitness components

Component	Search terms
Coordination	(manual dexterity) OR (manual ability) OR (manual speed) OR (coordination)
Reaction time	(reaction time) OR (movement time)
Balance	balance OR stability OR sway OR agility
Muscular strength	strength OR (muscular strength) OR (muscular endurance)
Muscular endurance	
Flexibility	flexibility OR (range of motion) (AND hip or AND shoulder)
Cardiorespiratory endurance	endurance OR (cardiorespiratory endurance) OR (cardiovascular endurance) OR (cardiovascular fitness) OR (cardiorespiratory fitness) OR (cardiorespiratory capacity) OR (cardiovascular capacity) OR aerobic OR (oxygen consumption)
Older adults	older adults OR old* OR senior OR geriatr* OR aged AND ((middle age(MeSH)) OR aged(MeSH))
Intellectual disability	(mental retardation) OR (intellectual disabilit*) OR (learning disabilit*) OR (developmental disabilit*) OR (cognitive disabilit*) OR (mental handicap) OR (Down syndrome)

Table 5 Description of important functional tasks per component

Components	Description important functional tasks
Manual dexterity	Picking up or grasping larger objects and moving them to another place
Reaction Time	Responding to a visual and/or auditive signal
Balance	Moving in and around house: walking (gait), turning, reaching, standing, rising from a chair, sitting. Multiple tasks cover the multidimensional concept of balance better than single tasks. Gait is an important aspect of balance.
Muscle strength and muscle endurance	Muscle endurance: Climbing stairs, walking, standing Strength: Carrying something heavy, opening doors.
Flexibility	Bending over (to dress oneself, pick up something)
Cardiorespiratory Endurance	Walking, standing

therapeutically and prognostically, than indirect and nonspecific tests [15]. To this end, for each component, 'functional' was described beforehand (Table 5). Important to realize is that all components always work together to execute a specific task, no task is completely executed by one component only. However, the functional tasks described in the table below are for the larger part influenced by the mentioned components.

Criterion 2: The instrument needed to have at least one reference to a reliability or validity study of this instrument.

Criterion 3: The instrument needed to be feasible for older adults with ID. Feasibility encompassed the following aspects: scoring (objectively is preferred), inclusion criteria, level of difficulty of the instructions to the participant, level of difficulty of the execution of the task itself, availability of reference values, requirements observer

Table 6 Number of instruments found using various sources

Component	Literature search	European report	Dutch report	CEBP	Experts	Total
Manual dexterity	15		1			16
Reaction Time	1				1	2
Balance	40		2	1	3	46
Muscle Strength and Endurance	15	1				16
Flexibility	13		1			14
Cardiorespiratory Endurance	14					14
Total	98	1	4	1	4	108

Table 7 Number of instruments used in specific populations

Component	General population	General older population	Adult population with ID	Older population with ID
Manual dexterity	16	10	3	
Reaction Time	2	2	1	
Balance	46	32	11	5
Muscle Strength and Endurance	16	11	8	1
Flexibility	14	10	2	1
Cardiorespiratory Endurance	14	9	1	
Total	108	74	26	7

and duration of tests . Some other aspects are relevant too, but are dependent on the specific setting of a study, such as requirements of circumstances and costs and mobility of equipment. With our aim in mind, objective scoring is considered the most important aspect in this article, as this will provide possibilities for widespread use and sharing and/or pooling of data in this specific target population.

These three criteria were used in this order, narrowing down the selection of possibly useful instruments with each criterion. An instrument had to meet all three criteria in order to be considered fit for selection. If more than one instrument for a specific component passed all criteria, further judgement of instruments was done in an expert meeting of 7 physiotherapists and movement experts with several years of experience in working with older adults with ID. They added their expert knowledge to the evaluation of feasibility and gave advice about which instruments would be the most suitable in practice.

RESULTS

Literature search

The literature search in the databases Pubmed, Web of Science and Embase generated 98 different instruments (Table 6). Google Scholar found two relevant reports of the European Network for Action on Ageing and Physical Activity: "European Report of an Expert Survey regarding Assessment Instruments on Physical Activity and Physical Functioning in Older People (Work Package 4)" [16] and the Dutch "National Report on Assessment Instruments for Physical Activity and Physical Functioning in Older People in the Netherlands" [17]. These reports identified 5 instruments not yet found in the literature search. The website of the Centre for Evidence-based Physiotherapy (CEBP) mentioned 1 instrument which was not collected yet by the other sources and experts mentioned an additional 4 instruments which were not found using any of the other sources. A total overview of all instruments can be found in Appendix 1.

The use of instruments in different subgroups, (older adults, in adults with intellectual disabilities (ID) and older adults with ID) was identified from the information available from the used sources and is shown in Table 7.

Evaluation of instruments

All 108 instruments were evaluated first on functionality. Of 108 instruments, 58 did not comply with the described criteria for functionality. See appendix 1 for a complete overview of the instruments.

The second criterion was applied to the remaining 50 instruments that were based on a functional task. The psychometric properties of 9 of the remaining 50 instruments were unavailable in all mentioned sources and were therefore excluded. Some of the instruments are widely studied, but others only have one or two references in all sources, which gives too little information to do a more qualitative in-depth review regarding this criterion (appendix 1).

The third criterion, feasibility, was applied to the remaining 41 instruments and will be discussed below per component.

Manual dexterity

For the component manual dexterity, 8 instruments are based on a functional task and had available psychometric properties. All 8 instruments used objective scoring as well. The Action Research Arm Test [18], the Jebsen Hand Function test [19], the Frenchay Arm test [20] and the Moberg Pick Up [21] test all work with different tasks with various objects. For people with intellectual disabilities some of these tasks are too difficult to execute, the instructions for a number of different objects are too complicated for a large part of this population and the various different objects could elicit several kinds of reactions besides the intended or instructed reaction. The MUGI observation checklist [22] and the NK Dexterity board [23] do not have reference values, so the results of these tests are difficult to interpret. The Box and Block test [24] and the Minnesota Manual Dexterity test [25] do not have the disadvantages mentioned above. Comparing these two, the Box and Block test has easier instructions (pick up blocks and place them in the box on the other side) than the Minnesota Manual Dexterity test (pick up blocks and place them in a specific sequence in a board). In this test, the specific sequence in placing the blocks in the board is required and might therefore be more difficult than the Box and Block test, where the outcome is simply the number of blocks replaced in 60 seconds. This makes the Box and Block test the preferred choice.

Reaction time

There is only one instrument to measure simple reaction time with an auditive and visual signal. An instrument with both signals is preferred because this includes more participants. This is a simple reaction time task on a laptop. The laptop produces a signal (auditive or visual) and the participant is asked to respond as quickly as possible by pressing any key on the keyboard [26-29]. The outcome is the median reaction time of 15 trials, in milliseconds.

Balance

Five multiple-task instruments to measure static and dynamic balance passed the first two selection criteria and 4 instruments to measure gait passed the first two selection criteria.

Of the multi-task instruments, the Pediatric Balance Scale [30], the Balance Outcome Measure for Elder Rehabilitation [31] and the Gait and Balance Scale [32] lack reference values, resulting in difficulties with interpreting the results of participants. The remaining two instruments are the Berg Balance Scale (BBS) [33] and Tinetti's Performance-Oriented Mobility Assessment (POMA) [15]. The level of difficulty of instructions and execution is almost equal for the first part of the test because the tasks are similar (sitting, rising from a chair, standing, eyes closed, turning 360 degrees), but the BBS proceeds with tasks with increasing difficulty (picking up object, tandem stance, standing one leg). Therefore this instrument is more difficult in instructions to and execution by the participant. In various POMA-studies a variation in number of test items and cut-off scores has been used [34], which leads to a confusing description of the instrument. In contrast the standardized BBS protocol has been used in all the selected papers. Despite the fact that the scoring of both the instruments is ordinally, the answering categories of the POMA are subjectively evaluated (i.e. unsteady versus steady), whereas the BBS scoring is based on objectively measurable numbers (i.e.

number of seconds, number of steps), making the BBS the preferred test to measure balance.

Of the 4 instruments measuring gait which have passed the first two selection criteria, two of the instruments involve expensive and/or immobile equipment. Therefore, these two instruments, the Wisconsin Gait Scale (which involves videotaping the walking tasks) [35] and the GAITrite (laboratory setting) [36] are not feasible to measure gait in this population. The Dynamic Gait Index [37] scores ordinally, but uses subjectively described answering categories, which makes this instrument less suitable. The fourth instrument, Walking speed, measures only gait speed (comfortable and fast) by measuring the time a participant needs to walk a defined distance (i.e. 3 meters, 10 meters). This instrument is not expensive or difficult, yet objective and mobile, so the most feasible way to measure gait in various settings.

Muscle strength and muscle endurance

A hand dynamometer, measuring grip strength, was the only instrument considered to be functional and having available psychometric properties to measure muscle strength [38].

To measure muscle endurance, 4 instruments passed the first two selection criteria. These instruments were the Arm Curl test [39], the Chair Stand 5 times [40], the Chair Stand 10 times [39] and the Chair Stand 30 seconds [39].

All of these tests were evaluated feasible as well, based on available information from literature. In the expert meeting, the Arm Curl test was judged to be too difficult to execute and to instruct to a participant, because of the endorotation while flexing the arm. The various versions of the Chair Stand were similar in execution, but the inclusion level differed slightly. In the Chair Stand 5 times and Chair Stand 10 times, the participant has to be able to stand up as quick as possible from a chair 5 or 10 times consequently to get a result on this test. The 30 second Chair Stand does not require a minimum of 5 rises from a chair and has therefore a lower participation threshold.

Flexibility

Seven instruments to measure flexibility met the first two selection criteria. As Cailliet [41] suggested, simultaneously stretching both hamstrings may result in excessive posterior disk compression due to the anterior portion of the vertebrae being pressed together [42]. Therefore, 4 instruments which use both legs at the same time, the Stand and Reach [4], the classical Sit and Reach [43], the V Sit and Reach [44] and the Modified Sit and Reach [45] are not recommendable for use in older people with ID. The other three instruments passed the criteria of feasibility and were discussed in the expert meeting:

Chair Sit and Reach [39], Back Saver Sit and Reach [44] and the Modified Back Saver Sit and Reach [42]. Comparing these three, the first difference is in starting position: for the Chair Sit and Reach and the Modified Back Saver Sit and Reach, the participant sits on a chair or a bench, while for the Back Saver Sit and Reach the participant takes place on the floor, which is less comfortable for older adults. The second difference is the direction of reaching: the Back Saver Sit and Reach and the Modified Back Saver Sit and Reach both reach horizontally, while the Chair Sit and Reach reaches downward, which could be frightening for the participant. The third difference is the difficulty of the starting position. The starting position of the Chair Sit and Reach is much less defined than the starting position of the other two tests, and needs more instruction. The starting position of the Back Saver Sit and Reach is more difficult to take than the starting position of the Modified Back Saver Sit and Reach, because the unstretched leg has to be bent to 90 degrees and for older adults this is an uncomfortable position. The Modified Back Saver Sit and Reach has none of the above disadvantages, and is therefore the most feasible. The expert meeting provided some recommendations to make this test easier and better executable for more older adults with intellectual disabilities. These recommendations were: 1) measure the distance from fingertips to malleolus lateralis, to avoid problems with foot deformations or spasms 2) measure the distance from the acromion to malleolus lateralis and the arm length, to compare participants with normal arm function with participants with abnormal arm function 3) if the leg cannot be stretched completely, measure the angle of the knee, using a goniometer.

Cardiovascular endurance

Ten instruments passed the two criteria of functionality and availability of psychometric properties. One of these instruments does not have reference values (2 Minutes walk [46]). The remaining nine instruments were all considered feasible, based on available information, and therefore were presented in the expert meeting. All instruments are based on the three interconnected variables distance, time and speed. When the distance is set, the participant needs to make an estimation of his/her optimal speed to walk this distance as quickly as possible. When the time is set, the participant again needs to make an estimation of his/her optimal speed to walk as much meters as possible. But exactly this planning of optimal speed is difficult for people with intellectual disabilities, often combined with little experience with their physical abilities. These factors lead to less feasibility of all instruments which require this estimation by the participants (Walking 1 mile [47], Walking 2 mile [48], Rockport 1 mile Field Test Equation [49], 6 Minute Walk [50] and 12 Minute Walk [51]). There are three instruments that have a set speed. The Groningen Walking test [14,52] has a starting speed of 3 km/h and increases in speed every three minutes for 12 minutes, thus controlling two out of three variables. This starting speed is too fast for a large part of the target population. The Incremental Shuttle Walking test [53] increases in speed every minute, and starts at a speed of 1,8 km/h, including a larger part of the target population. The Endurance Shuttle Walking test [54] needs the outcome of the ICSW to determine the speed at which this test is performed, which would cost a lot of extra time, thus also raising the inclusion level. This test is therefore less feasible than the ICSW by itself.

CONCLUSION AND DISCUSSION

We have operationalised physical fitness for older adults with intellectual disabilities by the following components: coordination, reaction time, balance, muscle strength, muscle endurance, flexibility and cardiorespiratory endurance. To measure physical fitness in this population, we propose the following functional and feasible instruments with known psychometric properties, suitable for widespread use: Box and Block test, Reaction time test with an auditive and visual signal, Berg Balance Scale, Walking speed comfortable and fast, Grip Strength with a hand dynamometer, 30 sec Chair Stand, Modified Back Saver Sit and Reach and the 10 m Incremental Shuttle Walking test.

In comparison to the total number of instruments, only a small number of instruments had been used in adults with ID or older adults without or with ID. This is not necessarily due to unsuitability of the other instruments, but more likely to the smaller amount of research that has been done in these populations. This is why the selection of instruments starts with all instruments found, not only those used in one of the specific populations.

The combination of ageing and having an intellectual disability sets very specific demands to instruments measuring physical fitness. Most of the proposed instruments differ from those already used in previous research in people with intellectual disabilities. In a majority of these studies, relatively more difficult instruments could be applied because the participants were young adults with mild to moderate intellectual disabilities [55-57], or elite athletes [58]. These groups are less demanding to be measured compared to an older group with the full range of levels of intellectual and physical disabilities. Moreover, a majority of the studies included relatively small numbers of participants, creating space and time for optimal guidance and solutions for mobility (or other) problems during execution of tasks. The selection of tests in this article will be executable even when there is limited time and/or a larger population to be measured.

The proposed instruments differ also from those already used in the general older population. Some of the instruments consist of familiar, daily tasks, which are not so common for older adults with intellectual disabilities, such as writing. Some of the instruments used in older adults are too complicated in verbal instructions.

We realize that others might prefer a different sequence in the criteria used, but because the final selection of instruments had to fulfill all three criteria, a different sequence would result in similar outcomes. Other researchers may prioritize criteria differently, or emphasize different aspects, depending on their specific clinical or research questions. This article aimed to propose a selection of tests which is functional, has known psychometric properties, while facing the specific demands set by this population, and offers possibilities for use in larger populations and for sharing and comparing of data.

This selection of eight instruments to measure physical fitness in older adults with intellectual disabilities was considered to be functional and feasible, with known psychometric properties in other populations. Future research is needed to establish the reliability and feasibility of the selected instruments and procedures in this specific population, a reliability and feasibility study by our research group is in progress.

REFERENCES

1. Bouchard C. and Shephard R.J., *Physical Activity, Fitness, and Health: The model and key concepts*, in *Physical Activity, Fitness and Health. International Proceedings and Consensus Statement*. 1994, Human Kinetics Publishers: Champaign.
2. Rosen M.J., Sorkin J.D., Goldberg A.P., et al., *Predictors of age-associated decline in maximal aerobic capacity: a comparison of four statistical models.* J Appl Physiol, 1998. **84**(6): p. 2163-70.
3. Mahoney F.I. and Barthel D.W., *Functional Evaluation: the Barthel Index.* Md State Med J, 1965. **14**: p. 61-5.
4. Bouchard C., Shephard R.J., and Stephens T., *Physical activity, fitness, and health: International proceedings en consensus statement*. 1994, Champaign: Human Kinetics Publishers.
5. *Physical Activity and Health. A report of the Surgeon General. Older Adults*, US Department of Health and Human Services, Editor. 1996.
6. Fleg J.L., Morrell C.H., Bos A.G., et al., *Accelerated longitudinal decline of aerobic capacity in healthy older adults.* Circulation, 2005. **112**(5): p. 674-82.
7. Graham A. and Reid G., *Physical fitness of adults with an intellectual disability: a 13-year follow-up study.* Res Q Exerc Sport, 2000. **71**(2): p. 152-61.
8. Temple V.A., Frey G.C., and Stanish H.I., *Physical activity of adults with mental retardation: review and research needs.* Am J Health Promot, 2006. **21**(1): p. 2-12.
9. van Schrojenstein Lantman-de Valk H.M., van den Akker M., Maaskant M.A., et al., *Prevalence and incidence of health problems in people with intellectual disability.* J Intellect Disabil Res, 1997. **41 (Pt 1)**: p. 42-51.
10. Evenhuis H.M., Theunissen M., Denkers I., et al., *Prevalence of visual and hearing impairment in a Dutch institutionalized population with intellectual disability.* J Intellect Disabil Res, 2001. **45**(Pt 5): p. 457-64.
11. Buchman A.S., Boyle P.A., Wilson R.S., et al., *Physical activity and motor decline in older persons.* Muscle Nerve, 2007. **35**(3): p. 354-62.
12. Pate R.R., *The evolving definition of fitness.* Quest, 1988. **40**: p. 174-179.
13. ACSM, *ACSM's Health-Related Physical Fitness Assessment Manual* 1st ed, ed. G.B. Dwyer and S.E. Davis. 2005, Baltimore, Lippincott: Williams & Wilkins. 180 p.
14. Lemmink K.A.P.M., *De Groninger Fitheidstest voor Ouderen. Ontwikkeling van een meetinstrument*. 1996, CIP-Gegevens Koninklijke Bibliotheek: Den Haag.
15. Tinetti M.E., *Performance-oriented assessment of mobility problems in elderly patients.* J Am Geriatr Soc, 1986. **34**(2): p. 119-26.
16. *European report: Expert survey regarding Assessment Instruments on Physical Activity and Physical Functioning in Older People*, in *Work Package 4*. 2007, European Network for Action on Ageing and Physical Activity: Sweden.
17. Vreede P.L.d. and Tak E.C.P.M., *National report on assessment instruments for physical activity and physical functioning in older people in the Netherlands*. 2007, TNO EUNAAPA: Leiden.

18. Lyle R.C., *A performance test for assessment of upper limb function in physical rehabilitation treatment and research*. Int J Rehabil Res, 1981. **4**(4): p. 483-92.
19. Jebsen R.H., Taylor N., Trieschmann R.B., et al., *An objective and standardized test of hand function.* Arch Phys Med Rehabil, 1969. **50**(6): p. 311-9.
20. Heller A., Wade D.T., Wood V.A., et al., *Arm function after stroke: measurement and recovery over the first three months.* J Neurol Neurosurg Psychiatry, 1987. **50**(6): p. 714-9.
21. Moberg E., *Objective methods for determining the functional value of sensibility in the hand.* J Bone Joint Surg Br, 1958. **40-B**(3): p. 454-76.
22. Ericsson I., *To measure and improve motor skills in practice.* Int J Pediatr Obes, 2008. **3 Suppl 1**: p. 21-7.
23. Turgeon T.R., MacDermid J.C., and Roth J.H., *Reliability of the NK dexterity board.* J Hand Ther, 1999. **12**(1): p. 7-15.
24. Mathiowetz V., Volland G., Kashman N., et al., *Adult norms for the Box and Block Test of manual dexterity.* Am J Occup Ther, 1985. **39**(6): p. 386-91.
25. Desrosiers J., Rochette A., Hebert R., et al., *The Minnesota Manual Dexterity Test: Reliability, Validity and Reference Values Studies with Healthy Elderly People.* Canadian Journal of Occupational Therapy, 1997. **64**(5): p. 270-276.
26. Hultsch D.F., MacDonald S.W., and Dixon R.A., *Variability in reaction time performance of younger and older adults.* J Gerontol B Psychol Sci Soc Sci, 2002. **57**(2): p. P101-15.
27. Myerson J., Robertson S., and Hale S., *Aging and intraindividual variability in performance: analyses of response time distributions.* J Exp Anal Behav, 2007. **88**(3): p. 319-37.
28. Gardepe J.P. and Runcie D., *Heart rate and reaction times for mentally retarded and nonretarded adults in subject- and experimenter-initiated tasks.* Am J Ment Defic, 1983. **88**(3): p. 314-20.
29. Lally M. and Nettelbeck T., *Intelligence, reaction time, and inspection time.* Am J Ment Defic, 1977. **82**(3): p. 273-81.
30. Franjoine M.R., Gunther J.S., and Taylor M.J., *Pediatric balance scale: a modified version of the berg balance scale for the school-age child with mild to moderate motor impairment.* Pediatr Phys Ther, 2003. **15**(2): p. 114-28.
31. Haines T., Kuys S.S., Morrison G., et al., *Development and validation of the balance outcome measure for elder rehabilitation.* Arch Phys Med Rehabil, 2007. **88**(12): p. 1614-21.
32. Thomas M., Jankovic J., Suteerawattananon M., et al., *Clinical gait and balance scale (GABS): validation and utilization.* J Neurol Sci, 2004. **217**(1): p. 89-99.
33. Berg K.O., Wood-Dauphinee S.L., Williams J.I., et al., *Measuring balance in the elderly: validation of an instrument.* Can J Public Health, 1992. **83 Suppl 2**: p. S7-11.
34. Kopke S. and Meyer G., *The Tinetti test: Babylon in geriatric assessment.* Z Gerontol Geriatr, 2006. **39**(4): p. 288-91.
35. Rodriquez A.A., Black P.O., Kile K.A., et al., *Gait training efficacy using a home-based practice model in chronic hemiplegia.* Arch Phys Med Rehabil, 1996. **77**(8): p. 801-5.

36. McDonough A.L., Batavia M., Chen F.C., et al., *The validity and reliability of the GAITRite system's measurements: A preliminary evaluation.* Arch Phys Med Rehabil, 2001. **82**(3): p. 419-25.
37. Shumway-Cook A. and Woollacott M., *Motor Control Theory and Applications*. 1995, Baltimore: Williams and Wilkins.
38. Mathiowetz V., Kashman N., Volland G., et al., *Grip and pinch strength: normative data for adults.* Arch Phys Med Rehabil, 1985. **66**(2): p. 69-74.
39. Rikli R.E. and Jones C.J., *Senior fitness test manual*. 2001: Human Kinetics Europe Ltd
40. Whitney S.L., Wrisley D.M., Marchetti G.F., et al., *Clinical measurement of sit-to-stand performance in people with balance disorders: validity of data for the Five-Times-Sit-to-Stand Test.* Phys Ther, 2005. **85**(10): p. 1034-45.
41. Cailliet R., *Low back pain syndrome*. 4th ed. 1988, Philadelphia: F.A. Davis. 176-179.
42. Hui S.S. and Yuen P.Y., *Validity of the modified back-saver sit-and-reach test: a comparison with other protocols.* Med Sci Sports Exerc, 2000. **32**(9): p. 1655-9.
43. AAHPERD, *Technical manual for the Health-related physical fitness test*. 1980, Reston, VA: American Alliance for health, physical education, recreation and dance (AAHPERD). 19-21.
44. (CIAR) C.I.f.a.r., *The Prudential FITNESSGRAM Test Administration Manual*. 1992, Dallas: Cooper Institute for Aerobic Research.
45. Hoeger W.W., Hopkins D.R., Button S., et al., *Comparing the sit and reach with the modified sit and reach in measuring flexibility in adolescents.* Pediatr Exerc Sci, 1990(2): p. 156-162.
46. Butland R.J., Pang J., Gross E.R., et al., *Two-, six-, and 12-minute walking tests in respiratory disease.* Br Med J (Clin Res Ed), 1982. **284**(6329): p. 1607-8.
47. Kline G.M., Porcari J.P., Hintermeister R., et al., *Estimation of VO2max from a one-mile track walk, gender, age, and body weight.* Med Sci Sports Exerc, 1987. **19**(3): p. 253-9.
48. Laukkanen R., Oja P., Pasanen M., et al., *Validity of a two kilometre walking test for estimating maximal aerobic power in overweight adults.* Int J Obes Relat Metab Disord, 1992. **16**(4): p. 263-8.
49. Rintala P., Dunn J.M., McCubbin J.A., et al., *Validity of a cardiorespiratory fitness test for men with mental retardation.* Med Sci Sports Exerc, 1992. **24**(8): p. 941-5.
50. Guyatt G.H., Sullivan M.J., Thompson P.J., et al., *The 6-minute walk: a new measure of exercise capacity in patients with chronic heart failure.* Can Med Assoc J, 1985. **132**(8): p. 919-23.
51. Cooper K.H., *A means of assessing maximal oxygen intake. Correlation between field and treadmill testing.* Jama, 1968. **203**(3): p. 201-4.
52. Lemmink K.A., Kemper H.C.G., De Greef M., et al., *Reliability of the Groningen Fitness Test for the Elderly.* J Aging Phys Act, 2001. **9**: p. 194-212.
53. Singh S.J., Morgan M.D., Scott S., et al., *Development of a shuttle walking test of disability in patients with chronic airways obstruction.* Thorax, 1992. **47**(12): p. 1019-24.
54. Revill S.M., Morgan M.D., Singh S.J., et al., *The endurance shuttle walk: a new field test for the assessment of endurance capacity in chronic obstructive pulmonary disease.* Thorax, 1999. **54**(3): p. 213-22.

55. Fernhall B., Pitetti K.H., Rimmer J.H., et al., *Cardiorespiratory capacity of individuals with mental retardation including Down syndrome.* Med Sci Sports Exerc, 1996. **28**(3): p. 366-71.
56. Pitetti K.H. and Boneh S., *Cardiovascular fitness as related to leg strength in adults with mental retardation*. Med Sci Sports Exerc, 1995. **27**(3): p. 423-8.
57. Rikli R.E. and Jones C.J., *Development and validation of a functional fitness test for community-residing older adults.* J Aging Phys Act, 1999. **7**: p. 129-161.
58. van de Vliet P., Rintala P., Frojd K., et al., *Physical fitness profile of elite athletes with intellectual disability.* Scand J Med Sci Sports, 2006. **16**(6): p. 417-25.

Appendix 1

Component	Name instrument	Source	Total instruments	Instruments used in older adults	Instruments used in people with ID	Instruments used in older adults with ID	Not selected because (1st, 2nd or 3rd criterion)
Manual dexterity	Action Research Arm Test	Literature search	yes	yes			Difficult instruction due to difference in objects (3)
	Box and Block test	Literature search	yes	yes			
	Finger tapping test	Literature search	yes	yes			Unusual task (1)
	Frenchay Arm Test	TNO aanvulling Nederland	yes	yes			Difficult instruction due to difference in objects (3)
	Jebsen Test	Literature search	yes	yes			Difficult instruction due to difference in objects (3)
	Minnesota Manual Dexterity test	Literature search	yes	yes			Difficult execution (3)
	Moberg Pick Up test	Literature search	yes	yes			Difficult instruction due to difference in objects (3)
	MUGI observation checklist	Literature search	yes				Lack of reference values (3)
	Nine Hole Peg test	Literature search	yes	yes			Fine finger dexterity(1)
	NK dexterity board	Literature search	yes				Lack of reference values (3)
	O'Connor test	Literature search	yes				Fine finger dexterity(1)
	Pearl transfer test	Literature search	yes		yes		Fine finger dexterity(1)
	Plate Tapping	Literature search	yes		yes		Unusual task (1)
	Purdue Pegboard test	Literature search	yes	yes	yes		Fine finger dexterity(1)
	Rosenbusch Test of Finger Dexterity	Literature search	yes				Fine finger dexterity(1)
	Soda Pop test (AAHPERD)	Literature search	yes	yes			No reliability data available (2)
Manual dexterity number of instruments found			16	10	3		
Reaction Time	React to visual or auditive stimulus by pushing a button	Literature search	yes	yes	yes		

	React to visual stimulus by pushing a button	Expert	yes	yes			Lack of reference values (3)
Reaction Time number of instruments found			2	2	1		
Balance	3,1 metres walking on 30 cm wide path	Literature search	yes	yes			No reliability data available (2)
	Balance Board	TNO aanvulling Nederland	yes	yes			Single task (1)
	Balance Outcome Measure for Elder Rehabilitation	Literature search	yes	yes			Lack of reference values (3)
	Berg's Balance Scale	Literature search	yes	yes	yes		
	Body sway on firm and compliant platform	Literature search	yes	yes			Single task (1)
	Bruininks-Oseretsky Test	Literature search	yes		yes		Too unspecified (1)
	Chair agility test (AAHPERD)	Literature search	yes	yes			Single task (1)
	Clinical Test of Sensory Interaction in Balance	Literature search	yes	yes	yes		Multi task scale, but only static balance (1)
	Dynamic Gait Index	Literature search	yes	yes	yes		Scoring subjectively (3)
	FICSIT 3-balance scale	Literature search	yes	yes			Multi task scale, but only static balance (1)
	FICSIT 4-balance scale	Literature search	yes	yes			Multi task scale, but only static balance (1)
	Figure of Eight	Literature search	yes	yes			Single task (1)
	Four Square Step Test	Literature search	yes				Single task (1)
	Functional Reach using elastic stick	Literature search	yes				Single task (1)
	Functional Reach/Forward Reach	Literature search	yes	yes	yes	yes	Single task (1)
	Gait and Balance Scale	Literature search	yes	yes			Lack of reference values (3)
	Gaitrite: swing/stance times, stride length en width	Literature search	yes	yes			High equipment costs and low mobility (3)

	Get Up and Go test	Literature search	yes	yes	yes	yes	Single task (1)
	Hauser Ambulation Index	Literature search	yes				Not performance-based (1)
	L Test	Literature search	yes	yes			Single task (1)
	Lateral Reach	Literature search	yes	yes			Single task (1)
	Modified Figure of Eight	Literature search	yes	yes			Single task (1)
	Multidirectional Reach Test	Literature search	yes	yes			Single task (1)
	Number of trials needed to stand on one leg for 30 seconds, eyes open	Literature search	yes		yes		Single task (1)
	One leg stance/Solec	Literature search	yes	yes	yes	yes	Single task (1)
	Papcsy-DePaepe test (profound)	Literature search	yes				Single task (1)
	Parallel Stance / Romberg test	Literature search	yes	yes			Single task (1)
	Pediatric Balance Scale	Literature search	yes				Lack of reference values (3)
	Rivermead Mobility Index	Literature search	yes				Not performance-based (1)
	Semitandem Stance (SPPB)	Literature search	yes	yes			Single task (1)
	Ski walking	Literature search	yes				Single task (1)
	Staplengteschaal (Steplength scale ed.)	Expert	yes				No reliability data available (2)
	Step test	Literature search	yes	yes			Single task (1)
	Stops walking while talking	TNO aanvulling Nederland	yes	yes			Single task (1)
	Tandem stance / Sharpened Romberg	Literature search	yes	yes	yes		Single task (1)
	Tandem walk	Literature search	yes	yes			Single task (1)
	The 180 Degree Turn	Literature search	yes	yes			Single task (1)
	The Full Turn 360	Literature search	yes		yes	yes	Single task (1)
	Timed Balance Test	Expert	yes				Single task (1)

	Timed Unsupported Steady Standing (TUSS)	Literature search	yes	yes			Single task (1)
	Tinetti Performance Oriented Mobility Assessment	Literature search	yes	yes			Scoring subjectively (3)
	Traplooptest: tijd om 7 treden op en af lopen (chairclimbtest: time to climb 7 stairs up and down ed.)	Expert	yes				Single task (1)
	TUG Manual	Literature search	yes	yes			Single task (1)
	TUG Timed Up and Go 5 meter	Literature search	yes	yes	yes	yes	Single task (1)
	Walking Speed	Literature search	yes	yes			
	Wisconson Gait Scale	CEBP	yes				High equipment costs and low mobility (3)
Balance number of instruments found			46	32	11	5	
Muscle Strength and Endurance	Arm Curl test (SPB, AAHPERD)	Literature search	yes	yes			Too difficult in execution (3)
	Bench Press	Literature search	yes		yes		Unusual task (1)
	Chair Stand 10 times	Literature search	yes	yes			High inclusion level (3)
	Chair Stand 3 times	Literature search	yes	yes			No reliability data available (2)
	Chair Stand 30 seconds	Literature search	yes	yes			
	Chair Stand 5 times (SPPB)	Literature search	yes	yes			High inclusion level (3)
	Chair Stand once	Literature search	yes	yes			No reliability data available (2)
	Climbing Boxes	TNO Questionnare	yes	yes			No reliability data available (2)
	Flexed arm hang	Literature search	yes	yes	yes		Unusual task (1)
	Flexors and extensors knee ankle Cybex	Literature search	yes	yes	yes		Unusual task (1)
	Grip Strength	Literature search	yes	yes	yes		
	Pull Ups	Literature search	yes		yes		Unusual task (1)
	Push Ups	Literature search	yes		yes		Unusual task (1)

	Quadriceps strength hand held dynamometer	Literature search	yes	yes		yes	Unusual task (1)
	Seated Leg Press Machine	Literature search	yes		yes		Unusual task (1)
	Timed Sit Ups	Literature search	yes		yes		Unusual task (1)
Muscle Strength and Endurance number of instruments found			16	11	8	1	
Flexibility	Back Saver Sit and Reach	Literature search	yes	yes			Difficult starting position (3)
	Back Scratch test	Literature search	yes	yes			Shoulder range of motion (1)
	Chair sit and reach (SFT)	Literature search	yes		yes		Difficult in execution (3)
	Felt covered round wooden table top, reach, goniometer	Literature search	yes	yes			Shoulder range of motion (1)
	Hand in Back	Literature search	yes	yes			Shoulder range of motion (1)
	Hand in Neck	Literature search	yes	yes			Shoulder range of motion (1)
	Modified Back Saver Sit and Reach	Literature search	yes				
	Modified sit and reach (AAHPERD)	Literature search	yes	yes			Difficult in execution (3)
	Pour out of Pot	Literature search	yes	yes			No reliability data available (2)
	Shoulder Circumduction Test	TNO aanvulling Nederland	yes	yes			Shoulder range of motion (1)
	Sit and reach (GFT) (AAHPERD	Literature search	yes	yes	yes		Difficult in execution (3)
	Stand and reach	Literature search	yes				Difficult in execution (3)
	Touch bell with feet on ascending line	Literature search	yes	yes		yes	No reliability data available (2)
	V Sit and Reach	Literature search	yes				Difficult in execution (3)
Flexibility number of instruments found			14	10	2	1	
Cardiorespiratory Endurance	12 minutes walking	Literature search	yes	yes			Difficult instructions (3)
	2 minutes walking	Literature search	yes	yes			Lack of reference values (3)
	3 minutes walking	Literature search	yes	yes			No reliability data available (2)
	6 minute walk test	Literature search	yes	yes			Difficult instructions (3)

	Chester Step test	Literature search	yes				Not walking (1)
	Duke Activity Status Index	Literature search	yes				Not walking (1)
	Endurance Shuttle Walking test	Literature search	yes	yes			High inclusion level (3)
	Groningen walking test	Literature search	yes	yes			High inclusion level (3)
	Half mile walk test (AAHPERD)	Literature search	yes	yes			Difficult instructions (3)
	Incremental Shuttle Walking test	Literature search	yes	yes			
	Rockport yes Mile Walking Field Test Equation (CEBP)	Literature search	yes				Difficult instructions (3)
	Treadmill or rowing ergometer VO2max	Literature search	yes	yes	yes		Not walking (1)
	Walking 1 mile	Literature search	yes				Difficult instructions (3)
	Walking 2 mile	Literature search	yes				Difficult instructions (3)
Cardiorespiratory Endurance number of instruments found			14	9	1		
Total			107	74	24	7	

Chapter 6

Feasibility and reliability of tests for measuring physical fitness in older adults with intellectual disabilities. A pilot study.

Thessa I.M. Hilgenkamp, Ruud van Wijck, Heleen M. Evenhuis

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ABSTRACT

Background: Physical fitness is relevant for well-being and health, but knowledge on the feasibility and reliability of instruments to measure physical fitness for older adults with intellectual disability, is lacking.

Methods: Feasibility and test-retest reliability of a physical fitness test battery (Box-and-block-test, Response-time-test, Walking speed, Grip strength, 30s-Chair-stand, 10m Incremental-shuttle-walking test and the Extended modified back-saver-sit-and-reach-test) were investigated in older adults with ID in a convenience sample of thirty-six older adults (mean age 65.9, range 50-89 years), with different levels of intellectual disability and mobility.

Results and conclusion: All tests which measure physical fitness in older adults with ID had moderate to excellent feasibility and had sufficient test-retest reliability (ICCs 0.63 – 0.96). No statistically significant learning effects were found.

INTRODUCTION

Physical fitness is necessary for older adults to maintain their independence and to prevent disability, and is therefore relevant to their well-being [1]. Although physical fitness declines naturally with age, older adults can maintain or improve their physical fitness by physical activity or structured exercise [2]. By doing so, they may increase their chances of living independently and without disability for a longer time.

The older population with intellectual disability (ID) is increasing, both by the ageing effect of the entire population, as in life expectancy, due to improved health care [3]. Several reasons indicate a risk of low physical fitness levels in this population. Lower physical fitness levels in younger adults with ID [4], low physical activity levels in older adults with ID [5], and high prevalence rates of multiple health problems, sensory impairments and motor impairments in the adult population with ID have been found [6,7]. These aspects may point towards lower levels of physical fitness for at least part of the population of older adults with ID, but so far, this has not been investigated.

Based on the descriptions of physical fitness used by the American College of Sports Medicine [8] and by Bouchard & Shephard [9], and the notion that some fitness components are more relevant for daily functioning than others [10], we proposed a combination of seven health-related and performance-related fitness components to describe physical fitness in older adults with ID: manual dexterity, response time, balance (static and dynamic), muscle strength, muscle endurance, aerobic endurance and flexibility. Subsequently, a literature search was conducted to find all available instruments to measure these fitness components. Of the retrieved instruments, we selected seven performance-based instruments based on their sound psychometric properties (mostly investigated in other populations), and their functionality and feasibility [11].

Before use of these instruments in older adults with ID in epidemiological research can be recommended, it is necessary to investigate their psychometric properties in a heterogeneous group, with varying limitations in cognition and mobility. In the present study we investigated the feasibility and test-retest reliability of seven selected performance-related tests for measuring components of physical fitness in older adults with ID.

METHODS

Participants

This pilot study is part of a large epidemiological study in older adults with ID titled 'Healthy ageing and intellectual disability (HA-ID)', of which the protocol was approved by the Medical Ethics Committee of the Erasmus University Medical Center Rotterdam, the Netherlands (MECnr. 2008-234), and of which recruitment and design have been published elsewhere [12]. All clients aged 50 years and older of a consort of three large Dutch ID services, or their legal representatives, were approached to give informed consent. The first 36 participants of this large epidemiological study were included in the present study as a heterogeneous sample of older adults with ID (Table 1).

Materials

Information about the seven selected performance-based physical fitness tests are presented in Table 2.

Instruction of observers

To ensure equal execution of all tests, all nine test observers received a test manual and a two-day training prior to the test days. Test observers were seven physiotherapists, one human movement scientist and one medical student, with several years of experience in working with people with intellectual disability.

Table 1 Characteristics of the study population

	Male	Female
Total (n)	12	24
Age (years)		
Mean (SD)	69.3 (9.9)	64.2 (9.8)
Range	53-89	50-86
Age categories (n)		
50-59 years	2	8
60-69 years	5	10
70-79 years	4	5
80-89 years	1	1
Severity of intellectual disability		
Borderline (IQ 70-80)	4	1
Mild (IQ 55-70)	1	7
Moderate (IQ 35-55)	6	10
Severe-profound (IQ <35)	1	6
Mobility		
Walking with no aid	9	12
Walking with aid	3	7
Wheelchair	0	5

Table 2 Information on the performance-based tests to measure physical fitness (ICC = intraclass correlation)

Physical parameter	Test name (abbreviation)	Applicability	Reliability
Manual dexterity	Box and block test (BBT) [18]	The participant has to move as many blocks from one side of a box to another in one minute	Interobserver reliability: ICC = 0.99 (n=37) [19] and test-retest reliability: ICC's of 0.89 and higher (n=95) [20].
Response time	Response time test (RTA and RTV) [21]	The participants had to respond to an auditive (RTA) or visual signal (RTV) by pressing a key of a laptop as quickly as possible.	Test-retest reliability: ICC = 0.75 (n=21)[22]
Dynamic balance	Walking speed (WSC and WSF) [23]	After 3 meters for acceleration, participants walked 5 meters at their personal comfortable speed (WSC) and than walked/ran 5 meters as fast as they could (WSF).	Interobserver reliability: ICC = 0.99, test-retest reliability: ICC = 0.99 (n=35) [24].
Muscle strength	Grip strength (GS) [25]	The participant squeezes a Jamar Hand Dynamometer (#5030J1, Sammons Preston Rolyan, USA) maximally in seated position [26].	Interobserver reliability: ICC = 0.98 (n=50) [27] and test-retest reliability: ICC = 0.98 (n=19) [28].
Muscle endurance	30s Chair stand (30sCS) [10]	The participant tries to sit and stand upright as often as possible in 30 seconds without using hands.	Interobserver reliability: ICC = 0.95 (n=15) [10] and ICC = 0.93 (n=82) [10,29]
Aerobic endurance	10m Incremental shuttle walking test (ISWT) [30]	The participant starts walking a ten-meter section at 0.50 m/s together with the test observer, who increased speed every minute; until the participant can no longer keep up with the pace.	Test retest reliability: ICC = 0.94 (n=353), Pearson correlations of 0.98 and higher (n=10) [30,31].
Flexibility	Extended version of the Modified back saver sit and reach test (EMBSSR) [11,32]	The participant sits on a chair, stretches one leg on a second chair. The arm length is measured when sitting straight and the distance from finger to heel, shoulder to heel and angle in the stretched leg are measured while bending over.	Test-retest reliability: ICC = 0.96 and 0.97 (n=158) [32].

Procedure

Participants performed the seven tests once on the first day (session 1), twice on the second day two weeks later (session 2 and session 3). Former research suggested the need for a practice session for tests of cardiovascular endurance as well as muscular strength [13-15]. For this reason, three tests were performed twice on the first day instead of once (10m Incremental-shuttle-walking-test, 30s Chair-stand and Grip strength).

Data analysis

Feasibility was operationalized in completion rates for the total sample and divided in quartiles, and characterised as low (≤25%), moderate (>25% and ≤50%), good (>50% and ≤75%) and excellent (>75%). For test-retest reliability, intraclass correlation coefficients (ICCs) were calculated between session 1 and session 2 of each test for long-time test-retest reliability (two-week interval), and between session 2 and 3 for short-time test-retest reliability. ICCs of 0.60 or higher were considered to be acceptable and ICCs of 0.9 or higher to be desirable. For a power of 0.80 we therefore needed a minimum number of 12 participants [16]. A learning effect was analyzed with Bland Altman analyses, if the zero is not included in the 95% confidence interval of the mean difference, a learning effect is considered to be present.

RESULTS

Feasibility

The Box-and-block-test and grip strength had excellent feasibility, the Visual-response-time test and 30 sec Chair-stand had moderate feasibility, and all other tests had good feasibility (see Table 3).

Test-retest reliability

Table 3 shows mean scores and standard deviations of all tests per session, as well as the intraclass correlation coefficients of the short-time and long-time interval. Test-retest reliability for both the short-time and long-time interval was acceptable or desirable for all tests.

Learning effect

The zero is included in all confidence intervals of the mean difference between the practice session and session 1 (30sCS 95%CI: -3.73 – 6.35; GS 95% CI: -5.93 – 4.51; ISWT 95%CI: -1.21 – 1.87).

DISCUSSION

This is the first study to investigate the feasibility and reliability of tests for measuring physical fitness in older people with ID. This study demonstrated that the seven studied tests to measure physical fitness had moderate to excellent feasibility and sufficient test-retest reliability in this specific population. The analyses revealed no statistically significant learning effect in the test results of the 10m Incremental-shuttle-walking-

Table 3 Completion percentages and results of all test sessions with test-retest reliability results

Test	%	Practice session		Session 1		Session 2		Session 3		Short-time Same-day interval		Long-time Two-week interval	
		Mean (SD)	n	Mean (SD)	n	Mean (SD)	n	Mean (SD)	n	ICC (95% C.I.)	n	ICC (95% C.I.)	n
BBT	86	NA	NA	25,7 (14.0)	31	24.3 (12.8)	32	27.1 (13.8)	31	0.90 (0.79-0.95)	31	0.90 (0.81-0.95)	30
RTV	47	NA	NA	1136.1 (452.5)	19	982.3 (418.5)	17	1036.9 (501.5)	16	0.75 (0.41-0.90)	16	0.72 (0.38-0.89)	17
RTA	53	NA	NA	1380.7 (973.6)	19	1197.3 (583.1)	18	1133.5 (718.4)	19	0.87 (0.69-0.95)	18	0.74 (0.43-0.90)	18
WSC	75	NA	NA	0.84(0.33)	26	0.85 (0.31)	28	0.89 (0.32)	26	0.96 (0.90-0.98)	26	0.93 (0.85-0.97)	26
WSF	50	NA	NA	1.36 (0.47)	18	1.48 (0.50)	19	1.43 (0.48)	18	0.96 (0.90-0.99)	17	0.90 (0.70-0.96)	17
30 s CS	44	7.3 (2.1)	18	9.0 (2.9)	16	9.3 (2.6)	16	8.3 (2.5)	15	0.72 (0.32-0.91)	15	0.65 (0.19-0.87)	14
GS	81	23.3 (7.6)	30	23.1 (7.9)	28	21.7 (7.9)	31	22.7 (8.1)	31	0.94 (0.87-0.97)	31	0.90 (0.80-0.95)	28
ISWT	61	3.5 (1.5)	24	4.1 (1.9)	19	3.9 (1.7)	23	4.1 (1.8)	21	0.90 (0.77-0.96)	21	0.76 (0.48-0.90)	18
EMBSSRL	75	NA	NA	-13.0 (11.9)	25	-10.1 (14.6)	28	-9.5 (14.7)	25	0.96 (0.91-0.98)	25	0.63 (0.29-0.83)	22
EMBSSRR	67	NA	NA	-13.9 (12.3)	26	-10.8 (11.8)	25	-9.0 (12.1)	24	0.95 (0.89-0.98)	23	0.71 (0.43-0.87)	22

BBT=Box-and-block test in number of blocks, RTV=Visual Response-time-test in milliseconds, RTA=Auditive Response-time-test in milliseconds, WSC=Walking speed comfortable in meter/second, WSF=Walking speed fast in meter/second, 30 s CS=30 second-chair-stand in number of sit-to-stands, GS=Grip strength in kilogram, ISWT=10m Incremental-shuttle-walking-test in number of completed minutes, EMBSSR=Extended Modified Back-saver-sit-and-reach left (EMBSSRL) and right (EMBSSRR) in centimetres test, the 30s Chair-stand and Grip strength. The older age of this sample might explain the lack of a learning effect [17].

For population-based epidemiological research, it is important to determine feasibility across age categories, residential settings, levels of ID and mobility levels, which were present in the current sample. Although numbers in subgroups were too small to make recommendations for clinical practice about which subgroups were unable to execute one or more physical fitness tests, the information on test-retest reliability and feasibility of this paper is useful for epidemiological research, which in turn will provide more information about the actual physical fitness levels in older adults with ID.

REFERENCES

1. WHO, *Global recommendations on physical activity for health*. 2010, World Health Organization: Geneva.
2. Chodzko-Zajko W.J., Proctor D.N., Fiatarone Singh M.A., et al., *American College of Sports Medicine position stand. Exercise and physical activity for older adults.* Med Sci Sports Exerc, 2009. **41**(7): p. 1510-30.
3. Patja K., Iivanainen M., Vesala H., et al., *Life expectancy of people with intellectual disability: a 35-year follow-up study.* J Intellect Disabil Res, 2000. **44 (Pt 5)**: p. 591-9.
4. Graham A. and Reid G., *Physical fitness of adults with an intellectual disability: a 13-year follow-up study.* Res Q Exerc Sport, 2000. **71**(2): p. 152-61.
5. Hilgenkamp T.I., Reis D., van Wijck R., et al., *Physical activity levels in older adults with intellectual disabilities are extremely low.* Res Dev Disabil, 2012. **33**(2): p. 477-486.
6. Evenhuis H.M., Theunissen M., Denkers I., et al., *Prevalence of visual and hearing impairment in a Dutch institutionalized population with intellectual disability.* J Intellect Disabil Res, 2001. **45**(Pt 5): p. 457-64.
7. van Schrojenstein Lantman-De Valk H.M., Metsemakers J.F., Haveman M.J., et al., *Health problems in people with intellectual disability in general practice: a comparative study.* Fam Pract, 2000. **17**(5): p. 405-7.
8. ACSM, *ACSM's Health-Related Physical Fitness Assessment Manual* 1st ed, ed. G.B. Dwyer and S.E. Davis. 2005, Baltimore, Lippincott: Williams & Wilkins. 180 p.
9. Bouchard C. and Shephard R.J., *Physical Activity, Fitness, and Health: The model and key concepts*, in *Physical Activity, Fitness and Health. International Proceedings and Consensus Statement*. 1994, Human Kinetics Publishers: Champaign.
10. Rikli R.E. and Jones C.J., *Senior fitness test manual*. 2001: Human Kinetics Europe Ltd
11. Hilgenkamp T.I., van Wijck R., and Evenhuis H.M., *Physical fitness in older people with ID-Concept and measuring instruments: a review*. Res Dev Disabil, 2010. **31**(5): p. 1027-38.
12. Hilgenkamp T.I., Bastiaanse L.P., Hermans H., et al., *Study healthy ageing and intellectual disabilities: Recruitment and design.* Res Dev Disabil, 2011. **32**(3): p. 1097–1106.
13. Blain H., Carriere I., Peninou G., et al., *Reliability of a new instrument for measuring maximum rising strength.* Am J Phys Med Rehabil, 2006. **85**(6): p. 502-8.
14. Solway S., Brooks D., Lacasse Y., et al., *A qualitative systematic overview of the measurement properties of functional walk tests used in the cardiorespiratory domain*. Chest, 2001. **119**(1): p. 256-70.
15. Ylinen J., Salo P., Nykanen M., et al., *Decreased isometric neck strength in women with chronic neck pain and the repeatability of neck strength measurements.* Arch Phys Med Rehabil, 2004. **85**(8): p. 1303-8.
16. Walter S.D., Eliasziw M., and Donner A., *Sample size and optimal designs for reliability studies.* Stat Med, 1998. **17**(1): p. 101-10.

17. Solana E., Poca M.A., Sahuquillo J., et al., *Cognitive and motor improvement after retesting in normal-pressure hydrocephalus: a real change or merely a learning effect?* J Neurosurg, 2009.
18. Mathiowetz V., Volland G., Kashman N., et al., *Adult norms for the Box and Block Test of manual dexterity.* Am J Occup Ther, 1985. **39**(6): p. 386-91.
19. Platz T., Pinkowski C., van Wijck F., et al., *Reliability and validity of arm function assessment with standardized guidelines for the Fugl-Meyer Test, Action Research Arm Test and Box and Block Test: a multicentre study.* Clin Rehabil, 2005. **19**(4): p. 404-11.
20. Desrosiers J., Bravo G., Hebert R., et al., *Validation of the Box and Block Test as a measure of dexterity of elderly people: reliability, validity, and norms studies.* Arch Phys Med Rehabil, 1994. **75**(7): p. 751-5.
21. Dunn J.M., *Reliability of selected psychomotor measures with mentally retarded adult males.* Percept Mot Skills, 1978. **46**(1): p. 295-301.
22. Lorbach E.R., Webster K.E., Menz H.B., et al., *Physiological falls risk assessment in older people with Alzheimer's disease.* Dement Geriatr Cogn Disord, 2007. **24**(4): p. 260-5.
23. Bohannon R.W., *Comfortable and maximum walking speed of adults aged 20-79 years: reference values and determinants.* Age Ageing, 1997. **26**(1): p. 15-9.
24. Tyson S.F. and DeSouza L.H., *Reliability and validity of functional balance tests post stroke.* Clin Rehabil, 2004. **18**(8): p. 916-23.
25. Mathiowetz V., Kashman N., Volland G., et al., *Grip and pinch strength: normative data for adults.* Arch Phys Med Rehabil, 1985. **66**(2): p. 69-74.
26. Fess E.E. and Moran C., *Clinical assessment recommendations*. 1981, Indianapolis, USA: American Society of Hand therapists Monograph.
27. Smidt N., van der Windt D.A., Assendelft W.J., et al., *Interobserver reproducibility of the assessment of severity of complaints, grip strength, and pressure pain threshold in patients with lateral epicondylitis.* Arch Phys Med Rehabil, 2002. **83**(8): p. 1145-50.
28. Paltamaa J., West H., Sarasoja T., et al., *Reliability of physical functioning measures in ambulatory subjects with MS.* Physiother Res Int, 2005. **10**(2): p. 93-109.
29. Gill S. and McBurney H., *Reliability of performance-based measures in people awaiting joint replacement surgery of the hip or knee.* Physiother Res Int, 2008. **13**(3): p. 141-52.
30. Singh S.J., Morgan M.D., Scott S., et al., *Development of a shuttle walking test of disability in patients with chronic airways obstruction*. Thorax, 1992. **47**(12): p. 1019-24.
31. Jolly K., Taylor R.S., Lip G.Y., et al., *Reproducibility and safety of the incremental shuttle walking test for cardiac rehabilitation.* Int J Cardiol, 2008. **125**(1): p. 144-5.
32. Hui S.S. and Yuen P.Y., *Validity of the modified back-saver sit-and-reach test: a comparison with other protocols.* Med Sci Sports Exerc, 2000. **32**(9): p. 1655-9.

Chapter 7

Feasibility of eight physical fitness tests in 1050 older adults with ID: Results of the HA-ID study

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Submitted

ABSTRACT

Although physical fitness is relevant for well-being and health, knowledge on feasibility of instruments to measure physical fitness in older adults with intellectual disabilities (ID) is lacking. As part of the study 'Healthy ageing and ID' with 1050 older clients with ID in three Dutch care services, feasibility of eight physical fitness tests was expressed in completion rates: Box-and-block-test, Response-time-test, Berg-balance-scale, Walking speed, Grip strength, 30s-Chair-stand, 10m Incremental-shuttle-walking test and the Extended modified-back-saver-sit-and-reach-test. All tests had moderate to good feasibility in all subgroups, except for participants with profound ID (all tests), severe ID (Response-time-test and Berg-balance-scale), and wheelchair users (all tests which involved the legs).

Used eight tests are feasible to measure physical fitness in most older adults with ID.

INTRODUCTION

Physical fitness is important for health and well-being of older adults [1-4]. Furthermore, physical fitness is a necessary attribute to independent functioning or to prevent disability [5-7].

The ageing population with intellectual disabilities (ID) is rapidly increasing due to longer life expectancy, as a result of improved healthcare, and an increase in absolute numbers of the total population [8]. Childhood mobility impairments, lifelong low physical activity levels [9,10], as well as multiple chronic health conditions, increasing with age, may be barriers to the maintenance of fitness in this group. Indeed, lower fitness than in the general population has already been demonstrated for younger adults with ID [11-13].

Low physical fitness is preventable or reversible in older adults by physical activity and structured exercise [14], which opens up possibilities to maintain or positively influence health and independence into old age. But to identify which groups would benefit most from intervention programmes or treatments, and to evaluate the effect of any intervention or treatment, instruments to measure physical fitness, applicable to this group, are required. So far, research has focused mainly on younger adults or adolescents, mostly with a mild or moderate level of ID [11-13,15,16]. Like in the general population, tests used in younger adults can be difficult for older adults, due to physical limitations caused by the ageing process. On the other hand, tests used in the general older population often rely, at least partly, on specific cognitive abilities, which cannot be assumed to be at the same level in the cognitively heterogeneous population with ID: some instruments consist of familiar, daily tasks, which are not so common for older adults with intellectual disabilities, such as writing in the Jebsen Hand Function test [17], and some of the instruments used in older adults have complicated verbal instructions, such as the Moberg Pick-up test [18], or the arm curl test [19]. It was therefore necessary to investigate how to measure physical fitness in this group. To propose a fitness test battery for older adults with ID, a multidimensional concept of physical fitness needed to be described for this group first. Based on existing theories on physical fitness [20,21], we have chosen the following aspects of fitness which are supposed to be of relevance to activities of daily life of ageing people: manual dexterity, reaction time, balance (static and dynamic), muscle strength, muscle endurance, cardiorespiratory endurance and flexibility [22]. In an extensive literature review all available instruments to measure physical fitness were identified, including those already used in older adults with ID or mild cognitive impairments. They were then evaluated for their functionality, validity and reliability in other populations. Expected feasibility in older adults with ID was evaluated by physiotherapists, experienced in working with this group. A thorough description of the selection process has been published elsewhere [22]. With this procedure, we assembled a battery consisting of eight tests, which proved to have sufficient test-retest reliability in a heterogeneous sample of 36 older people with ID [23]. Feasibility for use of these instruments in large-scale epidemiological research was confirmed in the latter study as well, but for use in clinical practice, a larger sample was required to provide detailed information about drop-out of certain subgroups of this population.

In previous research, differences in performance have been shown between men and women, age groups, different levels of ID , different levels of mobility, having Down syndrome or not, and being physically active [11-13,15,16,24,25]. These differences could influence completion rates of these subgroups as well, and therefore the study question of this paper is: What is the completion rate of the eight physical fitness tests in a large sample of older adults with ID, and in subgroups of this sample (based on gender, age, level of ID, presence of Down syndrome, level of mobility, level of physical activity)?

METHODS

Participants

This study was part of the large-scale Dutch cross-sectional study 'Healthy ageing and intellectual disabilities' (HA-ID), executed by a Dutch consort of three ID care services (Abrona at Huis ter Heide; Amarant at Tilburg; and Ipse de Bruggen at Zwammerdam), in collaboration with two university institutes (Intellectual Disability Medicine, Erasmus Medical Center at Rotterdam; and the Center for Human Movement Sciences, University Medical Center at Groningen). All 2150 clients with intellectual disabilities (ID), aged 50 years and over, of the three care providers were invited to participate, resulting in a near-representative sample of 1050 clients. Details about design, recruitment and representativeness of the sample have been presented elsewhere [26]. Data collection took place between February 2009 and July 2010.

Ethical approval was provided by the Medical Ethical Committee of the Erasmus Medical Center (MEC 2008-234) and by the ethical committees of the participating ID care services. Informed consent was obtained from all participants; however, unusual resistance was a reason for aborting measurements at all times.

Materials

Gender and age were collected from the administration systems of the ID care services. Professional caregivers provided information about mobility (independent, with walking aid, or wheelchair-bound). Level of ID was categorized by psychologists or behavioral therapists as: borderline (IQ=70-84), mild (IQ=50-69), moderate (IQ=35-49), severe (IQ=20-34) or profound (IQ <20) (based on ICD-10 criteria). The presence of

Table 1 Selection of physical fitness components and instruments for older adults with ID

Physical fitness component	Instrument
Manual dexterity	Box and block test
Response time	Response time test
Balance	Berg balance scale
	Walking speed
Muscle Endurance	30s Chair stand
Muscle Strength	Grip strength
Cardiorespiratory endurance	10m Incremental shuttle walking test
Flexibility	Extended Modified Back Saver Sit and Reach

Down syndrome was collected through the medical files. Level of physical activity was measured with a pedometer (NL-1000, detailed methods have been described elsewhere) [10] and classified in an active group (7500 steps/day or more) and a less active group (less than 7500 steps/day) [27]. Table 1 provides an overview of the battery of eight physical fitness tests [22].

For the Box and block test (BBT), a participant had to move as many coloured blocks of 2,5 cm^3 from one side of a wooden box to the other side in one minute [28]. The test instructor was instructed to be aware of the level of understanding of participants of the 'as fast as possible'-part of the instruction and whether the participant was picking up only one colour or colour sequences, or was placing the blocks very neatly (and consequently slowly) at the other side of the box. If these faulty executions would not change after attempts of the test instructor to correct them, the test was not completed successfully. Reliability and validity in the general population have been tested and were good [29,30]. Test-retest reliability in older adults with ID was good (ICC was 0.90 (same-day interval and two-week interval)) [23].

In the response time test, participants were asked to respond as quickly as possible to an auditive (door bell) or visual stimulus (white dot on the screen), by pressing a button on the keyboard of a laptop. Each condition (auditive signal (RTA) first, then visual signal (RTV)) was repeated 15 times, with random presentation of the signal (between 1.0 and 9.0 s). Time was recorded between the presentation of the stimulus and pushing the button, and the median of 15 scores was used as the participant's result for that condition. If the test instructor was not convinced the participant understood the action-reaction part of the instruction and the 'as fast as possible' part of the instruction, the test was not completed successfully. Reliability and validity in the general older population were shown [31,32].Test-retest reliability in older adults with ID was good (Visual: ICC was 0.75 (same-day interval) and 0.72 (two-week interval), Auditive: 0.87 (same-day interval) and 0.74 (two-week interval)) [23].

The Berg Balance Scale (BBS) consists of 14 balance tasks with varying difficulty, ranging from unsupported sitting in a chair to tandem stance and standing on one leg [33]. In this paper, a successful completion of the BBS meant that a participant was able to execute all 14 items of the test. The freely available original test instructions were followed, but some aids were used to enhance understanding of the tasks, such as two carpet feet and a carpet circle on the floor, to point out where the participant had to stand or turn around on. Use of walking aids was not allowed. Validity and reliability in the general older population have been demonstrated previously [34-36], as well as in the population with ID [37] and in the older population with ID [38].

Walking speed was measured three times for comfortable (WSC) and fast (WSF) speed over a distance of 5 meters (after 3 meters for acceleration). The three attempts of WSC were averaged to get the participant's result, for the WSF the best score out of three attempts was used as the participant's result. The participants had to walk the distance without someone walking alongside or physically supporting them, to avoid influencing the comfortable speed and the balance of the participant. Walking aids were allowed, but recorded by the test instructor. Reliability and validity in the general population was good [39,40]. Test-retest reliability in older adults with ID was good (comfortable: ICC was 0.96 (same-day interval) and 0.93 (two-week interval), fast: 0.96 (same-day interval) and 0.90 (two-week interval)) [23].

Muscle endurance was measured with the 30s Chair stand test (30sCS) [41]. The participant was asked to sit down and stand upright as often as possible in 30 seconds without using their hands. Test instructors did not record the result if participants could not stand up from a chair without supporting with their arms on arm rests, knees, or walking aid (after attempts of the test instructor to motivate participants to do so). Reliability and validity in the general older population was good [25]. Test-retest reliability in older adults with ID was moderate (ICC was 0.72 (same-day interval) and 0.65 (two-week interval)) [23].

Grip strength (GS) [42] was measured to determine muscle strength. The participant squeezed a Jamar Hand Dynamometer (#5030J1, Sammons Preston Rolyan, USA) to his or her maximum ability in seated position, according to the recommendations of the American Society of Hand Therapists [43]. The best result of three attempts for both the left and the right hand (with a one-minute pause between attempts), was recorded. A visual example was provided by squeezing a rubber ball by the test instructor. The test instructor had to be convinced the participant squeezed with maximal effort; otherwise he did not record the result. Reliability and validity in the general population was good [44,45]. Test-retest reliability in older adults with ID was good (ICC was 0.94 (same-day interval) and 0.90 (two-week interval)) [23].

For the 10m Incremental shuttle walking test (ISWT) [46], the participant starts walking a ten-meter section at 0.50 m/s together with the test instructor. Every minute, the test instructor increased walking speed by 0.17 m/s; the participant continued walking until he or she could no longer keep up with the pace. The number of completed minutes in which the participant is able to walk at the right speed was recorded, which resulted in a number of meters walked in this test, which can be used to calculate VO2max [47]. Test was stopped if the participant was too breathless to maintain the required speed or failed to complete a 10-meter shuttle in the time allowed [46]. The participants wore heart rate monitors to assess their effort during these tests and check whether this was sufficient for a valid test result. Validity of this test was confirmed [47]. Test retest reliability has been investigated in 10 patients with chronic airway obstruction and had Pearson correlations of 0.98 and higher, but a significant mean difference was observed between the first and the second session, suggesting that a practice session is necessary to obtain valid results [46]. In 353 patients attending cardiac rehabilitation, the ICC was 0.94, with again a significant mean difference between the first and second session, confirming the need for a practice walk [48]. The pilot study could not confirm this need definitively in this group, partly due to small numbers. To avoid the risk of underestimating cardiorespiratory endurance, the ISWT was executed twice for every participant. Test-retest reliability in older adults with ID was good (ICC 0.90 (same-day interval) and 0.76 (two-week interval)) [23].

Flexibility was measured with an extended version of the Modified back saver sit and reach test [49] (EMBSSR) [22], in which the participant sits on a chair, stretches one leg on a second chair and bends forward. The distance from the distal point of the phalanx distalis of the digitus medius to the malleolus lateralis was measured, while bending over. This test was executed for both legs. Hui et al. [49] measured from finger to heel, but due to high prevalences of deviations in foot position in people with ID, the ankle was considered to be a more stable, although more proximal, anatomical point across this population than the heel. For comparison reasons with the measurement of Hui from finger to heel, a standard correction of subtracting 6 centimeters will be applied to the measured results. Test-retest reliability and validity was good in the general population [49,50], and good to moderate in older adults with ID (left leg: ICC was 0.96 (same-day interval) and 0.63 (two-week interval), right leg: 0.95 (same-day interval) and 0.71 (two-week interval)) [23].

Safety information

The Revised Physical Activity Readiness Questionnaire (rPARQ) was administered by the professional caregivers in advance of participation in the physical fitness tests, to determine if these tests could be performed safely by the participant [51,52]. This instrument consists of seven questions regarding the presence of health conditions or complaints which can be answered with yes or no. If any of the questions was answered with yes or was left blank, the general practitioner or intellectual disability physician was consulted to determine whether exercise was safe for this particular participant, considering his/her medical history. If not, the tests involving physical effort were excluded from the assessment: Fast walking speed, 30 second Chair stand and the 10 m Incremental shuttle walking test.

Procedure

The physical fitness assessments were executed on locations familiar or close to participants: a large room within their home, a familiar day care center or a gym. Participants conducted the Box and Block test and the Response time test in a separate room from the other tests, to avoid visual distraction or distraction by noise.

All assessments with the physical fitness instruments were guided by test instructors, who all were physiotherapists, occupational therapists or physical activity instructors with experience with people with ID. They all followed a two-day course for the execution of the eight tests and received an instruction manual specifically designed for this study, with specific emphasis on scoring either a successful measurement with a result, or an unsuccessful measurement, without any results, to avoid ambiguity about the validity of the results.

In order to avoid undesirable influences of consecutive tests, both 10 m Incremental shuttle walking tests (ISWT) on the same day were executed at the beginning and at the end of the assessment, with at least an hour in between. Furthermore, a recovery period of at least 5 minutes was included after the execution of the ISWT. Tests which were more cognitively challenging (Box and block test, Response time tests, Berg balance scale) were executed in the first part of the test session after the first ISWT, to avoid the influence of fatigue. Flexibility was measured directly after the last ISWT, to use the exercise of this test as a warming-up to measure flexibility [53]. In all sessions one or more breaks were allowed if the participants showed signs of exhaustion or distraction.

Test instructions developed for people with normal intellectual capabilities give standardized descriptions on how to motivate the participant and how much encouragement is allowed during a test. Such standardized encouragement is unsuitable in people with intellectual disabilities because of the large variation in behavior and responses. To keep this motivational aspect as equal as possible, we prescribed 'maximal motivation' for all tests to the test instructors. In some cases, this meant that participants were motivated to engage in the assessments by constant verbal encouragement and verbal rewarding, in other cases the test instructor had to remain very calm and quiet to motivate the client as much as possible and to prevent stress or anxiety. The specific background, knowledge and experience of the test instructors were important conditions to ensure the most suitable 'maximal motivation' for every participant, while regarding safety as well.

Data analysis

For each physical fitness test, numbers of participants are provided, for the total sample and for all categories of baseline characteristics (gender, 10-years age-groups, level of ID, presence of Down syndrome, mobility impairment and level of physical activity (PA)). Because only 3 participants fell into the age category 90 years and over, they were merged with the preceding category (80+ years).

Completion rates were divided in quartiles, and characterised as low (≤25%), moderate (>25% and ≤50%), good (>50% and ≤75%) and excellent (>75%).

RESULTS

In Table 2, numbers and percentages of participants successfully performing each physical fitness test are presented, specified for gender, age category, level of ID, presence of Down syndrome, level of mobility and level of physical activity. For level of physical activity, only the most functionally able part of the participants could be measured successfully with the pedometer (257 successful out of 1050 participants). Of the 257 participants with a successful measurement with the pedometer, 3 did not participate in the physical fitness assessment due to behavioral problems or non-cooperation, and were left out in further analyses.

In Table 3, a summary of the results is given for use in clinical practice, with the labels low feasibility (≤25%), moderate feasibility (>25% and ≤50%), good feasibility (>50% and ≤75%) and excellent feasibility (>75%).

DISCUSSION

This large-sample study provides new and relevant information for clinical practice about the feasibility of eight physical fitness tests in older adults with ID. All eight tests had moderate to good feasibility in the total sample of 1050 older adults with ID. Subgroups which had trouble with some/all tests, were participants with profound ID (low feasibility on all tests), with severe ID (low feasibility on the Response time tests and the Berg balance scale), and wheelchair users (low feasibility on all tests which involved the legs). Other studies have also identified the need for specific instruments to measure physical fitness in adults with severe and profound intellectual and/or motor disabilities, in some studies combined with visual impairments [54-56].

On the other hand, the oldest age groups, participants with Down syndrome and participants with low level of physical activity all had moderate to excellent completion rates for all tests. The Berg balance scale and the 30 sec Chair stand had the lowest

Table 2 Numbers of participants of the total HA-ID study population and of the physical fitness tests

		HA-ID	BBT	RTA	RTV	BBS	WSC	WSF	30 s CS	GS	ISWT	EMBSSR
Total		1050	740 70%	566 54%	556 53%	508 48%	702 67%	554 53%	528 50%	725 69%	654 62%	634 60%
Gender	Male	539	369 68%	271 50%	264 49%	260 48%	361 67%	282 52%	271 50%	370 69%	341 63%	312 58%
	Female	511	371 73%	295 58%	292 57%	248 49%	341 67%	272 53%	257 50%	355 69%	313 61%	322 63%
Age (years)	50-59	493	340 69%	258 52%	257 52%	237 48%	340 69%	281 57%	275 56%	336 68%	331 67%	308 62%
	60-69	370	260 70%	198 54%	196 53%	191 52%	248 67%	195 53%	182 49%	256 69%	229 62%	220 59%
	70-79	162	123 76%	99 61%	92 57%	73 45%	103 64%	72 44%	64 40%	118 73%	85 52%	95 59%
	80+	25	17 68%	11 44%	11 44%	7 28%	11 44%	6 24%	7 28%	15 60%	9 36%	11 44%
Level of ID	Border-line	31	30 97%	28 90%	28 90%	28 90%	27 87%	23 74%	23 74%	30 97%	26 84%	30 97%
	Mild	223	193 87%	177 79%	176 79%	164 74%	178 80%	151 68%	152 68%	190 85%	159 71%	170 76%
	Moderate	506	389 77%	315 62%	305 60%	267 53%	366 72%	287 57%	282 56%	399 79%	336 66%	356 70%
	Severe	172	91 53%	30 17%	28 16%	31 18%	92 53%	67 39%	51 30%	78 45%	94 55%	53 31%
	Profound	91	17 19%	1 1%	1 1%	1 1%	18 20%	8 9%	5 5%	7 8%	23 25%	6 7%
	Unknown	27	20 74%	15 56%	18 67%	17 63%	21 78%	18 67%	15 56%	21 78%	16 59%	19 70%
Down syndrome	No	724	512 71%	386 53%	379 52%	344 48%	474 65%	370 51%	349 48%	491 68%	446 62%	426 59%
	Yes	149	81 54%	54 36%	52 35%	44 30%	89 60%	71 48%	65 44%	83 56%	88 59%	73 49%
	Unknown	177	147 83%	126 71%	125 71%	120 68%	139 79%	113 64%	114 64%	151 85%	120 68%	135 76%
Mobility	Indepen-dent	731	548 75%	423 58%	423 58%	416 57%	573 78%	476 65%	460 63%	543 74%	547 75%	495 68%
	With wal-king aid	151	112 74%	86 57%	76 50%	55 36%	93 62%	50 33%	45 30%	110 73%	82 54%	93 62%
	Wheel-chair	107	47 44%	29 27%	29 27%	10 9%	6 6%	3 3%	0 0%	41 38%	5 5%	19 18%

	Unknown	61	33 54%	28 46%	28 46%	27 44%	30 49%	25 41%	23 38%	31 51%	20 33%	27 44%
Level of PA (n=254)	Less active	163	158 97%	139 85%	138 85%	141 87%	163 100%	146 90%	141 87%	161 99%	150 92%	150 92%
	Active	91	89 98%	77 85%	80 88%	80 88%	90 99%	85 93%	87 96%	90 99%	88 97%	87 96%

HA-ID=Total number of participants in the study Healthy Ageing in Intellectual Disabilities, BBT=Box and Block test, RTA=Response Time test Auditive, RTV=Response Time test Visual, BBS=Berg Balance Scale, WSC=Walking speed comfortable speed, WSF=Walking speed fast speed, 30 s CS=30 second Chair Stand, GS=Grip strength, ISWT=10m Incremental Shuttle Walking Test, EMBSSR=Extended Modified Back Saver Sit and Reach, PA=physical activity

Table 3 Summary of the feasibility of the physical fitness tests for all subcategories of personal characteristics.

		BBT	RTA	RTV	BBS	WSC	WSF	30 s CS	GS	ISWT	EMBSSR
Total		good	good	good	mod.	good	good	mod.	good	good	good
Gender	Male	good	mod.	mod.	mod.	good	good	mod.	good	good	good
	Female	good	good	good	mod.	good	good	mod.	good	good	good
Age	50-59	good	good	good	mod.	good	good	Good	good	good	good
(years)	60-69	good	good	good	good	good	good	mod.	good	good	good
	70-79	exc.	good	good	mod.	good	mod.	mod.	good	good	good
	80+	good	mod.	mod.	mod.	mod.	low	mod.	good	mod.	mod.
Level of ID	Borderline	exc.	exc.	exc.	exc.	exc.	good	Good	exc.	exc.	exc.
	Mild	exc.	exc.	exc.	good	exc.	good	Good	exc.	good	exc.
	Moderate	exc.	good	good	good	good	good	Good	exc.	good	good
	Severe	good	low	low	low	good	mod.	mod.	mod.	good	mod.
	Profound	low	low	low	low	low	low	Low	low	low	low
Down syndrome	No	good	good	good	mod.	good	good	mod.	good	good	good
	Yes	good	mod.	mod.	mod.	good	mod.	mod.	good	good	mod.
Mobility	Independent	good	good	good	good	exc.	good	Good	good	good	good
	With walking aid	good	good	mod.	mod.	good	mod.	mod.	good	good	good
	Wheelchair	mod.	mod.	mod.	low	low	low	Low	mod.	low	low
Level of PA (n=254)	Less active	exc.	exc.	exc.	exc.	exc.	exc.	exc.	exc.	exc.	exc.
	Active	exc.	exc.	exc.	exc.	exc.	exc.	exc.	exc.	exc.	exc.

BBT=Box and Block test, RTA=Response Time test Auditive, RTV=Response Time test Visual, BBS=Berg Balance Scale, WSC=Walking speed comfortable speed, WSF=Walking speed fast speed, 30 s CS=30 second Chair Stand, GS=Grip strength, ISWT=10m Incremental Shuttle Walking Test, EMBSSR=Extended Modified Back Saver Sit and Reach, PA=physical activity, mod. =moderate, exc. =excellent completion rates across all subgroups, with good feasibility only in less severe ID and independent walkers. The Box and block test, comfortable walking speed and Grip strength had the highest completion rates for the total group, as well as for subgroups.

Because older persons with borderline or mild ID, who are living independently and not using formal ID services, have not been included in this study, the results are not applicable to that group. Since the trend in the presented results is more positive towards the more functionally able subgroups, it is to be expected that the independently living group can be measured with these same instruments as well. Since completion rates are highest in the youngest age group of this study (50-59 years), sufficient feasibility can be expected in younger adults too. In individuals with a combination of descriptive characteristics, the chance of completing a test can be derived by looking at the lowest completion rate of the separate categories involved, i.e. a participant with moderate level of ID in a wheelchair has a 38% chance of being able to complete the test successfully. For the 10 m Incremental shuttle walking test, probably not all participants who had a successful measurement would have reached a sufficient rate of exertion (85% of maximum heart rate) for a valid result of VO2max. More detailed analysis of this test in particular is necessary to answer this question. For use in clinical practice, even if a participant does not reach 85% of maximum heart rate, the completed number of shuttles still provides useful information for assessment and evaluation purposes.

Outcomes of this study are of particular importance to professionals who want to measure physical fitness in older adults with ID. It provides information in which groups these eight tests can be used with a sufficient chance of completing the test and generating useful results. Clinicians can use these instruments to assess participants at the start of a treatment, to decide what kind of intervention to choose, and to evaluate the effect of interventions aimed at improving specific components of physical fitness (subject to further research on sensitivity to detect small changes). These instruments can be used in program evaluation as well, because they proved to be feasible in the majority of older adults with ID. The field researcher can use the complete battery or separate tests, because no specific lab equipment is required. Because these instruments are being applied in the general population as well, comparison between populations comes within reach, resulting in increasing knowledge about physical fitness of (older) adults with ID, and its relevance for practice and policy.

REFERENCES

1. WHO, *Global health risks: mortality and burden of disease attributable to selected major risks.* 2009, World Health Organization, : Geneva, Switzerland.
2. WHO, *Global recommendations on physical activity for health*. 2010, World Health Organization: Geneva.
3. Mazzeo R.S. and Tanaka H., *Exercise prescription for the elderly: current recommendations.* Sports Med, 2001. **31**(11): p. 809-18.
4. DHHS, *Physical Activity Guidelines Advisory Committee Report*. 2008, U.S. Department of Health and Human Services, : Rockville (MD).
5. Cooper R., Kuh D., Cooper C., et al., *Objective measures of physical capability and subsequent health: a systematic review.* Age Ageing, 2011. **40**(1): p. 14-23.
6. ACSM, *American College of Sports Medicine Position Stand. Exercise and physical activity for older adults.* Med Sci Sports Exerc, 1998. **30**(6): p. 992-1008.
7. van Heuvelen M.J., Kempen G.I., Brouwer W.H., et al., *Physical fitness related to disability in older persons.* Gerontology, 2000. **46**(6): p. 333-41.
8. Patja K., Iivanainen M., Vesala H., et al., *Life expectancy of people with intellectual disability: a 35-year follow-up study.* J Intellect Disabil Res, 2000. **44 (Pt 5)**: p. 591-9.
9. Temple V.A., Frey G.C., and Stanish H.I., *Physical activity of adults with mental retardation: review and research needs.* Am J Health Promot, 2006. **21**(1): p. 2-12.
10. Hilgenkamp T.I., Reis D., van Wijck R., et al., *Physical activity levels in older adults with intellectual disabilities are extremely low.* Res Dev Disabil, 2012. **33**(2): p. 477-486.
11. Lahtinen U., Rintala P., and Malin A., *Physical performance of individuals with intellectual disability: a 30 year follow up.* Adapt Phys Activ Q, 2007. **24**(2): p. 125-43.
12. Carmeli E., Ayalon M., Barchad S., et al., *Isokinetic leg strength of institutionalized older adults with mental retardation with and without Down's syndrome.* J Strength Cond Res, 2002. **16**(2): p. 316-20.
13. Fernhall B., *Physical fitness and exercise training of individuals with mental retardation.* Med Sci Sports Exerc, 1993. **25**(4): p. 442-50.
14. Chodzko-Zajko W.J., Proctor D.N., Fiatarone Singh M.A., et al., *American College of Sports Medicine position stand. Exercise and physical activity for older adults.* Med Sci Sports Exerc, 2009. **41**(7): p. 1510-30.
15. Pitetti K.H., Climstein M., Mays M.J., et al., *Isokinetic arm and leg strength of adults with Down syndrome: a comparative study.* Arch Phys Med Rehabil, 1992. **73**(9): p. 847-50.
16. Carmeli E., Barchad S., Lenger R., et al., *Muscle power, locomotor performance and flexibility in aging mentally-retarded adults with and without Down's syndrome.* J Musculoskelet Neuronal Interact, 2002. **2**(5): p. 457-62.
17. Jebsen R.H., Taylor N., Trieschmann R.B., et al., *An objective and standardized test of hand function.* Arch Phys Med Rehabil, 1969. **50**(6): p. 311-9.

18. Moberg E., *Objective methods for determining the functional value of sensibility in the hand.* J Bone Joint Surg Br, 1958. **40-B**(3): p. 454-76.
19. AAHPERD, *Technical manual for the Health-related physical fitness test*. 1980, Reston, VA: American Alliance for health, physical education, recreation and dance (AAHPERD). 19-21.
20. ACSM, *ACSM's Health-Related Physical Fitness Assessment Manual* 1st ed, ed. G.B. Dwyer and S.E. Davis. 2005, Baltimore, Lippincott: Williams & Wilkins. 180 p.
21. Bouchard C. and Shephard R.J., *Physical Activity, Fitness, and Health: The model and key concepts*, in *Physical Activity, Fitness and Health. International Proceedings and Consensus Statement*. 1994, Human Kinetics Publishers: Champaign.
22. Hilgenkamp T.I., van Wijck R., and Evenhuis H.M., *Physical fitness in older people with ID-Concept and measuring instruments: a review.* Res Dev Disabil, 2010. **31**(5): p. 1027-38.
23. Hilgenkamp T.I., van Wijck R., and Evenhuis H., *Feasibility and reliability of tests for measuring physical fitness in older adults with intellectual disabilities. A pilot study.* J Intellect Dev Disabil, 2012. **In press**.
24. Bouchard C., Shephard R.J., and Stephens T., *Physical activity, fitness, and health: International proceedings en consensus statement*. 1994, Champaign: Human Kinetics Publishers.
25. Jones C.J., Rikli R.E., and Beam W.C., *A 30-s chair-stand test as a measure of lower body strength in community-residing older adults.* Res Q Exerc Sport, 1999. **70**(2): p. 113-9.
26. Hilgenkamp T.I., Bastiaanse L.P., Hermans H., et al., *Study healthy ageing and intellectual disabilities: Recruitment and design.* Res Dev Disabil, 2011. **32**(3): p. 1097–1106.
27. Tudor-Locke C., Hatano Y., Pangrazi R.P., et al., *Revisiting "how many steps are enough?".* Med Sci Sports Exerc, 2008. **40**(7 Suppl): p. S537-43.
28. Mathiowetz V., Volland G., Kashman N., et al., *Adult norms for the Box and Block Test of manual dexterity.* Am J Occup Ther, 1985. **39**(6): p. 386-91.
29. Desrosiers J., Bravo G., Hebert R., et al., *Validation of the Box and Block Test as a measure of dexterity of elderly people: reliability, validity, and norms studies.* Arch Phys Med Rehabil, 1994. **75**(7): p. 751-5.
30. Platz T., Pinkowski C., van Wijck F., et al., *Reliability and validity of arm function assessment with standardized guidelines for the Fugl-Meyer Test, Action Research Arm Test and Box and Block Test: a multicentre study.* Clin Rehabil, 2005. **19**(4): p. 404-11.
31. Lord S.R., Clark R.D., and Webster I.W., *Postural stability and associated physiological factors in a population of aged persons.* J Gerontol, 1991. **46**(3): p. M69-76.
32. Deary I.J. and Der G., *Reaction time explains IQ's association with death.* Psychol Sci, 2005. **16**(1): p. 64-9.
33. Berg K.O., Wood-Dauphinee S.L., Williams J.I., et al., *Measuring balance in the elderly: validation of an instrument.* Can J Public Health, 1992. **83 Suppl 2**: p. S7-11.
34. Steffen T. and Seney M., *Test-retest reliability and minimal detectable change on balance and ambulation tests, the 36-item short-form health survey, and the unified Parkinson disease rating scale in people with parkinsonism.* Phys Ther, 2008. **88**(6): p. 733-46.

35. Conradsson M., Lundin-Olsson L., Lindelof N., et al., *Berg balance scale: intrarater test-retest reliability among older people dependent in activities of daily living and living in residential care facilities.* Phys Ther, 2007. **87**(9): p. 1155-63.
36. Wang C.Y., Hsieh C.L., Olson S.L., et al., *Psychometric properties of the Berg Balance Scale in a community-dwelling elderly resident population in Taiwan.* J Formos Med Assoc, 2006. **105**(12): p. 992-1000.
37. Sackley C., Richardson P., McDonnell K., et al., *The reliability of balance, mobility and self-care measures in a population of adults with a learning disability known to a physiotherapy service.* Clin Rehabil, 2005. **19**(2): p. 216-23.
38. de Jonge P.A., Tonino M.A.M., and Hobbelen J.S., *Instruments to assess risk of falls among people with intellectual disabilities*, in *International congress of best practice in intellectual disability medicine*. 2010: Bristol (UK).
39. Steffen T.M., Hacker T.A., and Mollinger L., *Age- and gender-related test performance in community-dwelling elderly people: Six-Minute Walk Test, Berg Balance Scale, Timed Up & Go Test, and gait speeds.* Phys Ther, 2002. **82**(2): p. 128-37.
40. Abellan van Kan G., Rolland Y., Andrieu S., et al., *Gait speed at usual pace as a predictor of adverse outcomes in community-dwelling older people an International Academy on Nutrition and Aging (IANA) Task Force.* J Nutr Health Aging, 2009. **13**(10): p. 881-9.
41. Rikli R.E. and Jones C.J., *Senior fitness test manual*. 2001: Human Kinetics Europe Ltd
42. Mathiowetz V., Kashman N., Volland G., et al., *Grip and pinch strength: normative data for adults.* Arch Phys Med Rehabil, 1985. **66**(2): p. 69-74.
43. Fess E.E. and Moran C., *Clinical assessment recommendations*. 1981, Indianapolis, USA: American Society of Hand therapists Monograph.
44. Abizanda P., Navarro J.L., Garcia-Tomas M.I., et al., *Validity and usefulness of hand-held dynamometry for measuring muscle strength in community-dwelling older persons.* Arch Gerontol Geriatr, 2011.
45. Stark T., Walker B., Phillips J.K., et al., *Hand-held dynamometry correlation with the gold standard isokinetic dynamometry: a systematic review.* PM R, 2011. **3**(5): p. 472-9.
46. Singh S.J., Morgan M.D., Scott S., et al., *Development of a shuttle walking test of disability in patients with chronic airways obstruction.* Thorax, 1992. **47**(12): p. 1019-24.
47. Singh S.J., Morgan M.D., Hardman A.E., et al., *Comparison of oxygen uptake during a conventional treadmill test and the shuttle walking test in chronic airflow limitation.* Eur Respir J, 1994. **7**(11): p. 2016-20.
48. Jolly K., Taylor R.S., Lip G.Y., et al., *Reproducibility and safety of the incremental shuttle walking test for cardiac rehabilitation.* Int J Cardiol, 2008. **125**(1): p. 144-5.
49. Hui S.S. and Yuen P.Y., *Validity of the modified back-saver sit-and-reach test: a comparison with other protocols.* Med Sci Sports Exerc, 2000. **32**(9): p. 1655-9.
50. Minarro P.A., Andujar P.S., Garcia P.L., et al., *A comparison of the spine posture among several sit-and-reach test protocols.* J Sci Med Sport, 2007. **10**(6): p. 456-62.

51. Thomas S., Reading J., and Shephard R.J., *Revision of the Physical Activity Readiness Questionnaire (PAR-Q)*. Can J Sport Sci, 1992. **17**(4): p. 338-45.
52. Cardinal B.J., Esters J., and Cardinal M.K., *Evaluation of the revised physical activity readiness questionnaire in older adults.* Med Sci Sports Exerc, 1996. **28**(4): p. 468-72.
53. Williford H.N., East J.B., Smith F.H., et al., *Evaluation of warm-up for improvement in flexibility.* Am J Sports Med, 1986. **14**(4): p. 316-9.
54. Waninge A., Evenhuis I.J., van Wijck R., et al., *Feasibility and reliability of two different walking tests in subjects with severe intellectual and sensory disabilities.* Journal of applied research in intellectual disabilities: JARID, 2011. **24**(6): p. 518-527.
55. Waninge A., van Wijck R., Steenbergen B., et al., *Feasibility and reliability of the modified Berg Balance Scale in persons with severe intellectual and visual disabilities.* J Intellect Disabil Res, 2011. **55**(3): p. 292-301.
56. Gagnon D., Decary S., and Charbonneau M.F., *The timed manual wheelchair slalom test: a reliable and accurate performance-based outcome measure for individuals with spinal cord injury.* Arch Phys Med Rehabil, 2011. **92**(8): p. 1339-43.

Chapter 8

Low physical fitness levels in older adults with ID: Results of the HA-ID study

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ABSTRACT

Background: Physical fitness is as important to ageing adults with ID as in the general population, but to date, the physical fitness levels of this group are unknown.

Methods: Comfortable walking speed, muscle strength (grip strength), muscle endurance (30 second chair stand) and cardiorespiratory endurance (10 meter incremental shuttle walking test) were tested in a sample of 1050 older adults with ID, and results were compared with reference values from the general population.

Results: Across all age ranges, approximately two-third of the entire study population scored 'below average' or 'impaired'. Even the youngest age groups (50-59 or 50-54 years) in this sample achieve similar or worse results than age groups 20 to 30 years older in the general population.

Conclusion: Low physical fitness levels in older adults with ID demonstrate that this group is prone to unnecessary premature loss of functioning and health problems, and maintaining physical fitness should have priority in daily practice and policy.

INTRODUCTION

In old age, physical fitness plays a vital role in health and independence [1,2]. Low fitness is a risk factor for cardiovascular disease and musculoskeletal health conditions, such as osteoporosis and loss of muscle mass, and increases the risk of falls [3,4]. Low physical fitness is preventable or reversible by physical activity and structured exercise [5], which opens up possibilities to maintain or positively influence health and independence into old age.

The ageing population with intellectual disabilities (ID) is rapidly increasing, due to longer life expectancy as a result of improved healthcare on the one hand, and an increase in absolute numbers of the total population on the other [6]. Childhood mobility impairments, lifelong low physical activity levels [7,8], as well as multiple chronic health conditions[9], that increase with age, may pose risks for low physical fitness in this group. Indeed, lower fitness than in the general population has already been demonstrated for younger adults with ID [10-13]. Prevention and intervention of low fitness is of paramount importance to maintain skills for Activities of Daily Living (ADL), health and well-being, and prevent increase of care dependency and care costs [14-16]. To determine the priority of fitness programmes for health policies in older adults with ID, it is necessary to investigate the nature and scale of the problem of low physical fitness in this population.

Research in younger adults with ID has identified some components of physical fitness as major indicators for overall fitness, such as cardiovascular capacity, muscular strength and endurance, and obesity [13,17]. These components have been found to be important not only in daily functioning, but are related to future health outcomes in the general population [4]. In addition, comfortable walking speed yields very promising results in predicting adverse outcomes in the general population [18-20]. Since obesity is not included in the performance-related description of physical fitness in older adults with ID discussed earlier [21], this study will focus on cardiovascular capacity, muscle strength, muscle endurance and comfortable walking speed. The question of this paper is: What is the level of physical fitness of older adults with ID?

METHODS

Study design and participants

This study was part of the large-scale Dutch cross-sectional study 'Healthy ageing and intellectual disabilities' (HA-ID), executed by a consort of three ID care services (Abrona at Huis ter Heide; Amarant at Tilburg; and Ipse de Bruggen at Zwammerdam), in collaboration with two university institutes (Intellectual Disability Medicine, Erasmus Medical Center at Rotterdam; and the Center for Human Movement Sciences, University Medical Center at Groningen). All 2150 clients with intellectual disabilities (ID), aged 50 years and over, of the three care services were invited to participate, resulting in a near-representative sample of 1050 clients. Details about design, recruitment and representativeness of the sample have been presented elsewhere [22]. Data collection took place between February 2009 and July 2010. Because older persons with borderline or mild ID, who are not using formal ID services, were not included in this study, the results are not applicable to that group. Ethical approval was provided by the Medical Ethical Committee of the Erasmus Medical Center (MEC 2008-234) and by the ethical committees of the participating ID care services. Informed consent was obtained from all participants; however, unusual resistance was a reason for aborting measurements at all times [23].

Materials

General information

Gender and age of older adults with ID were collected from the administration systems of the care providers. Professional caregivers provided information about mobility (independent, with walking aid, or wheelchair-bound).

Physical fitness measurements

Comfortable walking speed (WSC) was measured over a distance of 5 meters (after 3 meters for acceleration), and three attempts were averaged to get the participant's result. The participants had to walk the distance without someone walking alongside or physically supporting them, to avoid influencing the comfortable speed and the balance of the participant. Participants who completed the test with a walking aid were omitted in the analyses. Reliability and validity in the general population were good [18,20,24-26]. Test-retest reliability in older adults with ID was good (ICCs were 0.96 (same-day interval) and 0.93 (two-week interval)) [27].

Muscle endurance was measured with the 30s Chair stand test (30sCS) [28]. The participant was asked to sit down and stand upright as often as possible in 30 seconds without using his/her hands. Reliability and validity in the general older population was good [29]. Test-retest reliability in older adults with ID was moderate (ICCs were 0.72 (same-day interval) and 0.65 (two-week interval)) [27].

Grip strength (GS) [30] was measured to determine muscle strength. The participant squeezed a Jamar Hand Dynamometer (#5030J1, Sammons Preston Rolyan, USA) to his or her maximum ability in seated position, according to the recommendations of the American Society of Hand Therapists [31]. The best result of three attempts for both the left and the right hand (with a one-minute pause between attempts) was recorded. A visual example was provided by squeezing a rubber ball by the test instructor. The test instructor had to be convinced that the participant squeezed with maximal effort; otherwise he did not record the result. Reliability and validity in the general population was good [32,33]. Test-retest reliability in older adults with ID was good (ICCs were 0.94 (same-day interval) and 0.90 (two-week interval)) [27].

For the 10m Incremental shuttle walking test (ISWT) [34], the participant started walking a ten-meter section at 0.50 m/s together with the test instructor. Every minute, the test instructor increased walking speed by 0.17 m/s according to the test procedure; the participant continued walking until he or she could no longer keep up with the pace. The number of completed minutes in which the participant is able to walk at the right speed was recorded, which resulted in a number of meters walked in this test, which can be used to calculate VO2max [35]. Testing was stopped if the participant was too breathless to maintain the required speed or failed to complete a 10-meter shuttle within the time allowed [34]. Continuous heart rate monitoring (Suunto T6C) provided objective information about the level of exertion of the participant, and the participant was asked how it went as well. The percentage of the predicted maximal heart rate (HRmax) achieved during the test was calculated (%HRmax = (maximal heart rate recorded during test / HRmax) * 100%). Only if participants achieved 85% of HRmax or higher, VO2max could be validly calculated with the formula: 4.19 + 0.025 * distance walked in meters [35]. HRmax was calculated with the formula of Fernhall [36]: Y = 210 - (0.56*age) - (15.5*DS), with Down syndrome (DS) coded as 2 and non-DS coded as 1. This formula was shown to predict HRmax in individuals with intellectual disability better than the standard formula which was used by Singh et al. [34,36]. The highest achieved % of HRmax of both recordings of the ISWT was used as a result.

Validity of this test was confirmed [35]. Test retest reliability has been investigated in 10 patients with chronic airway obstruction and had Pearson correlations of 0.98 and higher, but a significant mean difference was observed between the first and the second session, suggesting that a practice session is necessary to obtain valid results [34]. In 353 patients attending cardiac rehabilitation, the ICC was 0.94, with again a significant mean difference between the first and second session, confirming the need for a practice walk [37]. The pilot study could not confirm this need definitively in this group, partly due to small numbers. To avoid the risk of underestimating cardio-respiratory endurance, the ISWT was executed twice for every participant. Test-retest reliability in older adults with ID was good (ICCs were 0.90 (same-day interval) and 0.76 (two-week interval)) [27].

Safety information

The Revised Physical Activity Readiness Questionnaire (rPARQ) was administered by the professional caregivers in advance of participation in the physical fitness tests, to determine if the participant could participate safely in these tests [38,39]. If any of the questions was answered with 'yes', or was left blank, the general practitioner or intellectual disability physician was consulted to determine whether exercise was safe for this particular participant, considering his medical history. If not, the tests involving physical effort were excluded from the assessment: 30 second Chair stand and the 10 m Incremental shuttle walking test.

Procedure

The four tests were part of an extensive physical fitness assessment, which was conducted on locations familiar or close to participants: a large room within their home, a familiar day care center or a gym. All assessments with the physical fitness instruments were guided by test instructors, who all were physiotherapists, occupational therapists or physical activity instructors with experience with people with ID. They all followed a two-day course for the execution of all assessments and received an instruction manual specifically designed for this study.

In order to avoid undesirable influences of consecutive tests, both 10 m Incremental shuttle walking tests (ISWT) on the same day were executed with at least an hour in between. Test instructions developed for testing people with normal intellectual capabilities give standardized descriptions on how to motivate the participant and how much encouragement is allowed during a test. Such standardized encouragement is unsuitable in people with intellectual disabilities because of the large variation in behavior and responses. To keep this motivational aspect as equal as possible, we prescribed 'maximal motivation' to the test instructors for all tests. In some cases, this meant that participants were motivated to engage in the assessments by constant verbal encouragement and verbal rewarding, in other cases the test instructor had to remain very calm and quiet to motivate the client as much as possible and to prevent stress or anxiety. The specific background, knowledge and experience of the test instructors were important conditions to ensure the most suitable 'maximal motivation' for every participant, while regarding safety as well.

Reference values physical fitness tests

For comfortable walking speed, a meta-analysis of Bohannon and Williams Andrews (2011) of 41 studies with over 23,000 subjects provided weighted grand means and 95% confidence intervals of these weighted grand means for men and women per 10-years age category, suggesting that a score below the lower limit of this confidence interval is indicative of a 'below average' result [40].

Two meta-analyses were available for grip strength, the first provided adult normative values (12 studies, 3317 subjects), the second provided normative values for adults aged 75 years or over (7 studies, 739 subjects) [41,42]. Means with 95% confidence intervals are presented for men and women, for the left hand side and the right hand side, and for 5-years age categories separately. In these normative values, the distinction between the dominant and the non-dominant side is lacking, while the result of the dominant side is used to indicate maximum grip strength. To enable comparison between maximum grip strength in the current study, the right hand values are used as normative values, since the dominant side of most people is the right side. According to the authors, individual patients whose score is less than the lower limit of the 95% confidence interval of a specific stratum can be considered to be impaired [41], or at least less than average [42].

For the 30 second Chair stand, normative values are formulated by Rikli and Jones (1999) as the middle 50% of the distribution of scores of a large sample of older adults (n=7,183), specified for men and women and per 5-years age category. Scores below the 25th percentile are to be interpreted as below average, and above the 75th percentile as above average [43].

For VO2max, normative values are provided by the ACSM for men and women as well as for 10-years age categories from 20-29 years to 70-79 years (N men: 44,549, N women: 14,978, based on the Cooper Center Longitudinal Study database) [44]. ASCM presents these normative values in categories: superior, excellent, good, fair, poor and very poor. Research suggests that a score below the 20th percentile (category 'very poor') for every age category for men and women is associated with an increased risk of death from all causes [45].

All reference values are depicted in Table 1 (men) and Table 2 (women).

Data analysis

Bias in participation on the tests was checked by comparing test participants with non-participants within the total HA-ID study population on baseline characteristics (gender, 10-years age-groups, level of ID, presence of Down syndrome, mobility impairment) with Pearson chi-square tests. Because only 3 participants fell into the age category 90 years and over, they were merged with the preceding category.

For each test, mean physical fitness results (with standard deviations) were calculated and specified for men and women in 5-years age-groups or 10-years age-groups, depending on the reference values. Furthermore, percentages of participants with above average, average and below average results (as formulated in the reference studies) were calculated for each gender and age stratum.

Finally, the means of the different gender and age strata of the HA-ID population are compared with all gender and age strata of the general population, to investigate if

Table 1 Comparison for males between reference values of the general population and results of study population of HA-ID

		Men general population					Men HA-ID					
	age	n	mean	lower limit	upper limit	% below avg	n	mean	SD	% below avg	% avg	% above avg
WSC	50-59	436	1.43	1.12	1.49	2.5	156	1.11	0.37	50.0	34.6	15.4
	60-69	941	1.34	1.03	1.59	2.5	139	1.06	0.30	43.9	52.5	3.6
	70-79	3671	1.26	0.96	1.42	2.5	45	0.82	0.31	20.0	77.8	2.2
	80-89	1091	0.96	0.61	1.22	2.5	1	0.97	0	0	100	0
	Total					**2.5**				**43.4**	**47.8**	**8.8**
30 sec CS	50-54			N/A	N/A		55	10.44	3.18			
	55-59			N/A	N/A		70	9.86	2.97			
	60-64	241		14	19	25	72	9.49	3.74	86.1	12.5	1.4
	65-69	482		12	18	25	42	9.4	2.72	76.2	23.8	0
	70-74	515		12	17	25	19	9.58	5.69	84.2	10.5	5.3
	75-79	464		11	17	25	11	7.91	3.53	81.8	18.2	0
	80-84	241		10	15	25	2	6.00	1.41	100.0	0	0
	85-89	116		8	14	25	0	N/A	N/A			
	Total					**25**				**82.9**	**15.8**	**1.4**
GS	50-54	100	50.6	44.2	56.9	2.5	72	29.43	12.23	87.5	11.1	1.4
	55-59	100	44.1	36.7	51.4	2.5	92	28.78	10.32	78.3	19.6	2.2
	60-64	120	41.7	36.8	46.7	2.5	87	29.69	10.45	75.9	19.5	4.6
	65-69	82	41.7	35.4	47.9	2.5	57	29.28	8.71	75.4	24.6	0
	70-74	120	38.2	32.0	44.5	2.5	35	27.69	9.82	65.7	34.3	0
	75-79	114	33.0	27.1	38.9	2.5	22	24.86	6.69	59.1	40.9	0
	80-84	107	30.1	24.3	35.9	2.5	2	26.00	8.49	50.0	50.0	0
	85-89	35	25.8	22.8	28.8	2.5	3	18.33	10.21	66.7	0	33.3
	Total					**2.5**				**76.5**	**21.4**	**2.2**
VO2max	50-59	9102		31.0	54.3	20	36	16.40	5.83	100	0	0
	60-69	2682		27.3	51.1	20	10	14.52	5.81	100	0	0
	70-79	467		23.6	49.7	20	4	13.07	2.05	100	0	0
	80-89			N/A	N/A		1	7.19	N/A	100	0	0
	Total					**20**				**100**	**0**	**0**

avg=average score. N/A=not available. WSC=Walking speed comfortable speed in meter/second. 30 s CS=30 second Chair Stand in number of sit-to-stands. GS=Grip strength in kilogram. VO2max= maximal oxygen uptake in ml/kg/min based on the ISWT of the participants who achieved 85% of maxHR

Table 2 Comparison for females between reference values of the general population and results of study population of HA-ID

		Women general population					Women HA-ID					
	age	n	mean	lower limit avg	upper limit avg	% below avg	n	mean	SD	% below avg	% avg	% above avg
WSC	50-59	456	1.31	1.1	1.56	2.5	165	1.02	0.32	57.6	37.6	4.8
	60-69	5013	1.24	0.97	1.45	2.5	77	0.94	0.27	53.2	42.9	3.9
	70-79	8591	1.13	0.83	1.50	2.5	37	0.95	0.30	40.5	56.8	2.7
	80-89	2152	0.94	0.56	1.17	2.5	3	0.61	0.27	33.3	66.7	0
	Total					**2.5**				**53.9**	**41.8**	**4.3**
30 sec CS	50-54			N/A	N/A		70	9.76	2.87			
	55-59			N/A	N/A		80	9.11	2.88			
	60-64	620		12	17	25	41	9.32	3.81	78.0	17.1	4.9
	65-69	1084		11	16	25	27	8.04	3.18	74.1	25.9	0
	70-74	1298		10	15	25	22	8.86	3.62	68.2	22.7	9.1
	75-79	987		10	15	25	12	8.75	2.96	66.7	33.3	0
	80-84	543		9	14	25	4	8.50	4.2	50.0	50.0	0
	85-89	354		8	13	25	1	7.00	N/A	100.0	0	0
	Total					**25**				**72.9**	**23.4**	**3.7**
GS	50-54	116	30.9	26.7	35.2	2.5	82	21.34	8.83	70.7	24.4	4.9
	55-59	123	29.9	26.4	33.6	2.5	90	20.23	7.97	78.9	15.6	5.6
	60-64	132	25.9	22.2	29.6	2.5	65	20.08	7.13	66.2	26.2	7.7
	65-69	118	25.6	22.5	28.8	2.5	47	21.34	5.58	59.6	25.5	14.9
	70-74	166	24.2	20.7	27.8	2.5	38	17.92	6.47	60.5	34.2	5.3
	75-79	207	21.6	18.6	24.6	2.5	23	18.91	7.33	47.8	21.7	30.4
	80-84	166	17.3	14.8	19.9	2.5	5	17.40	6.11	40.0	20.0	40.0
	85-89	75	17.1	12.8	21.4	2.5	5	14.80	5.72	60.0	20.0	20.0
	Total					**2.5**				**67.3**	**23.4**	**9.3**
VO2max	50-59	3103		25.4	45.3	20	20	12.68	4.89	100.0	0	0
	60-69	1088		23.6	42.4	20	6	8.11	2.07	100.0	0	0
	70-79	209		21.1	42.4	20	3	15.02	4.76	100.0	0	0
	80-89			N/A	N/A		1	8.69	N/A	100.0	0	0
	Total					**20**				**100.0**	**0**	**0**

avg=average score, N/A=not available, WSC=Walking speed comfortable speed in meter/second. 30 s CS=30 second Chair Stand in number of sit-to-stands. GS=Grip strength in kilogram. VO2max= maximal oxygen uptake in ml/kg/min based on the ISWT of the participants who achieved 85% of maxHR

Table 3 Descriptives participants of HA-ID and of the four fitness tests and representativeness

	HA-ID	WSC	30 sec CS	GS	ISWT	VO2max
total N	1050	623	528	725	654	81
men	539	341	271	370	341	51
Age (years)						
mean (SD)	61.6 (8.0)	60.6 (7.3)	60.5 (7.3)	61.7 (8.0)	60.7 (7.5)	58.8 (6.9)
range	50-93	50-93	50-86	50-90	50-86	51-81
50-59 years	493	321^{+}	275^{+}	336	331^{+}	56^{+}
60-69 years	370	216	182	256	229	16^{-}
70-79 years	162	82	64^{-}	118	85^{-}	7
80-89 years	25	4^{-}	7	15	9	2
Pearson Chi-square		31.52*	19.70*	3.37	18.97*	17.80*
Level of ID						
Borderline	31	26^{+}	23^{+}	30^{+}	26^{+}	5
Mild	223	156^{+}	152^{+}	190^{+}	159^{+}	22
Moderate	506	325	282	399^{+}	336	41
Severe	172	81^{-}	51^{-}	78^{-}	94	10
Profound	91	17^{-}	5^{-}	7^{-}	23^{-}	3
Unknown	27	18	15	21	16	0
Pearson Chi-square		96.04*	143.91*	265.53*	74.91*	7.76
Down syndrome						
Yes	149	85	65	83^{-}	88	11
No	724	414	349	491	446	70
Unknown	177	124	114	151	120	0
Pearson Chi-square		0.00	1.04	8.05*	0.34	0.767
Mobility						
Independent	731	559^{+}	460^{+}	543^{+}	547^{+}	69
Walking aid	151	35^{-}	45^{-}	110	82^{-}	7
Wheelchair	107	2^{-}	0^{-}	41^{-}	5^{-}	1^{-}
Unknown	61	27	23	31	20	4
Pearson Chi-square		319.27*	180.14*	52.29*	207.01*	11.87*

HA-ID=study Healthy ageing and intellectual disabilities. WSC=Walking speed at comfortable speed. 30 s CS=30 second Chair Stand. GS=Grip strength. ISWT= Incremental Shuttle Walking test. VO2max= participants of the ISWT who achieved 85% of HRmax

* = $p < 0.05$

$^{+}$ = subgroup overrepresented in the test participants

$^{-}$ = subgroup underrepresented in the test participants the means of younger age groups (50-59 years) of the HA-ID population are within the average limits of the older age groups in the general population (70-79 or 80-89 years).

RESULTS

Descriptives of participants of HA-ID and of participants of the four fitness tests are provided in Table 3. The largest subgroups are: age 50-59 years, moderate ID, other etiologies than Down syndrome and being able to walk independently. Generally, adults with severe or profound ID and adults in a wheelchair could participate only moderately in the fitness tests and will therefore be underrepresented in the results; adults in the age category 50-59 were overrepresented, as were adults with borderline and mild ID and adults who are able to walk independently.

The total number of participants with VO2max results (n=81) is lower than the number of participants who executed the ISWT (n=654), because of problems with the heart rate registration by the Suunto heart rate monitors (n=63), no information on diagnosis of Down syndrome (n=113) (diagnosis was necessary to calculate HRmax, which in turn was required to determine sufficient effort during the test), and effort during execution of the test below 85% of HRmax (n=397).

Comparison of test results is presented for men and women in Table 1 and 2, and graphically presented in figure 1-4.

We conclude that a high percentage of participants of the HA-ID study population scored below the lower limit of the average range (i.e. are impaired). For walking speed, 43% of the men and 54% of the women scored below the average range of the general population for walking speed; using the reference values, this is 2,5% in the general older population. For the 30 sec Chair stand, 83% of the men and 73% of the women of the HA-ID participants scored below the lower limit of the average range of their age category, compared with 25% in the general older population. Impaired grip strength is present in 77% of the men and 67% of the women, in comparison with 20% in the general population. Finally, none of the participants who were able to exert themselves sufficiently, had a VO2max score above the lower limit of the average range in the general population.

Table 1 and 2 show that when comparing the mean of older adults with ID with the average ranges across different age categories in the general population, older adults with ID seem to score similarly to older adults in the general population who are 20-30 years older.

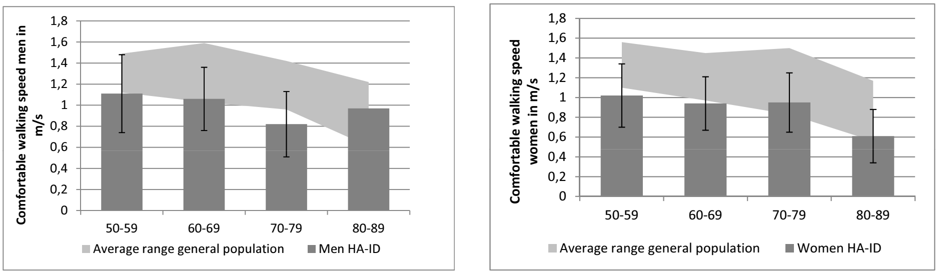

Figure 1a and 1b: Mean (with standard deviation) comfortable walking speed in the general population and HA-ID study population

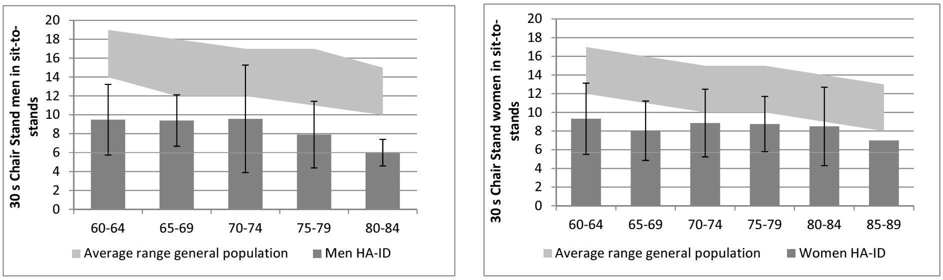

Figure 2a and 2b: Mean (with standard deviation) 30 second Chair stand in the general population and HA-ID study population

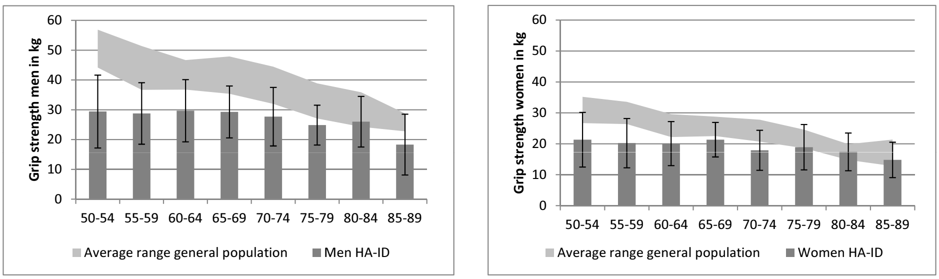

Figure 3a and 3b: Mean (with standard deviation) grip strength in the general population and HA-ID study population

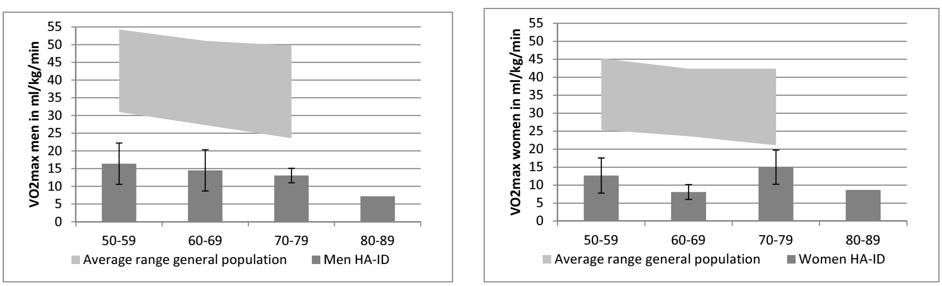

Figure 4a and 4b Mean (with standard deviation) VO2max in the general population and HA-ID study population

For comfortable walking speed in men, the means of HA-ID fell within the limits of their own age stratum, except for the 70-79 years old, which scored worse than the general population of that age, but were comparable to 80-89 years old in the general population. Women of 50-59 and 60-69 years old scored just below the average range of their age group in the general population, but were comparable to women of 10 years older of the general population.

For the 30 second Chair stand in men, the 50-55 HA-ID age group fell within the average range of the 80-84 years age group of the general population. All HA-ID groups between 55 and 75 fell within the average range of the 85-90 years old in the general population. Above 75 years old in the HA-ID group was comparable to above 90 years old in the general population. For women, 50-65 years-groups of HA-ID were comparable to 80-84 years old in the general population, older groups in HA-ID were comparable to 85 years old and over in the general population.

The biggest differences in grip strength between HA-ID and the general population were visible in the age-range from 50-75 years old. Men and women in HA-ID of 50-75 years old were comparable the 70-74 and 75-79 years old in the general population. From 80 years and over, the grip strength of HA-ID men was comparable to those of the general population.

VO2max levels of the youngest group were below the range of the oldest groups in the general population.

DISCUSSION

This first study of physical fitness in older adults with ID, applying instruments that have been evaluated thoroughly in the general population, shows that physical fitness levels in this group are

much lower than in the general older population. Across the tests addressing walking speed, grip strength, muscular endurance and cardiorespiratory endurance, percentages of participants scoring below the lower limits of average ranges in the general population, are astonishingly high. Across all age ranges, approximately two-third of the entire HA-ID study population scored 'below average' or 'impaired'. Even the youngest age groups (50-59 or 50-54 years) in this sample, achieve similar or even worse than age groups 20 to 30 years older in the general population. These low physical fitness levels are in agreement with previous research in younger adults with ID [10,11,13,46,47]. Furthermore, the underrepresentation of adults with severe and profound ID and adults in a wheelchair may cause these results to be an overestimation of the fitness levels in the actual population of older adults with ID as a whole.

These low physical fitness levels in older adults with ID could be interpreted as a signal of premature ageing in this population. The question remains however, whether low fitness is attributable to neurological impairments hampering optimal performance in physical tasks [48], a fundamentally different ageing process as has been identified in Down syndrome [49], or just to a lifelong sedentary lifestyle [50]. One may also wonder whether specific causes of intellectual disability may be accompanied with unidentified physical limitations (i.e.in maximum heart rate) which may restrict improvement of physical fitness levels to the same level as in persons without cognitive limitations. This is contradicted by research comparing athletes with ID and without ID, showing that physical fitness can be at the same level, although this does not seem to apply for strength measures [51,52].

The HA-ID population does not include older adults with ID without any form of registered professional support or care. Therefore, these results are not generalizable to this group, which consists mainly of older persons with borderline or mild ID who live independently. Within the HA-ID population, a bias during the informed consent procedure led to an underrepresentation of older adults with ID that receive only ambulatory support or only go to a day-care centre, which is the most independent group. Drop out during the physical fitness tests led to an underrepresentation of participants with severe or profound ID, and people in a wheelchair, and an overrepresentation of younger, independently walking older adults with borderline to mild ID.

Lack of understanding or motivation may have been a limitation of this study. Although the test instructors had been instructed to motivate the participants to maximally exert themselves, relying on their experience with this population, this remained difficult. This is indicative in itself of the limited experience of people with ID with physical exertion throughout their lives, causing fear of, or resistance against, unfamiliar bodily responses to exercise. This may have resulted in an underestimation of the participants' true capabilities, and emphasizes the importance of incorporating regular physical activity and exercise in their daily life.

The formula to calculate maximal heart rate might have overestimated the maximal heart rate, but not as much as the standard formulas for the general population [36]. This issue was previously raised in a study into the aerobic capacity of people with severe intellectual and sensory disabilities [53], but further research is necessary to provide more evidence and/or a more adequate formula to estimate maximal heart rate in this group.

Furthermore, since only a small percentage of the participants of the Incremental shuttle walking test achieved at least 85% of their predicted maximal heart rate, the usefulness of this test to estimate VO2max in older adults with ID could be questioned. But next to questioning the test, the experience of older adults with ID with exercise in general should be addressed. The first goal should be to implement exercise in this group widely, and only then is it possible to evaluate the usefulness of submaximal field tests to estimate VO2max.

This large amount of data, collected in the HA-ID study, will enable more research on this subject, in a population which is relatively new to health care organizations due to their increasing life expectancy. Our subjects of further research are the identification of risk groups within this specific population and differences between persons with specific etiological syndromes. More important, these data enable investigation of the functional implications of low fitness levels for daily functioning, for example to identify minimum fitness scores required for independent functioning, as has been suggested by Rikli and Jones (1999). There also is a need of longitudinal research, to validate physical fitness components against future functioning, falls, motor disability, morbidity, sarcopenia, frailty and eventually mortality.

This study shows low physical fitness levels in older adults with ID, and supports current recommendations of implementing a physical activity policy to enhance health [14,15], as research has already shown positive effects of exercise programs on physical fitness in this group [16,54]. Regular and widely-organized screening for physical fitness levels could help identify older adults who are at risk for disabilities in an early stage, and determine for whom, and what kind of, interventions are required in this vulnerable group.

REFERENCES

1. WHO, *Global health risks: mortality and burden of disease attributable to selected major risks.* 2009, World Health Organization, : Geneva, Switzerland.
2. WHO, *Global recommendations on physical activity for health*. 2010, World Health Organization: Geneva.
3. Mazzeo R.S. and Tanaka H., *Exercise prescription for the elderly: current recommendations.* Sports Med, 2001. **31**(11): p. 809-18.
4. DHHS, *Physical Activity Guidelines Advisory Committee Report*. 2008, U.S. Department of Health and Human Services, : Rockville (MD).
5. Chodzko-Zajko W.J., Proctor D.N., Fiatarone Singh M.A., et al., *American College of Sports Medicine position stand. Exercise and physical activity for older adults.* Med Sci Sports Exerc, 2009. **41**(7): p. 1510-30.
6. Patja K., Iivanainen M., Vesala H., et al., *Life expectancy of people with intellectual disability: a 35-year follow-up study.* J Intellect Disabil Res, 2000. **44 (Pt 5)**: p. 591-9.
7. Temple V.A., Frey G.C., and Stanish H.I., *Physical activity of adults with mental retardation: review and research needs.* Am J Health Promot, 2006. **21**(1): p. 2-12.
8. Hilgenkamp T.I., Reis D., van Wijck R., et al., *Physical activity levels in older adults with intellectual disabilities are extremely low.* Res Dev Disabil, 2012. **33**(2): p. 477-486.
9. van Schrojenstein Lantman-De Valk H.M., Metsemakers J.F., Haveman M.J., et al., *Health problems in people with intellectual disability in general practice: a comparative study.* Fam Pract, 2000. **17**(5): p. 405-7.
10. Graham A. and Reid G., *Physical fitness of adults with an intellectual disability: a 13-year follow-up study.* Res Q Exerc Sport, 2000. **71**(2): p. 152-61.
11. Lahtinen U., Rintala P., and Malin A., *Physical performance of individuals with intellectual disability: a 30 year follow up.* Adapt Phys Activ Q, 2007. **24**(2): p. 125-43.
12. Carmeli E., Ayalon M., Barchad S., et al., *Isokinetic leg strength of institutionalized older adults with mental retardation with and without Down's syndrome.* J Strength Cond Res, 2002. **16**(2): p. 316-20.
13. Fernhall B., *Physical fitness and exercise training of individuals with mental retardation.* Med Sci Sports Exerc, 1993. **25**(4): p. 442-50.
14. Bartlo P. and Klein P.J., *Physical activity benefits and needs in adults with intellectual disabilities: systematic review of the literature.* Am J Intellect Dev Disabil, 2011. **116**(3): p. 220-32.
15. Heller T., McCubbin J.A., Drum C., et al., *Physical Activity and Nutrition Health Promotion Interventions: What is Working for People With Intellectual Disabilities?* Intellect Dev Disabil, 2011. **49**(1): p. 26-36.
16. Calders P., Elmaghoub S., de Mettelinge T.R., et al., *Effect of combined exercise training on physical and metabolic fitness in adults with intellectual disability: a controlled trial.* Clin Rehabil, 2011.

17. Pitetti K.H., Rimmer J.H., and Fernhall B., *Physical fitness and adults with mental retardation. An overview of current research and future directions.* Sports Med, 1993. **16**(1): p. 23-56.
18. Abellan van Kan G., Rolland Y., Andrieu S., et al., *Gait speed at usual pace as a predictor of adverse outcomes in community-dwelling older people an International Academy on Nutrition and Aging (IANA) Task Force.* J Nutr Health Aging, 2009. **13**(10): p. 881-9.
19. Cooper R., Kuh D., Cooper C., et al., *Objective measures of physical capability and subsequent health: a systematic review.* Age Ageing, 2011. **40**(1): p. 14-23.
20. Cooper R., Kuh D., Hardy R., et al., *Objectively measured physical capability levels and mortality: systematic review and meta-analysis.* BMJ, 2010. **341**: p. c4467.
21. Hilgenkamp T.I., van Wijck R., and Evenhuis H.M., *Physical fitness in older people with ID-Concept and measuring instruments: a review.* Res Dev Disabil, 2010. **31**(5): p. 1027-38.
22. Hilgenkamp T.I., Bastiaanse L.P., Hermans H., et al., *Study healthy ageing and intellectual disabilities: Recruitment and design.* Res Dev Disabil, 2011. **32**(3): p. 1097–1106.
23. WMO, *Medical Research Involving Human Subjects Act*. 1999: http://www.ccmo-online.nl/main.asp.
24. Steffen T. and Seney M., *Test-retest reliability and minimal detectable change on balance and ambulation tests, the 36-item short-form health survey, and the unified Parkinson disease rating scale in people with parkinsonism.* Phys Ther, 2008. **88**(6): p. 733-46.
25. Steffen T.M., Hacker T.A., and Mollinger L., *Age- and gender-related test performance in community-dwelling elderly people: Six-Minute Walk Test, Berg Balance Scale, Timed Up & Go Test, and gait speeds.* Phys Ther, 2002. **82**(2): p. 128-37.
26. Connelly D.M., Stevenson T.J., and Vandervoort A.A., *Between- and within-rater reliability of walking tests in a frail elderly population.* Physiotherapy Canada, 1996. **48**(1): p. 47-51.
27. Hilgenkamp T.I., van Wijck R., and Evenhuis H., *Feasibility and reliability of tests for measuring physical fitness in older adults with intellectual disabilities. A pilot study.* J Intellect Dev Disabil, 2012. **In press**.
28. Rikli R.E. and Jones C.J., *Senior fitness test manual*. 2001: Human Kinetics Europe Ltd
29. Jones C.J., Rikli R.E., and Beam W.C., *A 30-s chair-stand test as a measure of lower body strength in community-residing older adults.* Res Q Exerc Sport, 1999. **70**(2): p. 113-9.
30. Mathiowetz V., Kashman N., Volland G., et al., *Grip and pinch strength: normative data for adults.* Arch Phys Med Rehabil, 1985. **66**(2): p. 69-74.
31. Fess E.E. and Moran C., *Clinical assessment recommendations*. 1981, Indianapolis, USA: American Society of Hand therapists Monograph.
32. Abizanda P., Navarro J.L., Garcia-Tomas M.I., et al., *Validity and usefulness of hand-held dynamometry for measuring muscle strength in community-dwelling older persons.* Arch Gerontol Geriatr, 2011.
33. Stark T., Walker B., Phillips J.K., et al., *Hand-held dynamometry correlation with the gold standard isokinetic dynamometry: a systematic review.* PM R, 2011. **3**(5): p. 472-9.

34. Singh S.J., Morgan M.D., Scott S., et al., *Development of a shuttle walking test of disability in patients with chronic airways obstruction*. Thorax, 1992. **47**(12): p. 1019-24.
35. Singh S.J., Morgan M.D., Hardman A.E., et al., *Comparison of oxygen uptake during a conventional treadmill test and the shuttle walking test in chronic airflow limitation.* Eur Respir J, 1994. **7**(11): p. 2016-20.
36. Fernhall B., McCubbin J.A., Pitetti K.H., et al., *Prediction of maximal heart rate in individuals with mental retardation.* Med Sci Sports Exerc, 2001. **33**(10): p. 1655-60.
37. Jolly K., Taylor R.S., Lip G.Y., et al., *Reproducibility and safety of the incremental shuttle walking test for cardiac rehabilitation.* Int J Cardiol, 2008. **125**(1): p. 144-5.
38. Thomas S., Reading J., and Shephard R.J., *Revision of the Physical Activity Readiness Questionnaire (PAR-Q)*. Can J Sport Sci, 1992. **17**(4): p. 338-45.
39. Cardinal B.J., Esters J., and Cardinal M.K., *Evaluation of the revised physical activity readiness questionnaire in older adults.* Med Sci Sports Exerc, 1996. **28**(4): p. 468-72.
40. Bohannon R.W. and Williams Andrews A., *Normal walking speed: a descriptive meta-analysis.* Physiotherapy, 2011. **97**(3): p. 182-9.
41. Bohannon R.W., Peolsson A., Massy-Westropp N., et al., *Reference values for adult grip strength measured with a Jamar dynamometer: a descriptive meta-analysis.* Physiotherapy, 2006. **92**(1): p. 11-15.
42. Bohannon R.W., Bear-Lehman J., Desrosiers J., et al., *Average grip strength: a meta-analysis of data obtained with a Jamar dynamometer from individuals 75 years or more of age.* J Geriatr Phys Ther, 2007. **30**(1): p. 28-30.
43. Rikli R.E. and Jones J., *Functional fitness normative scores for community-residing older adults, ages 60-94.* J Aging Phys Act, 1999. **7**: p. 162-181.
44. ACSM, *ACSM's Guidelines for exercise testing and prescription*. 8th edition ed. 2010, Philadelphia, PA: Lippincott Williams & Wilkins.
45. Blair S.N., Kohl H.W., 3rd, Barlow C.E., et al., *Changes in physical fitness and all-cause mortality. A prospective study of healthy and unhealthy men.* Jama, 1995. **273**(14): p. 1093-8.
46. Pitetti K. and boneh S., *Physical fitness and performance in adults with mental retardation.* Adapt Phys Activ Q, 1995. **12**(4): p. 391.
47. Skowronski W., Horvat M., Nocera J., et al., *Eurofit special: European fitness battery score variation among individuals with intellectual disabilities.* Adapt Phys Activ Q, 2009. **26**(1): p. 54-67.
48. Rolland Y., Abellan van Kan G., Nourhashemi F., et al., *An abnormal "one-leg balance" test predicts cognitive decline during Alzheimer's disease.* J Alzheimers Dis, 2009. **16**(3): p. 525-31.
49. Barnhart R.C. and Connolly B., *Aging and Down syndrome: implications for physical therapy.* Phys Ther, 2007. **87**(10): p. 1399-406.
50. Pitetti K.H. and Campbell K.D., *Mentally retarded individuals--a population at risk?* Med Sci Sports Exerc, 1991. **23**(5): p. 586-93.
51. van de Vliet P., Rintala P., Frojd K., et al., *Physical fitness profile of elite athletes with intellectual disability.* Scand J Med Sci Sports, 2006. **16**(6): p. 417-25.

52. Frey G.C., McCubbin J.A., Hannigan-Downs S., et al., *Physical fitness of trained runners with and without mild mental retardation.* Adapt Phys Activ Q, 1999. **16**(2): p. 126-137.
53. Waninge A., Evenhuis I.J., van Wijck R., et al., *Feasibility and reliability of two different walking tests in subjects with severe intellectual and sensory disabilities.* Journal of applied research in intellectual disabilities: JARID, 2011. **24**(6): p. 518-527.
54. Wu C.L., Lin J.D., Hu J., et al., *The effectiveness of healthy physical fitness programs on people with intellectual disabilities living in a disability institution: six-month short-term effect.* Res Dev Disabil, 2010. **31**(3): p. 713-7.

Chapter 9

Subgroups associated with lower physical fitness in older adults with ID: Results of the HA-ID study

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Submitted

ABSTRACT

Background: Although physical fitness is generally very low in older adults with intellectual disabilities (ID), levels may differ across subgroups. It is important to identify which subgroups need to be targeted specifically in physical activity interventions, fitness interventions and reference values.

Methods: Physical fitness was measured with the Box-and-block-test, Response-time-test, Berg-balance-scale, Walking speed, Grip strength, 30s-Chair-stand, 10m Incremental-shuttle-walking test and the Extended modified-back-saver-sit-and-reach-test in a large sample of older adults with ID (n=1050). Subgroups associated with lower physical fitness levels were identified applying multivariate linear regression analyses.

Results: Both fixed personal characteristics such as being older, being female, having more severe ID and having Down syndrome and modifiable or preventable factors such as physical activity levels, mobility impairments and a need of more intensive care, are independently associated with lower levels of multiple physical fitness components.

Conclusion: This first study identifies subgroups of older adults with ID which require adapted reference values, and subgroups that need to be specifically targeted in fitness promotion programmes.

INTRODUCTION

Physical fitness is important to independence and well-being [1]. In older adults with intellectual disabilities (ID), average fitness levels prove to be very low: Across all age categories, approximately two-thirds of older adults with ID have lower than average physical fitness levels in comparison to the general population [2]. This may be caused by lifestyle-related aspects, but also by comorbid neurological and physiological limitations [3]. If so, reference values for the general population may not always be applicable to this population. Fitness levels may vary across subgroups of this population. Therefore, it is of major importance to identify on the one hand which subgroups are disadvantaged due to unchangeable personal characteristics, which may be used to determine subgroup-specific reference values, and on the other hand due to modifiable or preventable variables, which can be targeted specifically in rehabilitation as well as with physical activity and fitness interventions.

In previous research in adults with ID, valuable information regarding vulnerable subgroups has been presented. Age has been shown to have a negative effect on muscle strength and endurance [3,4], static balance and manual dexterity [5] and cardiovascular endurance and flexibility [4]. Gender has been demonstrated to make a difference in muscle strength/endurance [5,6], balance [6], cardiorespiratory endurance [7], and flexibility [6]. The level of ID seems to be associated with balance and manual dexterity [5], muscle strength and muscle endurance in children and adolescents [6], and reaction time [8]. Down syndrome is the most prevalent genetic syndrome causing intellectual disability (18-22% of all people with ID) [9,10] , and physical characteristics associated with this syndrome, such as muscle hypotonicity, joint hypermobility and cardiac disorders [11,12], could influence results of physical fitness tests. Indeed, adults with Down syndrome score lower on reaction time [13], manual dexterity [5], muscle strength and endurance [3,5,14-16] and cardiorespiratory endurance [3,7,17] than people with ID by other causes. Flexibility is either similar between adults with or without DS [16], or larger in adults with Down syndrome [18].

Methodological limitations however, reduce the applicability of the results to other populations such as older adults with ID. Small sample sizes (below <100) hamper the study of subgroups and, together with the exclusive participation of people with mild to moderate ID in most studies, limit the generalizability to larger populations or to subgroups with more severe ID [3-5,16,19]. Furthermore, previous studies were conducted predominantly with adults younger than 50 years [6,7,20] Because physical fitness has shown to be age-specific in the general population [21,22], results in younger groups are not applicable to older adults. Since most fitness research in people with ID has focused on cardiorespiratory endurance, muscle strength, muscle endurance and to some minor extent flexibility [3,19,20,23], information about performance in other fitness components, such as manual dexterity, reaction time and balance, is scarce [5,13].

Limitations also appear when looking at studied subgroups, which are mostly based on gender, age, and Down syndrome [5,24,25]. Due to the small numbers however, only univariate analyses could be performed, whereas these characteristics could very well be interrelated. Only limited information is available about subgroups based on level of intellectual disability [6], or based on level of physical activity [23,26], and no information was found about associations with level of mobility (independent, walking aid or wheelchair) and with the intensity of professional care (type of setting), factors that are associated with physical activity levels in this group [27,28]. Level of mobility comprises both lifelong mobility impairments, originating in childhood, and age-related and life-style related mobility impairments. The intensity of professional care is not only determined by physical limitations in daily functioning, but also by co-morbidities, autism and behavioral problems. On the other hand, the type of setting can hamper physical activity, for example by traffic safety issues. Type of setting, level of mobility and level of physical activity all are changeable variables, and investigating the association with physical fitness might provide directions for interventions and policy in ID care services.

To date, no study has objectively addressed physical fitness on a broad range of components, in a population-based sample of older adults with ID, large enough to distinguish subgroups based on multiple personal characteristics and to investigate the association of these characteristics with fitness in a multivariate analysis. Therefore, we aimed to investigate which subgroups (gender, age, type of setting, level of ID, Down syndrome, level of mobility and level of physical activity) are associated with lower physical fitness in the older population with ID.

METHODS

Study design and participants

This study was part of the large-scale Dutch cross-sectional study 'Healthy ageing and intellectual disabilities' (HA-ID), executed by a consort of three ID care services (Abrona at Huis ter Heide; Amarant at Tilburg; and Ipse de Bruggen at Zwammerdam), in collaboration with two university institutes (Intellectual Disability Medicine, Erasmus Medical Center at Rotterdam; and the Center for Human Movement Sciences, University Medical Center at Groningen). All 2150 clients with intellectual disabilities (ID), aged 50 years and over, of the three ID care services were invited to participate, resulting in a near-representative sample of 1050 clients. Details about design, recruitment and representativeness of the sample have been presented elsewhere [29]. Data collection took place between February 2009 and July 2010.

Ethical approval was provided by the Medical Ethical Committee of the Erasmus Medical Center (MEC 2008-234) and by the ethical committees of the participating ID care services. Informed consent was obtained from all participants; however, unusual resistance was a reason for aborting measurements at all times [30].

Data collection

General information
Gender, age and type of setting were collected from the administration systems of the care providers. Professional caregivers provided information about mobility (independent, walking with an aid, or wheelchair-bound). Level of ID was categorized by psychologists or behavioral therapists as: borderline (IQ=70-84), mild (IQ=50-69), moderate (IQ=35-49), severe (IQ=20-34) or profound (IQ <20) (based on ICD-10 criteria). The presence of Down syndrome was collected through the medical files. Level of physical activity was measured with a pedometer (NL-1000, detailed methods are described elsewhere) [28] and classified in an active group (7500 steps/day or more) and a less active group (less than 7500 steps/day) [31,32].

Physical fitness measurements
Physical fitness was measured with a range of instruments and a standard testing procedure, which are described in detail elsewhere [33]. Manual dexterity was measured with the Box and block test (BBT) [34], response time with a response time laptop test with a visual (RTV) and an auditive signal (RTA) [35,36]. Balance was measured with the Berg balance scale (BBS) [37], and with measuring comfortable (WSC) and fast walking speed (WSF) [38-40]. Muscle endurance was measured with the 30 second chair stand (30sCS) [41,42], while muscle strength was measured with grip strength (GS) [43,44]. Cardio-respiratory endurance was measured with the 10 meter Incremental shuttle walking test, in which heart rate was continuously monitored [45,46]. The achieved percentage of the predicted maximal heart rate [47] was used as an outcome variable of this test (%HRmax), as well as the calculated VO2max [48]. Flexibility was measured with an extended version of the modified back saver sit and reach (EMBSSR) [49,50].

Feasibility and reliability of these instruments was good in older adults with ID [51]. All assessments were conducted by test instructors, who all were physiotherapists, occupational therapists or physical activity instructors with experience with working with people with ID. They all followed a two-day course for the execution of the eight tests and received an instruction manual specifically designed for this study.

Safety information

The Revised Physical Activity Readiness Questionnaire (rPARQ) was administered by the professional caregivers in advance of participation in the physical fitness tests, to determine if these tests could be performed safely by the participant [52,53]. This instrument consists of seven questions regarding the presence of health conditions or complaints which can be answered with yes or no. If any of the questions was answered with yes or was left blank, the general practitioner or intellectual disability physician was consulted to determine whether exercise was safe for this particular participant, considering his medical history. If not, the tests involving physical effort were excluded from the assessment: fast walking speed, 30 second Chair stand and the 10 m Incremental shuttle walking test.

Data analysis

Firstly, physical fitness tests results were calculated for all categories of the independent variables separately (age in 10 years categories). Bias caused by drop-out was calculated by comparing participants with non-participants on baseline characteristics (gender, 10-years age-groups, level of ID, presence of Down syndrome, mobility impairment and level of physical activity (PA)) with Pearson chi-square tests. Because only 3 participants fell into the age category 90 years and over, they were merged with the preceding category.

To determine if categories of categorical variables (level of mobility, level of ID and type of setting) could be grouped together (which would simplify the interpretation of the following regression analyses), all categories were compared with one another with univariate general linear models and post hoc pairwise comparisons with Bonferroni correction. Categories that did not differ significantly from each other were combined, and dichotomous dummy variables were created for the remaining categories of these three variables.

To determine subgroups associated with lower scores on separate physical fitness tests, a multiple linear regression model was used for each of the continuous test results as dependent variables and with gender (male-female), age (in years), type of setting (central setting, community-based group home, living independently with ambulatory support and living with relatives), level of ID (borderline, mild, moderate, severe and profound), Down syndrome (yes-no), level of mobility (independent, walking with aid, wheelchair) and level of physical activity (below and above 7500 steps/day) as independent variables, all entered simultaneously, except for level of physical activity.

The number of participants with a valid result on physical activity level was quite low (n=257), which results in a more selected sample [28] if this variable is included in the regression analysis. Therefore, for each physical fitness test, two regression analyses were conducted: one without and one with level of physical activity entered together with the other variables. Multicollinearity was checked with the Variance Inflation Factor (VIF), which needs to be below 10 for all predictor variables [54].

RESULTS

Descriptives

Descriptives of the total HA-ID study population are presented in Table 1, whereas a detailed overview of numbers of participants per test and results of all physical fitness tests are presented in appendix 1, specified for all categories of the independent variables.

For all tests, participants differed significantly from non-participants on level of ID (more drop-out with more severe level of ID) and on level of mobility (wheelchair-bound participants are underrepresented, whereas independently walking participants were overrepresented in most tests except the Box and block test and both Response time tests). Gender only caused a bias in both response time tests (males are somewhat underrepresented, females are somewhat overrepresented in both tests), and age only caused a bias in participation in the fast walking speed assessment, the 30 sec Chair stand and the Incremental shuttle walking test (mostly because the 70-79 years old group was underrepresented). Participants with Down syndrome were under-represented in all tests, except for both walking speed assessments, the 30 sec Chair stand and the Incremental shuttle walking test. The physically more active group was overrepresented only in the 30 sec Chair stand (data not presented).

Univariate analyses of categorical variables

Based on differences between separate categories, categorical variables were recoded into dummy variables. For type of setting, the category 'with relatives' was too small (n=7) and not consistently comparable to the other categories, and was therefore omitted. The remaining three categories were recoded into two dummy variables, with 'central setting' as baseline category. Because borderline and mild ID consistently did not differ from each other, and neither did severe and profound ID, these variables were combined, and two dummy variables were created with 'borderline-mild' as baseline category. Mobility levels were recoded as two dummy variables with 'independent walking' as baseline category.

Results of the univariate analyses of the three categorical independent variables (type of setting, level of ID and level of mobility) are presented in appendix 2.

Table 1 Descriptives of the HA-ID study population

		N
Total		1050
Gender	Male	539
	Female	511
Age (years)	Mean (SD	61.6 (8.0)
	Range	50-93
	50-59 years	493
	60-69 years	370
	70-79 years	162
	80+ years	25
Type of setting	Central setting	557
	Community-based	432
	Ambulatory support	43
	With relatives	7
Level of ID	Borderline	31
	Mild	223
	Moderate	506
	Severe	172
	Profound	91
	Unknown	27
Down syndrome	No down syndrome	724
	Down syndrome	149
	Unknown	177
Mobility	Independent	731
	With walking aid	151
	Wheelchair	107
	Unknown	61
Level of physical activity	Less active	164
	Active	93
	Unknown	793

Subgroup analyses

Results of all multivariate regression models are presented in Table 2, with the number of participants included in the models, the explained variance (adjusted R-square) and the unstandardized coefficients (B) for all independent variables, representing the independent association of that subgroup with physical fitness. Variance inflation factor (VIF) was always well below 10.

Table 2: Results of the regression analyses for each physical fitness tests, for a model without level of PA (=physical activity) and a model with PA included.

	N	Adjusted R^2	F	Female	Older age (years)	Community-based (vs central)	Independent (vs central)	Moderate (vs borderline-mild)	Severe-profound (vs borderline-mild)	Down syndrome	Walking aid (vs independent)	Wheelchair (vs independent)	Physically active	Constant
BBT														
Model without PA	558	0.47	55.72	0.48	-0.18**	7.17**	10.4**	-6.91**	-14.39**	-5.60**	-5.89**	-9.10**		43.57**
Model with PA	186	0.25	7.88	1.96	-0.02	4.35**	0.58	-7.87**	-18.43**	-3.02	-5.77		3.18	37.70
RTV														
Model without PA	401	0.24	15.36	52.43	8.62	-460.92**	-618.72**	327.25**	1075.47**	263.55*	90.94	413.20*		481.13
Model with PA	162	0.15	4.12	144.31	8.31	-127.87	-382.18*	244.25**	363.03	549.76**	-255.56		119.98	172.35
RTA														
Model without PA	412	0.19	11.45	110.98	30.79**	-405.26**	-716.67**	305.63**	1224.31**	275.40	22.75	244.28		-937.21*
Model with PA	164	0.12	3.51	88.13	25.06*	-263.49	-571.89*	218.76	1149.20**	256.27	-315.48		109.50	-734.26
BBS														
Model without PA	360	0.62	64.72	-0.99	-0.14**	2.16**	2.89	-1.93*	-2.92*	-1.02	-12.67**	-40.37**		58.43**
Model with PA	164	0.21	5.71	0.44	-0.08	1.36*	1.10	-1.23*	-2.46	0.52	-4.67**		1.64**	54.56**
WSC														
Model without PA	529	0.33	30.42	-0.089**	-0.009**	0.109**	0.216**	-0.059*	-0.177**	-0.118**	-0.299**	-0.467**		1.621**
Model with PA	191	0.091	3.125	-0.073*	-0.003	0.009	0.102	-0.037	-0.100	-0.035	-0.152*		0.072*	1.405**
WSF														
Model without PA	412	0.292	19.81	-0.475**	-0.031**	0.316**	0.324	-0.154	-0.504**	-0.098	-0.530**	-0.297		3.960**
Model with PA	176	0.261	7.883	-0.420**	-0.018*	0.109	0.113	-0.149	-0.482	0.493*	-0.274		0.533**	3.183**

30s CS														
Model without PA	389	0.19	12.39	-0.42	-0.06*	0.84**	2.01**	-1.60**	-2.44**	-0.91*	-1.87**	N/A		13.67**
Model with PA	172	0.09	2.92	-0.20	0.00	0.20	1.74	-1.46**	-2.04	0.12	-0.37		1.04*	11.08
GS														
Model without PA	540	0.38	37.89	-12.82**	-2.93**	3.01**	1.34	-4.58**	-6.87**	-4.70**	-2.22*	-4.16**		39.46**
Model with PA	189	0.33	11.46	-9.77**	-0.09	-0.29	-2.05	-4.85**	-11.05**	-4.70*	-1.83		0.31	40.84**
ISWT: %HRmax														
Model without PA	452	0.01	1.60	1.99	-0.12*	0.84	-0.37	-2.11	-3.73	-2.01	-3.06	3.68		85.76**
Model with PA	165	0.01	1.16	-0.87	-0.32	-1.64	6.60	-2.07	-5.11	-1.39	0.44		3.68	95.86**
ISWT: VO2max														
Model without PA	77	0.26	4.03	-3.35**	-0.09	1.43	6.34	-2.24	-3.61	-1.73	-4.01	4.11		21.94**
Model with PA	38	0.48	4.76	-1.90	0.13	-1.74	-0.73	-5.05**	-1.83	1.48	-2.49		6.21**	9.97
EMBSSR														
Model without PA	469	0.14	9.33	6.20**	-0.15	1.25	-1.54	-0.35	-0.45	10.34**	-3.22	-5.53		43.33**
Model with PA	176	0.14	4.17	8.22**	0.02	0.48	-0.70	-0.97	4.05	12.81**	-3.41		2.01	33.64**

* = $p < 0.05$, ** = $p < 0.01$, BBT=Box and Block test, RTA=Response Time test Auditive, RTV=Response Time test Visual, BBS=Berg Balance Scale, WSC=Walking speed comfortable speed, WSF=Walking speed fast, 30 s CS=30 second Chair Stand, GS=Grip strength, ISWT=10m Incremental Shuttle Walking Test in achieved % of heart rate reserve and VO2max of the participants who achieved 85% of HRR, EMBSSR=Extended Modified Back Saver Sit and Reach.

Regression analyses without physical activity level

Explained variance ranged from 1% (HRmax) to 62% (Berg balance scale).

Women scored worse than men on walking speed (comfortable and fast), grip strength and cardiorespiratory endurance, but better on flexibility.

With increasing age, results were lower on all tests, except cardiorespiratory endurance and flexibility. Living in a setting with more intensive support or care had negative associations with manual dexterity, response time, comfortable walking speed and muscular endurance. For balance, fast walking speed and grip strength, the same effect was present, but only for the comparison of community-based settings with central settings.

More severe intellectual disability was negatively associated with all tests, except with the achieved percentage of maximal heart rate, cardiorespiratory endurance and flexibility.

Independent from level of ID, Down syndrome resulted in lower scores on manual dexterity, response time (only for the visual task), comfortable walking speed, muscle endurance of the legs and grip strength, but higher scores on flexibility.

Walking with a walking aid was associated with lower scores on manual dexterity, balance, comfortable walking speed, muscular endurance of the legs and grip strength. Wheelchair-bound participants had lower scores on the same tests as participants with walking aids, except for fast walking speed and muscular endurance of the legs. This was due to the small or absent number of wheelchair bound participants in these tests. Additionally, wheelchair-bound participants scored lower on response time (visual task).

Regression analyses with physical activity level

The models with physical activity levels (PA) include a smaller, but functionally more able sample of older adults with ID. Explained variance ranged from 1% (%HRmax) to 48% (VO2max).

Women in this group had lower results than men on walking speed (comfortable and fast) and grip strength, and scored better on flexibility.

Within this sample, increasing age only was negatively associated with fast walking speed, and a living facility with more intensive care (type of setting) was associated negatively only with manual dexterity and response time.

More severe intellectual disability was negatively associated with all tests, except walking speed (both comfortable and fast), the achieved percentage of maximal heart rate and flexibility. In this sample there was a difference in cardiorespiratory endurance between borderline-mild and moderate level of ID, which was not significant in the larger sample, used in the regression analyses without PA.

Down syndrome resulted in lower scores on response time (only for the visual task) and fast walking speed, but also in higher scores on flexibility.

Walking with an aid resulted in lower scores only for balance, and wheel-chair-bound participants were not included in this sample.

Physically active participants scored higher on balance, comfortable walking speed, fast walking speed, muscular endurance of the legs and cardiorespiratory endurance.

DISCUSSION

This study was the first to address physical fitness in a population-based sample of older adults with ID which was large enough to investigate the independent association of multiple factors with low physical fitness levels. Several fixed personal characteristics were associated negatively with physical fitness levels, and need to be taken into account when formulating reference values: ageing adults, women, adults with more severe ID and adults with Down syndrome. In the general population, specific reference values have been formulated for both genders and for different age categories [55], and our results demonstrate that this applies to the older population with ID as well. Additionally, Down syndrome and more severe level of ID are negatively associated with physical fitness, independent of physical activity level, and this suggests that the neurological and physiological characteristics of this group may hamper similar fitness performance as in the general population, which underpins the need for subgroup-specific reference values.

Mobility impairments are negatively associated with physical fitness levels in most tests. While 'using a walking aid' already was negatively associated with physical fitness levels in comparison with people who can walk without any aids, being wheelchair-bound often was even more negatively associated with physical fitness. The part of the group with childhood mobility impairments may require adapted reference values for some tests. For the part of the population of older adults in which mobility impairments are age-related or lifestyle-related, the urgency arises to keep them as active as possible to postpone mobility impairments for as long as possible. Living in a facility with higher intensity of care is, independently from abovementioned factors such as physical activity levels, and severe ID, associated with low levels of physical fitness. Although a part of the population may be allocated to this type of setting due to an age-related decline in daily functioning skills and increase in required care, the residents of this type of setting mostly have other, non-age-related, personal characteristics that require the high intensity of care, such as co-morbidities, autism or behavioral problems. This indicates that the type of setting in itself is not directly related to physical fitness levels, but rather the specific population in this type of setting, which does not mean that physical fitness programmes would not be beneficial to these groups. The ageing group of older adults could very well be specifically targeted for physical fitness interventions, to maintain their daily functioning skills for as long as possible, as well as to postpone transfers to a facility with high intensity of care.

The independent negative association of fitness with modifiable or preventable factors, such as physical activity, impaired mobility level and living in a facility with high intensity of care, underlines strongly the importance of keeping this population in general as active as possible. The often low explained variance of these regression models confirms that lower physical fitness levels are not restricted to these subgroups alone, but are applicable to a larger part of this population. As was discussed previously, exercise and physical fitness programmes need to be implemented widely in this population [2].

When comparing our results to previous research, a more detailed description per test is possible for the associations with age, gender and Down syndrome. In addition to confirming previous research in adults with ID about the negative effect of age on muscle strength and endurance [3,4], static balance and manual dexterity [5], increasing age has now been demonstrated to be independently associated with reaction time with the auditive signal, balance and walking speed in older adults with ID. This age-effect has been demonstrated extensively in the general population as well, and has been incorporated in reference values [55]. Surprisingly, age is not independently associated with reaction time with the visual signal, which might indicate that age-related visual problems are more often detected and treated than age-related hearing problems. In contradiction with research in the general population [22,56], and with research in adults with ID [4,20], cardiorespiratory endurance in older adults does not seem to be affected by older age, which is probably explained by a bottom effect: very low scores (with little variation) across all subgroups in this study.

In line with previous research in people with ID, being female is independently associated with lower muscle strength [5,6], lower cardiorespiratory endurance [7] and better flexibility [6]. Balance was not found to be negatively associated with female gender in this study, in contradiction with previous research in people with ID [6], but walking speed, another measure for dynamic balance, was. The results are different from those in the general population regarding muscle endurance (men better than women) [57] and walking speed (no difference between men and women in the general population) [58]. For muscle endurance this might again be explained by a bottom effect in our study, but the difference in walking speed between men and women in our study remains unexplained.

As in previous studies comparing people with ID with and without Down syndrome [3,5,14-16,18], older adults with Down syndrome score worse on manual dexterity, visual reaction time, muscle strength and endurance and better on flexibility. In addition to previous research, we found lower scores on walking speed (both comfortable and maximal). No independent association was found between Down syndrome and reaction time with an auditive signal, despite the very high risk of hearing impairment [59], and between Down syndrome and cardiorespiratory endurance, despite the relatively large body of evidence on differences in cardiorespiratory endurance between adults with and without DS [3,7,17]. This is possibly explained by the low results in this group, with little variation across different categories and small numbers in each category.

As in the general population, being physically active proved to make a positive difference in balance, walking speed (comfortable and fast), muscle endurance and cardiorespiratory endurance [60,61], but being physically active did not make a difference for manual dexterity, reaction time, grip strength and flexibility in older adults with ID. These variables seem to be influenced predominantly by a cognitive aspect, considering the large coefficients in the regression analyses for level of ID. This might explain why physical activity level does not contribute in explaining the performance on specifically these components.

Some combinations of categories in the regression analyses are impossible, for example living independently with ambulatory support and having severe ID. Conclusions drawn from these analyses are restricted to the possible combinations of subcategories. Another limitation is the sample used. It is near-representative for older clients of ID care services, so these outcomes cannot be generalized to older adults with ID in general. Specifically, older adults with borderline or mild ID who are living independently in the community are not represented in this sample. Drop out in the physical fitness tests has caused a bias, with an underrepresentation of people with severe or profound ID and people in a wheelchair in all tests. Measuring physical fitness in these groups requires newly developed procedures and adapted tests, as has been explored and proved for people with ID and sensory impairments by Waninge et al. [62,63].

This study provides valuable information for research and practice because of the large sample and the wide range of objective measurements of physical fitness. It emphasizes the necessity to evaluate and stimulate physical fitness in the entire population of adults with ID, in older adults with ID as much as in younger adults with ID [64]. This may prevent unnecessary loss of functional capacities, age-related increase of mobility impairments, and an early need to move to a more intensive care facility. Every improvement in the amount of daily physical activity can contribute to such positive effects [65].

For use in clinical practice and research, data presented in this study give new insight into participation and outcomes on a wide range of physical fitness components in older adults with ID, shown in a detailed table specified for multiple subgroups.

This study enables us to identify subgroups, based on fixed personal characteristics, which may need to be taken into account when formulating reference norms for physical fitness in this population. This raises the question on what groups future reference values can be based: The entire older population of older adults with ID, or specifically the more active part? Or is it necessary to investigate the maximal abilities of (older) adults with ID, after intensive training regimens, and measured with more direct measures (such as measuring maximal oxygen uptake during exercise, or balance tasks with mobile gait analysis equipment)? Another approach in formulating reference values is to determine the threshold of physical fitness which is minimally required for maintaining daily functioning, or to prevent high risks of future health problems. This study is a necessary first step in gaining knowledge on physical fitness in older adults with ID. This process may lead to formulating reference values for physical fitness in this population as a next step, and can be used for evaluation of individuals and groups in research and clinical practice.

REFERENCES

1. WHO, *Global recommendations on physical activity for health*. 2010, World Health Organization: Geneva.
2. Hilgenkamp T.I., van Wijck R., and Evenhuis H.M., *Low physical fitness levels in older adults with ID: Results of the HA-ID study.* Res Dev Disabil, 2012. **33** (4): p. 1048-1058.
3. Fernhall B., *Physical fitness and exercise training of individuals with mental retardation.* Med Sci Sports Exerc, 1993. **25**(4): p. 442-50.
4. Graham A. and Reid G., *Physical fitness of adults with an intellectual disability: a 13-year follow-up study.* Res Q Exerc Sport, 2000. **71**(2): p. 152-61.
5. Lahtinen U., Rintala P., and Malin A., *Physical performance of individuals with intellectual disability: a 30 year follow up.* Adapt Phys Activ Q, 2007. **24**(2): p. 125-43.
6. Skowronski W., Horvat M., Nocera J., et al., *Eurofit special: European fitness battery score variation among individuals with intellectual disabilities.* Adapt Phys Activ Q, 2009. **26**(1): p. 54-67.
7. Fernhall B., Pitetti K.H., Rimmer J.H., et al., *Cardiorespiratory capacity of individuals with mental retardation including Down syndrome.* Med Sci Sports Exerc, 1996. **28**(3): p. 366-71.
8. Lally M. and Nettelbeck T., *Intelligence, reaction time, and inspection time.* Am J Ment Defic, 1977. **82**(3): p. 273-81.
9. Cooper S.A., Smiley E., Morrison J., et al., *Mental ill-health in adults with intellectual disabilities: prevalence and associated factors.* Br J Psychiatry, 2007. **190**: p. 27-35.
10. van Schrojenstein Lantman-de Valk H.M., van den Akker M., Maaskant M.A., et al., *Prevalence and incidence of health problems in people with intellectual disability.* J Intellect Disabil Res, 1997. **41 (Pt 1)**: p. 42-51.
11. Burt D.B., Loveland K.A., Chen Y.W., et al., *Aging in adults with Down syndrome: report from a longitudinal study.* Am J Ment Retard, 1995. **100**(3): p. 262-70.
12. Cooper S.A., *Clinical study of the effects of age on the physical health of adults with mental retardation.* Am J Ment Retard, 1998. **102**(6): p. 582-9.
13. Inui N., Yamanishi M., and Tada S., *Simple reaction times and timing of serial reactions of adolescents with mental retardation, autism, and Down syndrome.* Percept Mot Skills, 1995. **81**(3 Pt 1): p. 739-45.
14. Pitetti K.H., Climstein M., Mays M.J., et al., *Isokinetic arm and leg strength of adults with Down syndrome: a comparative study.* Arch Phys Med Rehabil, 1992. **73**(9): p. 847-50.
15. Carmeli E., Ayalon M., Barchad S., et al., *Isokinetic leg strength of institutionalized older adults with mental retardation with and without Down's syndrome.* J Strength Cond Res, 2002. **16**(2): p. 316-20.
16. Carmeli E., Barchad S., Lenger R., et al., *Muscle power, locomotor performance and flexibility in aging mentally-retarded adults with and without Down's syndrome.* J Musculoskelet Neuronal Interact, 2002. **2**(5): p. 457-62.

17. Pitetti K.H., Climstein M., Campbell K.D., et al., *The cardiovascular capacities of adults with Down syndrome: a comparative study.* Med Sci Sports Exerc, 1992. **24**(1): p. 13-9.
18. Angelopoulou N., Tsimaras V., Christoulas K., et al., *Measurement of range of motion in individuals with mental retardation and with or without Down syndrome.* Percept Mot Skills, 1999. **89**(2): p. 550-6.
19. Pitetti K.H., Rimmer J.H., and Fernhall B., *Physical fitness and adults with mental retardation. An overview of current research and future directions.* Sports Med, 1993. **16**(1): p. 23-56.
20. Baynard T., Pitetti K.H., Guerra M., et al., *Age-related changes in aerobic capacity in individuals with mental retardation: a 20-yr review.* Med Sci Sports Exerc, 2008. **40**(11): p. 1984-9.
21. Onder G., Penninx B.W., Lapuerta P., et al., *Change in physical performance over time in older women: the Women's Health and Aging Study.* J Gerontol A Biol Sci Med Sci, 2002. **57**(5): p. M289-93.
22. Fleg J.L., Morrell C.H., Bos A.G., et al., *Accelerated longitudinal decline of aerobic capacity in healthy older adults.* Circulation, 2005. **112**(5): p. 674-82.
23. Cuesta-Vargas A.I., Paz-Lourido B., and Rodriguez A., *Physical fitness profile in adults with intellectual disabilities: Differences between levels of sport practice.* Res Dev Disabil, 2010.
24. Carmeli E., Ariav C., Bar-Yossef T., et al., *Movement skills of younger versus older adults with and without Down syndrome.* Res Dev Disabil, 2012. **33**(1): p. 165-71.
25. Mendonca G.V., Pereira F.D., and Fernhall B., *Oxygen uptake kinetics during exercise in adults with Down syndrome.* Eur J Appl Physiol, 2010. **110**(3): p. 575-83.
26. Un N. and Erbahceci F., *The evaluation of reaction time on mentally retarded children.* Pediatr Rehabil, 2001. **4**(1): p. 17-20.
27. Finlayson J., Jackson A., Cooper S.A., et al., *Understanding predictors of low physical activity in adults with intellectual disabilities.* Journal of applied research in intellectual disabilities, 2009. **22**: p. 236-247.
28. Hilgenkamp T.I., Reis D., van Wijck R., et al., *Physical activity levels in older adults with intellectual disabilities are extremely low.* Res Dev Disabil, 2012. **33**(2): p. 477-486.
29. Hilgenkamp T.I., Bastiaanse L.P., Hermans H., et al., *Study healthy ageing and intellectual disabilities: Recruitment and design.* Res Dev Disabil, 2011. **32**(3): p. 1097–1106.
30. WMO, *Medical Research Involving Human Subjects Act*. 1999: http://www.ccmo-online.nl/main.asp.
31. Marshall S.J., Levy S.S., Tudor-Locke C.E., et al., *Translating physical activity recommendations into a pedometer-based step goal: 3000 steps in 30 minutes.* Am J Prev Med, 2009. **36**(5): p. 410-5.
32. Rowe D.A., Kemble C.D., Robinson T.S., et al., *Daily walking in older adults: day-to-day variability and criterion-referenced validity of total daily step counts.* J Phys Act Health, 2007. **4**(4): p. 434-46.
33. Hilgenkamp T.I., van Wijck R., and Evenhuis H.M., *Feasibility of eight physical fitness tests in 1050 older adults with ID: results of the HA-ID study.* Submitted.
34. Mathiowetz V., Volland G., Kashman N., et al., *Adult norms for the Box and Block Test of manual dexterity.* Am J Occup Ther, 1985. **39**(6): p. 386-91.

35. Lord S.R., Clark R.D., and Webster I.W., *Postural stability and associated physiological factors in a population of aged persons.* J Gerontol, 1991. **46**(3): p. M69-76.
36. Deary I.J. and Der G., *Reaction time explains IQ's association with death.* Psychol Sci, 2005. **16**(1): p. 64-9.
37. Berg K.O., Wood-Dauphinee S.L., Williams J.I., et al., *Measuring balance in the elderly: validation of an instrument*. Can J Public Health, 1992. **83 Suppl 2**: p. S7-11.
38. Abellan van Kan G., Rolland Y., Andrieu S., et al., *Gait speed at usual pace as a predictor of adverse outcomes in community-dwelling older people an International Academy on Nutrition and Aging (IANA) Task Force.* J Nutr Health Aging, 2009. **13**(10): p. 881-9.
39. Bohannon R.W. and Williams Andrews A., *Normal walking speed: a descriptive meta-analysis.* Physiotherapy, 2011. **97**(3): p. 182-9.
40. Connelly D.M., Stevenson T.J., and Vandervoort A.A., *Between- and within-rater reliability of walking tests in a frail elderly population.* Physiotherapy Canada, 1996. **48**(1): p. 47-51.
41. Rikli R.E. and Jones C.J., *Senior fitness test manual*. 2001: Human Kinetics Europe Ltd
42. Jones C.J., Rikli R.E., and Beam W.C., *A 30-s chair-stand test as a measure of lower body strength in community-residing older adults.* Res Q Exerc Sport, 1999. **70**(2): p. 113-9.
43. Mathiowetz V., Kashman N., Volland G., et al., *Grip and pinch strength: normative data for adults.* Arch Phys Med Rehabil, 1985. **66**(2): p. 69-74.
44. Stark T., Walker B., Phillips J.K., et al., *Hand-held dynamometry correlation with the gold standard isokinetic dynamometry: a systematic review.* PM R, 2011. **3**(5): p. 472-9.
45. Singh S.J., Morgan M.D., Scott S., et al., *Development of a shuttle walking test of disability in patients with chronic airways obstruction*. Thorax, 1992. **47**(12): p. 1019-24.
46. Jolly K., Taylor R.S., Lip G.Y., et al., *Reproducibility and safety of the incremental shuttle walking test for cardiac rehabilitation*. Int J Cardiol, 2008. **125**(1): p. 144-5.
47. Fernhall B., McCubbin J.A., Pitetti K.H., et al., *Prediction of maximal heart rate in individuals with mental retardation.* Med Sci Sports Exerc, 2001. **33**(10): p. 1655-60.
48. Singh S.J., Morgan M.D., Hardman A.E., et al., *Comparison of oxygen uptake during a conventional treadmill test and the shuttle walking test in chronic airflow limitation.* Eur Respir J, 1994. **7**(11): p. 2016-20.
49. Hui S.S. and Yuen P.Y., *Validity of the modified back-saver sit-and-reach test: a comparison with other protocols.* Med Sci Sports Exerc, 2000. **32**(9): p. 1655-9.
50. Minarro P.A., Andujar P.S., Garcia P.L., et al., *A comparison of the spine posture among several sit-and-reach test protocols.* J Sci Med Sport, 2007. **10**(6): p. 456-62.
51. Hilgenkamp T.I., van Wijck R., and Evenhuis H., *Feasibility and reliability of tests for measuring physical fitness in older adults with intellectual disabilities. A pilot study.* J Intellect Dev Disabil, 2012. **In press**.
52. Thomas S., Reading J., and Shephard R.J., *Revision of the Physical Activity Readiness Questionnaire (PAR-Q).* Can J Sport Sci, 1992. **17**(4): p. 338-45.

53. Cardinal B.J., Esters J., and Cardinal M.K., *Evaluation of the revised physical activity readiness questionnaire in older adults.* Med Sci Sports Exerc, 1996. **28**(4): p. 468-72.
54. Myers R., *Classical and modern regression with applications*. 2nd edition ed. 1990, Boston, MA: Duxbury.
55. ACSM, *ACSM's Guidelines for exercise testing and prescription*. 8th edition ed. 2010, Philadelphia, PA: Lippincott Williams & Wilkins.
56. Shephard R.J., Berridge M., and Montelpare W., *On the generality of the "sit and reach" test: an analysis of flexibility data for an aging population.* Res Q Exerc Sport, 1990. **61**(4): p. 326-30.
57. Desrosiers J., Bravo G., Hebert R., et al., *Normative data for grip strength of elderly men and women.* Am J Occup Ther, 1995. **49**(7): p. 637-44.
58. Bohannon R.W., *Comfortable and maximum walking speed of adults aged 20-79 years: reference values and determinants.* Age Ageing, 1997. **26**(1): p. 15-9.
59. Meuwese-Jongejeugd A., Vink M., van Zanten B., et al., *Prevalence of hearing loss in 1598 adults with an intellectual disability: cross-sectional population based study.* Int J Audiol, 2006. **45**(11): p. 660-9.
60. Voorrips L.E., Lemmink K.A., van Heuvelen M.J., et al., *The physical condition of elderly women differing in habitual physical activity.* Med Sci Sports Exerc, 1993. **25**(10): p. 1152-7.
61. Buchman A.S., Boyle P.A., Wilson R.S., et al., *Physical activity and motor decline in older persons.* Muscle Nerve, 2007. **35**(3): p. 354-62.
62. Waninge A., Evenhuis I.J., van Wijck R., et al., *Feasibility and reliability of two different walking tests in subjects with severe intellectual and sensory disabilities.* Journal of applied research in intellectual disabilities: JARID, 2011. **24**(6): p. 518-527.
63. Waninge A., van Wijck R., Steenbergen B., et al., *Feasibility and reliability of the modified Berg Balance Scale in persons with severe intellectual and visual disabilities.* J Intellect Disabil Res, 2011. **55**(3): p. 292-301.
64. Bartlo P. and Klein P.J., *Physical activity benefits and needs in adults with intellectual disabilities: systematic review of the literature.* Am J Intellect Dev Disabil, 2011. **116**(3): p. 220-32.
65. Tudor-Locke C., Hatano Y., Pangrazi R.P., et al., *Revisiting "how many steps are enough?".* Med Sci Sports Exerc, 2008. **40**(7 Suppl): p. S537-43.

Appendix 1 Mean scores (with standard deviations) and numbers of participants of physical fitness tests in older adults with ID

	HA-ID	BBT		RTA		RTV		BBS		WSC		WSF		30 s CS		GS		ISWT %HRmax		ISWT VO2max		EMBSSR	
	n	m (sd)	n	m (sd)	n	m (sd)	n	m (sd)	n	m (sd)	n	m (sd)	n	m (sd)	n	m (sd)	n	m (sd)	n	m (sd)	n	m(sd)	n
Total	1050	28.76 (12.65)	740	1074 (849)	566	1044 (1019)	556	47.17 (9.78)	508	0.97 (0.35)	702	1.69 (0.79)	554	9.42 (3.33)	528	24.55 (10.04)	725	72.79 (14.99)	478	14.21 (5.66)	81	38.51 (14.07)	634
Gender																							
Male	539	28.65 (12.44)	369	969 (990)	271	1015 (782)	264	48.34 (8.09)	260	1.02 (0.35)	361	1.88 (0.85)	282	9.68 (3.48)	271	28.76 (10.32)	370	71.68 (13.89)	251	15.59 (5.72)	51	35.74 (14.67)	312
Female	511	28.86 (12.86)	371	1112 (1042)	295	1128 (904)	292	45.95 (11.17)	248	0.92 (0.33)	341	1.49 (0.63)	272	9.15 (3.16)	257	20.16 (7.56)	355	74.01 (16.06)	227	11.87 (4.77)	30	41.19 (12.94)	322
Age																							
50-59 years	493	29.24 (13.47)	340	982 (831)	258	1107 (918)	257	48.65 (9.09)	237	1.04 (0.36)	340	1.88 (0.84)	281	9.73 (2.98)	275	24.82 (10.67)	336	74.35 (15.84)	246	15.07 (5.76)	56	41.37 (13.89)	308
60-69 years	370	29.53 (11.54)	260	947 (871)	198	995 (748)	196	46.71 (9.60)	191	0.96 (0.32)	248	1.56 (0.67)	195	9.21 (3.47)	182	25.63 (9.58)	256	71.08 (14.14)	162	12.11 (5.65)	16	35.85 (13.33)	220
70-79 years	162	26.99 (11.89)	123	1272 (1479)	99	1133 (854)	92	44.18 (10.78)	73	0.83 (0.32)	103	1.33 (0.55)	72	8.89 (4.18)	64	22.31 (8.82)	118	71.46 (13.01)	61	13.90 (3.28)	7	35.91 (14.63)	95
80+ years	25	20.00 (13.66)	17	2181 (1539)	11	1231 (836)	11	41.00 (16.54)	7	0.66 (0.25)	11	1.01 (0.33)	6	7.57 (3.26)	7	17.87 (7.28)	15	69.72 (16.22)	9	7.94 (1.06)	2	33.91 (14.63)	11
Type of setting																							
Central setting	557	22.17 (11.00)	333	1407 (1121)	207	1445 (1003)	201	43.95 (12.38)	156	0.87 (0.34)	307	1.45 (0.73)	214	8.46 (3.18)	194	21.42 (9.75)	306	72.11 (15.09)	249	12.18 (4.50)	38	38.44 (14.40)	248
Community-based	432	33.44 (11.09)	358	865 (903)	312	886 (657)	308	48.16 (8.36)	305	1.04 (0.33)	346	1.81 (0.77)	297	9.71 (3.03)	290	26.45 (9.31)	369	73.40 (14.11)	207	15.97 (5.80)	40	38.63 (13.84)	337
Ambulatory support	43	41.55 (9.77)	42	480 (276)	41	563 (277)	41	52.20 (2.96)	41	1.24 (0.26)	40	2.08 (0.68)	37	12.21 (4.34)	38	30.79 (11.47)	42	73.61 (22.85)	18	21.69 (6.36)	2	38.24 (13.92)	41
With relatives	7	25.86 (12.46)	7	1691 (1928)	6	1823 (1481)	6	46.67 (6.35)	6	0.83 (0.42)	9	1.69 (1.06)	6	8.83 (3.00)	6	23.50 (10.27)	8	79.57 (11.66)	4	5.94 (N/A)	1	37.13 (16.86)	8

Level of ID																							
Borderline	31	41.00 (14.05)	30	496 (248)	28	501 (227)	28	51.11 (4.13)	28	1.19 (0.39)	27	2.24 (1.02)	23	10.17 (4.02)	23	30.03 (10.91)	30	76.02 (22.26)	18	16.74 (7.76)	5	39.23 (13.63)	30
Mild	223	36.46 (11.29)	193	781 (683)	177	785 (583)	176	49.17 (8.94)	164	1.07 (0.32)	178	1.85 (0.79)	151	10.87 (3.45)	152	28.73 (10.55)	190	74.19 (15.35)	105	16.80 (6.42)	22	38.45 (14.00)	170
Moderate	506	27.50 (10.76)	389	1132 (1062)	315	1178 (796)	305	46.13 (10.34)	267	0.96 (0.34)	366	1.66 (0.72)	287	8.96 (2.96)	282	23.26 (8.92)	399	73.13 (15.12)	243	13.26 (4.60)	41	38.57 (14.18)	356
Severe	172	17.02 (9.01)	91	2033 (1524)	30	2063 (1346)	28	42.55 (11.12)	31	0.82 (0.31)	92	1.42 (0.70)	67	7.96 (2.98)	51	19.32 (9.22)	78	70.61 (12.81)	79	13.19 (5.07)	10	38.79 (15.11)	53
Profound	91	12.71 (6.47)	17	1126 (N/A)	1	1034 (N/A)	1	54.00 (N/A)	1	0.73 (0.42)	18	1.14 (1.04)	8	7.20 (3.27)	5	17.71 (11.21)	7	70.41 (13.69)	23	7.27 (1.38)	3	36.17 (8.89)	6
Unknown	27	27.60 (9.12)	20	1335 (1415)	15	1505 (1531)	18	45.82 (6.79)	17	0.92 (0.31)	21	1.33 (0.70)	18	8.07 (3.79)	15	25.19 (10.42)	21	66.70 (8.78)	10	N/A		36.74 (13.13)	19
DS																							
No DS	724	28.41 (12.64)	512	1047 (1089)	386	1049 (832)	379	46.53 (10.73)	334	0.96 (0.34)	474	1.65 (0.79)	370	9.34 (3.34)	349	24.42 (9.82)	491	73.05 (15.35)	403	14.85 (5.54)	70	36.49 (13.44)	426
DS	149	22.17 (10.71)	81	1390 (866)	54	1478 (939)	52	47.64 (5.54)	44	0.88 (0.32)	89	1.62 (0.74)	71	8.11 (2.55)	65	19.07 (8.82)	83	71.36 (12.91)	75	12.03 (4.84)	11	48.36 (12.13)	73
Unknown	177	33.61 (11.79)	147	887 (815)	126	983 (822)	125	48.84 (7.78)	120	1.07 (0.37)	139	1.85 (0.75)	113	10.43 (3.44)	114	27.98 (10.00)	151	N/A	0	N/A		39.56 (14.72)	135
Mobility																							
Independent	731	31.21 (12.38)	548	986 (948)	423	1027 (789)	423	49.69 (4.88)	416	1.04 (0.32)	573	1.76 (0.76)	476	9.63 (3.27)	460	25.83 (10.05)	543	72.95 (15.03)	402	14.85 (5.54)	69	39.43 (13.96)	495
With walking aid	151	22.51 (9.51)	112	1215 (1272)	86	1154 (1063)	76	35.45 (13.11)	55	0.62 (0.25)	93	0.94 (0.39)	50	6.96 (2.98)	45	20.83 (8.28)	110	69.30 (11.45)	59	8.26 (3.40)	7	34.73 (13.65)	93
Wheelchair	107	15.38 (10.51)	47	1475 (1311)	29	1665 (1078)	29	7.20 (6.91)	10	0.44 (0.26)	6	0.82 (0.23)	3	N/A	0	17.20 (8.95)	41	76.74 (14.45)	4	14.69 (N/A)	1	32.47 (15.44)	19
Unknown	61	28.21 (9.75)	33	947 (693)	26	966 (558)	28	47.04 (10.29)	27	0.96 (0.35)	30	1.79 (0.84)	25	10.13 (3.33)	23	25.10 (9.90)	31	82.31 (23.01)	13	13.38 (6.37)	4	38.78 (14.18)	27

Level of PA																							
Less active	164	34.47 (10.61)	158	798 (728)	139	863 (533)	138	48.22 (7.33)	141	1.15 (0.22)	163	1.81 (0.56)	146	10.27 (3.28)	141	26.61 (9.13)	161	74.44 (15.95)	114	12.55 (4.49)	20	39.78 (13.87)	150
Active	93	39.78 (11.46)	89	717 (823)	77	822 (630)	80	51.42 (6.79)	80	1.27 (0.26)	90	2.35 (0.80)	85	11.79 (2.82)	87	30.62 (11.16)	90	80.10 (18.30)	61	19.67 (4.69)	20	41.93 (13.84)	87
Unknown	793	24.94 (11.56)	493	1214 (1118)	350	1220 (962)	338	44.29 (11.65)	287	0.85 (0.34)	449	1.46 (0.75)	323	8.34 (3.02)	300	22.69 (9.53)	474	70.93 (13.91)	304	12.35 (4.92)	41	37.28 (14.07)	397

HA-ID=Total study population 'Healthy ageing and intellectual disability', BBT=Box and Block test in number of blocks, RTA=Response Time test Auditive in milliseconds, RTV=Response Time test Visual in milliseconds, BBS=Berg Balance Scale in total score, WSC=Walking speed comfortable speed in meter/second, WSF=Walking speed fast speed in meter/second, 30 s CS=30 second Chair Stand in number of sit-to-stands, GS=Grip strength in kilogram, ISWT=10m Incremental Shuttle Walking Test in achieved % of heart rate reserve and the number and VO2max of the participants who achieved 85% of HRR, EMBSSR=Extended Modified Back Saver Sit and Reach in centimetres (N/A = not available, too few participants)

ID=intellectual disability, DS=Down syndrome

Appendix 2: Significant differences between categories of participants for all tests.

	Type of setting	Level of ID	Level of mobility
BBT	F=80.517, p<0.001 Central vs community Central vs independent Community vs independent Independent vs relatives	F=71.990, p<0.001 All combinations, except: Borderline vs mild Severe vs profound	F=57.179, p<0.001 All combinations
RTA	F=18.509, p<0.001 Central vs community Central vs independent Independent vs relatives	F=14.149, p<0.001 Borderline vs moderate Borderline vs severe Mild vs moderate Mild vs severe Moderate vs severe	F=4.401, p=0.013 Wheelchair vs independent
RTV	F=27.869, p<0.001 Central vs community Central vs independent Community vs relatives Independent vs relatives	F=23.938, p<0.001 Borderline vs moderate Borderline vs severe Mild vs moderate Mild vs severe Moderate vs severe	F=7.958, p<0.001 Wheelchair vs independent. wheelchair vs walking aid
BBS	F=10.890, p<0.001 Central vs community Central vs independent	F=5.553, p<0.001 Borderline vs severe Mild vs moderate Mild vs severe	F=319.394, p<0.001 All combinations
WSC	F=23.651, p<0.001 Central vs community Central vs independent Community vs independent Independent vs relatives	F=13.419, p<0.001 All combinations, except: Borderline vs mild Severe vs profound	F=78.833, p<0.001 Independent vs walking aid, independent vs wheelchair
WSF	F=12.560, p<0.001 Central vs community Central vs independent	F=8.036, p<0.001 Borderline vs moderate Borderline vs severe Borderline vs profound Mild vs severe	F=28.615, p<0.001 Independent vs walking aid
30 s CS	F=16.384, p<0.001 Central vs community Central vs independent Community vs independent	F=13.057, p<0.001 Mild vs moderate Mild vs severe	F=27.751, p<0.001 Independent vs walking aid
GS	F=21.402, p<0.001 Central vs community Central vs independent Community vs independent	F=20.230, p<0.001 All combinations, except: Borderline vs mild Moderate vs profound Severe vs profound	F=24.449, p<0.001 Independent vs walking aid, independent vs wheelchair
ISWT			
- %HRmax	NS	NS	NS
- VO2max	F=5.618, p=0.002 No specific combinations	F=3.227, p=0.017 No specific combinations	F=4.737, p=0.012 Independent vs walking aid
EMBSSR	NS	NS	F=6.271, p=0.002 Independent vs walking aid

BBT=Box and Block test, RTA=Response Time test Auditive, RTV=Response Time test Visual, BBS=Berg Balance Scale, WSC=Walking speed comfortable, WSF=Walking speed fast, 30 s CS=30 second Chair Stand, GS=Grip strength, ISWT=10m Incremental Shuttle Walking Test, EMBSSR=Extended Modified Back Saver Sit and Reach, NS = non-significant

Chapter 10

(Instrumental) activities of daily living in older adults with intellectual disability

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ABSTRACT

Background: Daily living skills are important to ageing adults with intellectual disabilities (ID) to maintain as independent as possible for as long as possible. The purpose of this study was to investigate the level of these skills in older adults with ID and to investigate the influence of gender, age, level of ID and mobility on these skills.

Measurements: Daily living skills were measured with the Barthel Index (for Activities of Daily Living, ADL) and the Lawton IADL scale (for Instrumental Activities of Daily Living, IADL) in 989 adults with ID aged 50 years and over living in community-based and institutional settings. Descriptives were presented by categories of gender, age, level of ID and mobility. Regression analysis was used to investigate the influence of these variables on total and item scores of ADL and IADL questionnaires.

Results: ADL and IADL scores in older adults with ID are comparable to those of vulnerable patient groups. Total ADL score was mainly determined by mobility, while total IADL score was mainly determined by level of ID. Of all 18 separate items of these questionnaires, 11 were determined more by mobility than level of ID.

Conclusion: The Barthel Index and Lawton IADL scale are recommended for future use in research and clinical practice in this group. This study stresses the need to support mobility in older adults with ID as much as possible, in order to optimalize independency in this group.

INTRODUCTION

Daily functioning is an important predictor of hospital admission and mortality in older adults [1-3], but moreover, how well older adults can take care of themselves determines their independence [4]. To determine the level of self-care, the concept of Activities of Daily Living (ADL) is frequently used. ADL consists of a number of activities such as continence, eating, walking or grooming. Because of this basic level of self-care, instruments measuring ADL have a ceiling effect and are therefore not indicative of a person's ability to actually live in the community [5]. Instrumental ADL (IADL), which includes activities such as preparing a meal or using the telephone, can be more sensitive in detecting dysfunction in elderly people than self-care assessments alone [6]. Both ADL and IADL are therefore an essential part of a patients' functional status, as is also demonstrated in the International Classification of Functioning from the World Health Organization (WHO) [7].

ADL and IADL are known to deteriorate with ageing [4,8] and adults with intellectual disabilities (ID) have longer life expectancies and therefore experience a longer ageing process than ever before [9]. With increasing age, lower functioning in Activities of Daily Living (ADL) has been shown in a large cross-sectional sample of 10,532 American older adults with ID, measured with the Minnesota Developmental Programming Behavior Scales [10]. In a longitudinal study of a Dutch population of 1,602 resident clients of ID care providers, ADL skills decreased after the age of 60, whereas in people with Down syndrome this was apparent after 40 years [11]. In this study, ADL was measured by a newly developed ADL scale with four items: body care, getting (un)dressed, using the toilet and eating [12]. Although this age-related decline in ADL functioning seems to start earlier in life for older adults with ID than in the general population, it is difficult to compare this group with other populations due to the lack of use of widespread and standardized instruments to measure ADL in these studies.

Gender has been suggested to influence item and sum scores of ADL and IADL measures [5], especially the items food preparation, housekeeping and laundry [13].

Furthermore, cognitive capacities are known to influence ADL and IADL skills [14,15]. In 101 Israeli adults with ID of 40 years and over, the level of ID was shown to influence ADL [16], but this was measured with a self-made questionnaire of four ADL items (eating, dressing, washing and bathing) [17] and these results are therefore difficult to compare with other populations. Mobility has shown to be an important determinant of ADL and IADL skills in older adults [18,19], but has never been studied as such in older adults with ID.

For older adults with ID themselves, ADL and IADL are important concepts to measure, because these are determined by physical and cognitive capacities, which can be influenced to some extent by specific training or support [20-25]. People with ID often experience a lifelong dependency of others in some form, and it is therefore important to maintain as much independence as possible.

On the other hand, for care providers, ADL and IADL are determining in estimating and tailoring the provision of care for their ageing clients, considering present and future needs of these clients [9,11,16,26].

For both points of view, it would be of particular interest to investigate to what extent ADL and IADL items are influenced by personal characteristics, such as gender, age, level of ID and mobility. These points of interest are addressed by the following research questions:

- How do older adults with ID score on ADL and IADL?
- To what extent are ADL and IADL influenced by gender, age, level of ID and mobility in this population?

METHODS

Design

This study is part of a large, cross-sectional study to measure health in older adults with ID, which has been executed in the Netherlands in 2009 and 2010 by a consort of two academic institutes and three care providers for people with ID. Subthemes in this study were: 1. Physical activity and fitness, 2. Nutrition and nutritional state, and 3. Mood and anxiety [27]. Assessing ADL and IADL was part of the subtheme concerning Physical activity and fitness. Ethical approval was obtained (number 2008-234) from the Ethics Committee of the Erasmus University Medical Center. The study followed the guidelines of the Declaration of Helsinki [28].

Population and consent procedure

A full description of the base population and the informed consent procedure has been published elsewhere [27]. The base population consisted of clients aged 50 years and over who receive support or care of the three care providers. This base population therefore excluded older adults with ID not receiving any support or care from a care provider. All clients aged 50 years and over of the three care providers were invited to participate (N=2150), informed consent was received for 1069 clients, of which 1050 clients participated in the assessments [27].

Outcome measures

General information
Gender and age were collected through available administrative systems of the involved care organizations. Level of ID was collected through the files of the behavioral therapists and was categorized into borderline, mild, moderate, severe and profound. Mobility was divided into three categories: able to walk independently, able to walk with support (cane, walker or walking frame), or wheelchair-bound, all evaluated in the familiar home environment by the professional caregiver.

Activities of daily living (ADL)
ADL was assessed with the Barthel Index [29]. This scale consists of eight items (continence bowels and bladder, grooming, toilet use, feeding, transfer, walking, dressing, climbing stairs and bathing) with item scorings between 2 and 4 categories and a total score ranging from 0 (completely dependent) to 20 (completely independent) [30,31]. This scale was used in the format of an informant-based questionnaire, completed by professional caregivers of the participants, based on what someone was able to do.

A wide variety of standardized instruments to assess ADL exists, but the Barthel Index [29] is the one most frequently used and has good psychometric properties [30,32-34]. Completion of the Barthel Index by an informed nurse or relative is as reliable as testing the patient himself [31]. These arguments make the Barthel Index suitable for use in older adults with ID, because not all older adults with ID have sufficient verbal and/or cognitive capabilities to complete this questionnaire themselves. Furthermore, the use of the Barthel Index enables comparisons with other vulnerable populations.

Instrumental activities of daily living (IADL)
IADL was measured using the Lawton IADL Scale [13]. The scale consists of eight items (ability to use telephone, shopping groceries, food preparation, light and heavy housekeeping, laundry, transportation, medication use, handling finances). Different scoring systems have been used, all of which have similar predictive validity for several outcome variables (i.e. mental status, depressive symptoms, psychosocial functioning, living situation, number of medications) [35]. Vittengl et al. recommended to use scoring procedures as simple as possible such as dichotomous scoring (0=less able, 1=more able) [36].

In a recent review this scale turned out to be the only one used to specifically assess Instrumental Activities of Daily Living in hospitalized older medical patients [37]. For older adults with dementia, there was a significant correlation between self-rated IADL by older adults themselves compared with a rating of them by a clinician [38]. These arguments make the Lawton's IADL scale a suitable instrument in older adults with ID.

In a study of 1072 Asian adults aged 60 years and over, the researchers distinguished a cognitive domain and a physical domain in the IADL scale [39]. Furthermore, cultural concerns and gender bias could influence the outcome and comparability of the scale across different study populations [5]. This scale was also used in the format of an informant-based questionnaire, completed by professional caregivers of the participants, based on what someone was able to do.

Statistical analysis

First, descriptive characteristics of the study population are provided, with a non-response analysis of the participants with consent to participate but with no completed ADL and IADL questionnaires.

Secondly, ADL results of the participants, categorized by gender, age, level of ID and level of mobility are presented.

Thirdly, the influence of characteristics of this study population is investigated by multiple regression models. In the first step, baseline characteristics are entered into the model: gender and age. In the second step, level of ID and mobility are entered together, to calculate the unique contribution of both predictors to the outcome.

With Spearman correlation coefficients is investigated first if multicollinearity exists (i.e. very high correlations between predictors, making them unsuitable for use in the same regression model) and for the same purpose the Variance Inflation Factor (VIF) is presented for the regression models. A VIF of 10 or higher would give cause for concern [40].

For total scores of the Barthel Index and Lawton's IADL Scale, linear multiple regression is used. The regression coefficients (b's) tell us to what degree each predictor affects the outcome if the effects of all other predictors are held constant. The standardized b's (labeled beta's (β's)) enable us to compare the magnitude of the influence of the different predictors. The explaining value of this model is calculated with R^2, as the percentage of variance explained by the model.

Multiple logistic regression analysis is used to investigate the influence of personal characteristics on all separate items of both scales, to this end, all items are rescaled into 0=independent or 1=dependent (in any form). The magnitude of the influence of the predictors can be compared by calculating the odds ratio (provided by SPSS as Exp(b)). The odds ratio is the change in odds of the outcome by a unit change of the predictor. The explaining value of the model is calculated with Hosmer and Lemeshow R^2, which divides the chi-square of the new model by the -2loglikelihood of the original model with only the constant, and by Cox and Snell's R^2 [41] and Nagelkerke's R^2, two similar measures provided by the statistical package. To interpret these results correctly, the following scoring is applied for gender (men=0, women=1), age (50-59=1, 60-69=2, 70-79=3, 80-89=4, 90-99=5), level of ID (borderline=0, mild=1, moderate=3, severe=4, profound=5). In the regression analyses all participants with unknown level of ID are excluded (n=22). All analyses were performed with SPSS 15.0.

RESULTS

Of the complete study population of the large epidemiological study [27], 61 participants of which there were no completed ADL and IADL questionnaires were excluded, leaving a total study population of 989 older adults with intellectual disabilities. Characteristics of the study population and the non-responders are shown in Table 1. Differences were tested with Pearson Chi-square and were not significant. Participants with unknown level of ID (n=22) were excluded from all regression analyses.

Results on ADL and IADL

Total ADL and IADL results are presented in Table 2 for all categories of gender, age, level of ID, mobility. Interquartile ranges and 1st and 3rd quartiles are provided to offer an estimation of the range of the results. Of this population, 14.5% is completely independent in self-care (ADL), whereas 2.3% is able to live completely independenty (IADL). The mean number of items performed completely independent per participant is 4.4 (SD=3.4) for the Barthel Index, and 1.4 (SD=2.2) for the Lawton IADL scale. Results of separate items are presented in more detail per category of gender, age, level of ID and mobility in Appendix 1.

Influence of gender, age, level of ID and mobility

In correlation and regression analyses, after exclusion of 22 participants with unknown level of ID, the data of the remaining 967 participants was used.

Multicollinearity (high correlations between independent variables in the model) is not present in this population. Although several correlation coefficients between the independent variables are significant at the 0.01 level, they are quite low (Spearman r =.097 to .200) and therefore will not cause any problems when entered into regression models.

In Table 3, the results of the multiple linear regression analyses for the total outcomes of the Barthel Index and the Lawton IADL Scale are presented. Gender does not influence the outcomes of the total scales significantly. For the Barthel Index the most important predictor (with highest β) is mobility, for the Lawton IADL scale the most important predictor is Level of ID (printed in bold in Table 5). Average VIF is 1.073, which is well below 10, so multicollinearity does not exist between the variables entered into the regression models.

Table 1 Characteristics of the study population

		Participants		Non-responders
		N	% of category	N
Total		989	100.0	61
Gender	Male	509	51.5	29
	Female	480	48.5	32
Age	50-59	459	46.4	34
	60-69	347	35.1	23
	70-79	158	16.0	4
	80-89	22	2.2	0
	90-99	3	0.3	0
Level of ID	Borderline	31	3.1	0
	Mild	210	21.2	14
	Moderate	472	47.7	34
	Severe	165	16.7	6
	Profound	89	9.0	2
	Unknown	22	2.2	1
Mobility	Walks independently	731	73.9	44
	Walks with support	151	15.3	3
	Wheelchair	107	10.8	3

Table 2 Total ADL and IADL Results

Variable	Category	BI Total (range 0-20)					LIADL (range 8-24)				
		mean	SD	IQR	1st quartile	3rd quartile	mean	SD	IQR	1st quartile	3rd quartile
Total		13.86	5.77	8.00	11.00	19.00	11.88	4.69	6.00	8.00	14.00
Gender	Male	14.14	5.77	8.00	11.00	19.00	11.65	4.41	6.00	8.00	14.00
	Female	13.56	5.75	8.00	10.00	18.00	12.12	4.97	7.00	8.00	15.00
Age	50-59	14.36	5.57	7.00	12.00	19.00	12.02	4.86	7.00	8.00	15.00
	60-69	14.08	5.86	8.00	11.00	19.00	12.08	4.71	7.00	8.00	15.00
	70-79	12.58	5.77	9.00	9.00	18.00	11.35	4.25	5.25	8.00	13.25
	80-89	10.05	5.56	9.50	4.75	14.25	9.95	3.12	3.00	8.00	11.00
	90-99	8.33	6.35	11.00	1.00	12.00	8.00	0.00	0.00	8.00	8.00
Level of ID	Borderline	18.06	3.10	2.00	18.00	20.00	17.94	4.94	7.00	15.00	22.00
	Mild	16.36	4.42	5.25	14.75	20.00	15.82	5.00	8.00	12.00	20.00
	Moderate	14.69	5.12	6.00	13.00	19.00	11.56	4.00	5.00	8.00	13.00
	Severe	11.14	5.59	9.00	7.00	16.00	8.46	0.87	1.00	8.00	9.00
	Profound	6.70	5.42	11.00	1.00	12.00	8.06	0.31	0.00	8.00	8.00
Mobility	Walks independently	15.84	4.22	5.00	14.00	19.00	12.71	5.00	8.00	8.00	16.00
	Walks with support	11.66	4.33	7.00	8.00	15.00	10.23	2.83	4.00	8.00	12.00
	Wheelchair	3.43	4.13	6.00	0.00	6.00	8.51	1.27	0.00	8.00	8.00

Table 3: Regression models of total scores of Barthel Index and Lawton IADL Scale.

		b- coefficient	SE	β	95% CI lower bound	95% CI upper bound	R^2
Barthel Index	Gender	-0.355	0.25	-0.031	-0.837	0.127	0.577
	Age	-0.460**	0.15	-0.065	-0.758	-0.161	
	Level ID	-2.243**	0.14	-0.363	-2.508	-1.979	
	Mobility	-4.991**	0.19	**-0.582**	-5.364	-4.618	
Lawton IADL Scale	Gender	0.092	0.24	0.010	-0.381	0.564	0.381
	Age	-0.606**	0.15	-0.106	-0.898	-0.314	
	Level ID	-2.738**	0.13	**-0.548**	-2.998	-2.479	
	Mobility	-1.228**	0.19	-0.177	-1.593	-0.862	

*** = significant at p<0.01*

(Gender (man=0, woman=1), age (50-59=1, 60-69=2, 70-79=3, 80-89=4, 90-99=5), level of ID (ID) (borderline=0, mild=1, moderate=3, severe=4, profound=5), mobility (MOB) (0=no support, 1=support, 2=wheelchair).

Appendix 2 presents the results of the multiple logistic regression analyses performed for all separate items of both scales. Per item, the variable with the largest OR is printed in bold.

For item 9 of the Barthel Index (Stairs), the participants who did not have any stairs in their living facility were excluded (n=292); the logistic regression analysis of this item was performed with the data of the remaining 675 participants. For item 4 of the Lawton IADL scale (Housekeeping), the analysis was not possible due to lack of any variance in outcome on this item for two out of three categories of mobility: participants who were independent in housekeeping (n=99) were all completely mobile (not using support or a wheelchair).

Gender significantly affects the outcomes of only 5 items: women have higher odds to be more dependent than men in the items Bladder and Stairs (Barthel Index) and men have higher odds to be more dependent than women in the items Grooming (Barthel Index), Laundry and Medication (Lawton IADL Scale).

The odds of being dependent significantly increased with older age in 5 items: the items Bowels, Bladder, Stairs and Bathing of the Barthel Index, and of the item Groceries of the Lawton IADL Scale.

For all items, both level of ID and mobility significantly affect the outcome. The unique contribution of both the level of ID and mobility can be compared by means of the odds ratios. Of the Barthel Index, 8 out of 10 items are influenced more by mobility than by level of ID, the remaining two are influenced less by mobility than by level of ID.

Of the Lawton IADL scale, 3 out of 8 items are more influenced by mobility than by level of ID, the remaining 4 items are influenced less by mobility than by level of ID (Telephone use, Groceries, Transfer and Finances) (printed in bold in Appendix 2).

CONCLUSION AND DISCUSSION

This paper presents results on ADL and IADL in a nearly representative sample of 989 clients of Dutch intellectual disability care providers aged 50 years and over. Total ADL and IADL scores are primarily determined by cognitive levels and mobility, to a lesser extent by age, and not by gender. Total ADL score was mostly determined by mobility, while total IADL score was mostly determined by level of ID. However, when looking at individual items of both scales, this does not apply to all items separately. Of the Barthel Index, grooming and feeding are more determined by level of ID than by mobility, whereas of Lawton's IADL scale, only three out of eight items are more determined by level of ID (telephone use, groceries and finances), and the rest of the items is more determined by mobility.

For some items, the influence of mobility and level of ID is almost equal, although one is printed in bold based on a higher point estimate of the odds ratio in Appendix 2. Looking at the 95% confidence intervals though, these values are not very different.

In a population where cognitive capabilities are expected to be more restricting in ADL and IADL capabilities than in the general population, these results stress the necessity of lifelong support to maintain or optimize mobility in this group. These results concur with a study in a representative sample of 781 Spanish people aged 65 or over, where the most important activities of daily living in terms of self-rated health, were those involving mobility (walking stairs, ambulation and transfers) [21].

Gender has been suggested to influence the items food preparation, housekeeping and laundry [13]. In contrast with these results, in our population gender contributed significantly in explaining the Barthel items bladder, grooming and walking stairs and Lawton's IADL item laundry and medication (men are more independent in bladder continence and walking stairs, whereas women are more independent in grooming and laundry and medication, see Appendix 2). Food preparation and housekeeping, items where a gender bias is usually present but not in this study, are only executed independently by persons with borderline and mild ID, which is a relatively small subgroup in the client population of Dutch ID care providers.

Increasing age significantly affected four out of ten items of the Barthel index (continence bowel and bladder, stairs and bathing) and one out of eight items of the Lawton IADL scale (groceries). This age-related detoriation gives care providers direction to design their support or care for this group.

Clear descending trends in ADL and IADL are observed across age, more severe ID and decreasing mobility in this study. In comparison with other research in older adults with intellectual disabilities, these trends are not surprising. Janicki et al. presented similar trends in ADL with ageing using three ADL items (toileting, dressing/grooming and eating) [10], while the findings of Maaskant et al concerning the drop in ADL-skills (measured with four ADL items: body care, dressing, toileting, eating) after age 60 years is supported by our results as well [11].

Although these trends were already seen in previous research, it is hard to directly compare studies, for they have used different ways to determine skills in ADL and IADL. This paper has shown the Barthel Index and the Lawton IADL scale to be useful and relevant instruments to collect data about ADL and IADL in this population in a standardized way. The use of these instruments provides opportunities to compare ADL and IADL of this population with other (older) populations.

In the literature, results of the Barthel Index are presented in different ways. The first is to present the percentage participants which is completely independent in ADL. Fourteen percent of our population (aged 50 years and over) is completely independent in ADL. In a cross sectional, representative sample of non-institutionalised older adults with normal intelligence in Spain (aged 65 and over, N=781), 39% was completely independent in ADL [21]. In stroke patients, the percentage of patients completely independent in ADL was measured in the first week after stroke (12%), 3 weeks after stroke (31%) and 6 months after stroke (47%) [30]. Elderly cancer patients (N=181) and elderly hospital patients (N=127) were assessed with the Barthel Index, and the percentages patients who were completely independent in ADL were respectively 74% and 69% [42]. In conclusion, the population with ID aged 50 years and over, using any support by specialized care providers is even more independent than stroke patients, geriatric patients, cancer patients or adults aged 65 years and over in the general population.

Another way to present results is by providing medians with interquartile range (IQR) or means with standard deviation. As the Barthel Index is frequently used to evaluate improvements in functional status after a medical treatment or rehabilitation, most published studies describe older patients admitted to a (geriatric) medical facility. Data are recalculated where necessary from scoring of 0-100 to 0-20, to make comparison easier. In our study, the mean and standard deviation were 13.72 and 5.84, with an IQR of 11-18. In a study of 778 older Chinese adults, admitted to a geriatric rehabilitation unit, the mean Barthel Index score at admission was 13.2 ± 5.0 (recalculated from scoring of 0-100 to 0-20) and at discharge 14.6 ± 4.9[22]. In another study, a pre-admission

Barthel Index score was obtained from 447 clinically stable elderly patients of a rehabilitation care unit (mean age 77.8 ± 9.8); their mean was 17.3 ± 3.8 [43]. Eighty frail elderly service flat residents were assessed with the Barthel Index. The median (IQR) of 9 well-nourished residents was 17 (16-17), of 47 residents with risk of malnutrition it was 16 (11-17) and of 24 malnourished residents it was 12.5 (9-15)[44]. In a study of 118 stroke patients at a rehabilitation unit, the median (and interquartile range) of the Barthel Index at admission was 5 (1,5-8) and at discharge 10 (6-13) [45]. Laake et al assessed different patient groups and presented median sum scores (and interquartile ranges) for 60 geriatric patients (median 13, IQR 9-15), 87 stroke patients (median 14, IQR 4-19) and 102 hip fracture patients (median 11, IQR 9-15) [46]. With these presentation of data, our study population of older adults aged 50 years and over with ID is comparable to the most vulnerable older subpopulations and patients in terms of independence of ADL.

Although the Lawton IADL scale was the most frequently used standardized instrument to assess IADL functioning in older medical patients [37], the amount of data of IADL skills is not nearly as large as for the Barthel Index for ADL. The few studies that do use a standardized instrument like the Lawton IADL scale, present a summarized score only: the number of items that could be performed completely independent. In black and white geriatric patients (n=2364) IADL was assessed at admission to a hospital and 2 weeks before admission with Lawton IADL scale and their scores varied from 2.5 to 3.9 [47]. Preadmission IADL scores of a sample of 1279 geriatric patients was collected and was 4.5 (SD=2.3) [48]. In a sample of 2557 geriatric patients, cognitive function at admission to a hospital was used to classify three separate groups. The group with little or no impaired cognitive function (n=1470) scored 5.9 two weeks before admission, and 4.3 at admission, with 35.1% of the patients completely independent in all IADL items. The group with mildly impaired cognitive function (n=365) scored 4.7 two weeks before admission, and 3.4 at admission, with 25.4% of the patients completely independent in all IADL items. The third group, with moderate to severe cognitive impairments (n=722) scored 2.0 two weeks before admission, and 0.9 at admission, with 4.4% of the patients completely independent in all IADL items[49]. These numbers show that older adults with ID (50 years and over) are less independent in IADL than geriatric patients (approximately 70 years and over) when admitted to a hospital for an acute medical condition, but comparable with a group of geriatric patients when admitted to a hospital for an acute medical condition, who are moderately to severely cognitively impaired.

Although level of ID and mobility are important, they do not fully explain the variance ADL and IADL performance. Explained variance ranged from 0.143 to 0.577, which leaves room for other variables to be of influence in ADL and IADL performance, such as mood, anxiety, drug use, specific co-morbidities or circumstances/habits of their living facility. The aim of this paper was to assess the individual contribution of the used variables, rather than finding a model to explain as much of the variance as possible

The response rate of the measurement of ADL and IADL within the sample of participants of the large epidemiological study was high (989 out of 1050 participants) and this group did not differ from the total group of participants. However, the sample of 1050 participants was slightly different from the non-participants of the total study (n=2322), with an underrepresentation of older adults with supported living with ambulant care only.

Although this paper describes a large sample of older adults with ID, this population is a client population of specialized care providers. Specifically older adults with mild and borderline ID not using any specialized support, are missing in this sample. Since there is no governmental registry of ID in the Netherlands, no information can be given about the number and characteristics of people with ID, not connected to a care provider.

The Barthel Index and Lawton IADL scale are useful, internationally used instruments to measure ADL and IADL and are applicable to an elderly population of 50+ with ID. We recommend them for use in research and clinical practice in order to enable comparisons of populations. Secondly, this paper stresses the importance of mobility in maintaining independence in self-care and living as much as possible in older adults with intellectual disabilities. Although this population has independence levels comparable to frail older populations, this group could still benefit from specialized interventions improving or maintaining mobility levels such as enhancing daily physical activity and fitness.

REFERENCES

1. Ferrucci L., Guralnik J.M., Pahor M., et al., *Hospital diagnoses, Medicare charges, and nursing home admissions in the year when older persons become severely disabled.* JAMA, 1997. **277**(9): p. 728-34.
2. Reuben D.B., Siu A.L., and Kimpau S., *The predictive validity of self-report and performance-based measures of function and health.* J Gerontol, 1992. **47**(4): p. M106-10.
3. Reuben D.B., Rubenstein L.V., Hirsch S.H., et al., *Value of functional status as a predictor of mortality: results of a prospective study.* Am J Med, 1992. **93**(6): p. 663-9.
4. Hebert R., *Functional decline in old age.* CMAJ, 1997. **157**(8): p. 1037-45.
5. Ward G., Jagger C., and Harper W., *A review of instrumental ADL assessments for use with elderly people.* Reviews in clinical gerontology, 1998(8): p. 65-71.
6. Kane R.A. and Kane R.L., *Assessment of older people: self maintaining and instrumental activities of daily living.* 1981, Toronto: Lexington Books.
7. WHO. *International classification of functioning, disability and health*. 2001. Geneva.
8. Ishizaki T., Kai I., Kobayashi Y., et al., *The effect of aging on functional decline among older Japanese living in a community: a 5-year longitudinal data analysis.* Aging Clin Exp Res, 2004. **16**(3): p. 233-9.
9. McCallion P. and McCarron M., *Ageing and intellectual disabilities: a review of recent literature.* Current opinion in Psychiatry, 2004. **17**: p. 349-352.
10. Janicki M.P. and Jacobson J.W., *Generational trends in sensory, physical, and behavioral abilities among older mentally retarded persons.* Am J Ment Defic, 1986. **90**(5): p. 490-500.
11. Maaskant M.A., van den Akker M., Kessels A.G., et al., *Care dependence and activities of daily living in relation to ageing: results of a longitudinal study.* J Intellect Disabil Res, 1996. **40 (Pt 6)**: p. 535-43.
12. Maaskant M.A., Kessels A.G., Frederiks M.A., et al., *Care dependence and services planning.* J Intellect Disabil Res, 1994. **38 (Pt 3)**: p. 299-15.
13. Lawton M.P. and Brody E.M., *Assessment of older people: self-maintaining and instrumental activities of daily living.* Gerontologist, 1969. **9**(3): p. 179-86.
14. Koehler M., Kliegel M., Wiese B., et al., *Malperformance in verbal fluency and delayed recall as cognitive risk factors for impairment in instrumental activities of daily living.* Dement Geriatr Cogn Disord, 2011. **31**(1): p. 81-8.
15. Mehta K.M., Yaffe K., and Covinsky K.E., *Cognitive impairment, depressive symptoms, and functional decline in older people.* J Am Geriatr Soc, 2002. **50**(6): p. 1045-50.
16. Lifshitz H., Merrick J., and Morad M., *Health status and ADL functioning of older persons with intellectual disability: Community residence versus residential care centers.* Res Dev Disabil, 2008. **29**(4): p. 301-15.
17. Merrick J., Davidson P.W., Morad M., et al., *Older adults with intellectual disability in residential care centers in Israel: health status and service utilization.* Am J Ment Retard, 2004. **109**(5): p. 413-20.
18. Mahoney J.E., Sager M.A., and Jalaluddin M., *Use of an ambulation assistive device predicts functional decline associated with hospitalization.* J Gerontol A Biol Sci Med Sci, 1999. **54**(2): p. M83-8.
19. Wilms H.U., Riedel-Heller S.G., and Angermeyer M.C., *Limitations in activities of daily living and instrumental activities of daily living capacity in a representative sample: disentangling dementia- and mobility-related effects.* Compr Psychiatry, 2007. **48**(1): p. 95-101.

20. Daniels R., van Rossum E., de Witte L., et al., *Interventions to prevent disability in frail community-dwelling elderly: a systematic review.* BMC Health Serv Res, 2008. **8**: p. 278.
21. Gama E.V., Damian J.E., Perez de Molino J., et al., *Association of individual activities of daily living with self-rated health in older people.* Age Ageing, 2000. **29**(3): p. 267-70.
22. Luk J.K., Chiu P.K., and Chu L.W., *Rehabilitation of older Chinese patients with different cognitive functions: how do they differ in outcome?* Arch Phys Med Rehabil, 2008. **89**(9): p. 1714-9.
23. Glaesmer H., Kunstler J., and Reuter W., *[Improvement of functional deficits, physical mobility and cognitive function by treatment in a geriatric day hospital].* Z Gerontol Geriatr, 2003. **36**(6): p. 475-83.
24. Esperanza A., Miralles R., Rius I., et al., *Evaluation of functional improvement in older patients with cognitive impairment, depression and/or delirium admitted to a geriatric convalescence hospitalization unit.* Arch Gerontol Geriatr Suppl, 2004(9): p. 149-53.
25. Seeman T.E., Charpentier P.A., Berkman L.F., et al., *Predicting changes in physical performance in a high-functioning elderly cohort: MacArthur studies of successful aging.* J Gerontol, 1994. **49**(3): p. M97-108.
26. Hogg J., *Intellectual disability and ageing: ecological perspectives from recent research.* J Intellect Disabil Res, 1997. **41 (Pt 2)**: p. 136-43.
27. Hilgenkamp T.I., Bastiaanse L.P., Hermans H., et al., *Study healthy ageing and intellectual disabilities: Recruitment and design.* Res Dev Disabil, 2011. **32**(3): p. 1097–1106.
28. Helsinki. *World Medical Associaton Declaration of Helsinki, Ethical Principles for Medical Research Involving Human Subjects*. 2008; Available from: http://www.wma.net/en/30publications/10policies/b3/.
29. Mahoney F.I. and Barthel D.W., *Functional Evaluation: the Barthel Index.* Md State Med J, 1965. **14**: p. 61-5.
30. Wade D.T. and Hewer R.L., *Functional abilities after stroke: measurement, natural history and prognosis.* J Neurol Neurosurg Psychiatry, 1987. **50**(2): p. 177-82.
31. Collin C., Wade D.T., Davies S., et al., *The Barthel ADL Index: a reliability study.* Int Disabil Stud, 1988. **10**(2): p. 61-3.
32. Wade D.T. and Collin C., *The Barthel ADL Index: a standard measure of physical disability?* Int Disabil Stud, 1988. **10**(2): p. 64-7.
33. Green J., Forster A., and Young J., *A test-retest reliability study of the Barthel Index, the Rivermead Mobility Index, the Nottingham Extended Activities of Daily Living Scale and the Frenchay Activities Index in stroke patients.* Disabil Rehabil, 2001. **23**(15): p. 670-6.
34. Gresham G.E., Phillips T.F., and Labi M.L., *ADL status in stroke: relative merits of three standard indexes.* Arch Phys Med Rehabil, 1980. **61**(8): p. 355-8.
35. Vittengl J.R., White C.N., McGovern R.J., et al., *Comparative validity of seven scoring systems for the instrumental activities of daily living scale in rural elders.* Aging Ment Health, 2006. **10**(1): p. 40-7.
36. Boyle P.A., Paul R., Moser D., et al., *Cognitive and neurologic predictors of functional impairment in vascular dementia.* Am J Geriatr Psychiatry, 2003. **11**(1): p. 103-6.
37. Buurman B.M., van Munster B.C., Korevaar J.C., et al., *Variability in measuring (instrumental) activities of daily living functioning and functional decline in hospitalized older medical patients: a systematic review.* J Clin Epidemiol, 2010: p. Epub ahead of print.
38. Albert S.M., Bear-Lehman J., Burkhardt A., et al., *Variation in sources of clinician-rated and self-rated instrumental activities of daily living disability.* J Gerontol A Biol Sci Med Sci, 2006. **61**(8): p. 826-31.

39. Ng T.P., Niti M., Chiam P.C., et al., *Physical and cognitive domains of the Instrumental Activities of Daily Living: validation in a multiethnic population of Asian older adults.* J Gerontol A Biol Sci Med Sci, 2006. **61**(7): p. 726-35.
40. Myers R., *Classical and modern regression with applications*. 2nd edition ed. 1990, Boston, MA: Duxbury.
41. Cox D.R. and SNell D.J., *The analysis of binary data*. 2nd edition ed. 1989, London, UK: Chapman & Hall.
42. Roehrig B., Hoeffken K., Pientka L., et al., *How many and which items of activities of daily living (ADL) and instrumental activities of daily living (IADL) are necessary for screening.* Crit Rev Oncol Hematol, 2007. **62**(2): p. 164-71.
43. Guerini F., Frisoni G.B., Morghen S., et al., *Clinical instability as a predictor of negative outcomes among elderly patients admitted to a rehabilitation ward.* J Am Med Dir Assoc, 2010. **11**(6): p. 443-8.
44. Odlund Olin A., Koochek A., Ljungqvist O., et al., *Nutritional status, well-being and functional ability in frail elderly service flat residents.* Eur J Clin Nutr, 2005. **59**(2): p. 263-70.
45. Hsueh I.P., Lin J.H., Jeng J.S., et al., *Comparison of the psychometric characteristics of the functional independence measure, 5 item Barthel index, and 10 item Barthel index in patients with stroke.* J Neurol Neurosurg Psychiatry, 2002. **73**(2): p. 188-90.
46. Laake K., Laake P., Ranhoff A.H., et al., *The Barthel ADL index: factor structure depends upon the category of patient.* Age Ageing, 1995. **24**(5): p. 393-7.
47. Sands L.P., Landefeld C.S., Ayers S.M., et al., *Disparities between black and white patients in functional improvement after hospitalization for an acute illness.* J Am Geriatr Soc, 2005. **53**(10): p. 1811-6.
48. Sager M.A., Franke T., Inouye S.K., et al., *Functional outcomes of acute medical illness and hospitalization in older persons.* Arch Intern Med, 1996. **156**(6): p. 645-52.
49. Sands L.P., Yaffe K., Covinsky K., et al., *Cognitive screening predicts magnitude of functional recovery from admission to 3 months after discharge in hospitalized elders.* J Gerontol A Biol Sci Med Sci, 2003. **58**(1): p. 37-45.

Appendix 1 Percentage of participants completely independent per item

	Total	Gender		Age					Level of ID					Mobility		
		Male	Fe-male	50-59	60-69	70-79	80-89	90-99	Border-line	Mild	Mode-rate	Se-vere	Pro-found	Inde-pen-dent	With support	Wheel-chair
N	989	509	480	459	347	158	22	3	31	210	472	165	89	731	151	107
Barthel Index																
1. Bowels	60.0	60.5	59.4	64.1	61.4	49.4	36.4	0.0	80.6	74.3	65.9	43.0	14.6	69.1	46.4	16.8
2. Bladder	53.1	59.1	46.7	58.4	54.5	39.9	18.2	33.3	77.4	61.9	58.1	43.6	12.4	63.1	30.5	16.8
3. Grooming	30.7	26.9	34.8	30.5	32.6	29.1	22.7	0.0	77.4	57.1	28.8	6.7	2.2	36.7	21.2	3.7
4. Toilet use	55.6	56.0	55.2	56.2	59.7	48.7	31.8	33.3	83.9	75.2	61.7	30.3	11.2	66.2	41.1	3.7
5. Feeding	60.2	59.3	61.0	60.3	60.2	60.8	54.5	33.3	93.5	82.4	68.6	28.5	5.6	69.6	47.0	14.0
6. Transfer	74.5	77.0	71.9	76.3	75.2	69.0	68.2	66.7	93.5	85.7	80.1	58.8	36.0	87.7	59.6	5.6
7. Mobility	75.7	78.0	73.3	78.2	78.4	68.4	40.9	33.3	93.5	83.8	79.4	64.8	47.2	90.4	56.3	2.8
8. Dressing	55.4	57.0	53.8	57.5	57.6	47.5	40.9	0.0	93.5	79.0	62.1	23.6	10.1	66.2	39.1	4.7
9. Stairs	51.8	58.3	44.8	59.7	54.2	31.0	4.5	0.0	77.4	67.1	53.4	39.4	20.2	68.3	8.6	0.0
10. Bathing	36.1	38.1	34.0	39.9	38.6	24.7	4.5	0.0	71.0	59.5	37.9	10.9	3.4	44.7	16.6	4.7
Lawton IADL Scale																
1. Telephone use	25.8	24.6	27.1	26.4	26.2	25.3	13.6	0.0	77.4	58.1	20.8	1.2	0.0	30.4	19.9	2.8
2. Groceries	28.3	28.5	28.1	29.4	30.8	22.8	9.1	0.0	74.2	55.2	27.3	3.6	0.0	35.3	11.9	3.7
3. Food preparation	12.6	12.0	13.3	12.0	15.6	8.9	9.1	0.0	45.2	29.0	9.5	0.0	0.0	16.1	4.6	0.0
4. Housekeeping	10.2	9.6	10.8	13.1	10.4	2.5	4.5	0.0	29.0	21.9	8.9	1.2	0.0	13.8	0.0	0.0
5. Laundry	11.0	5.9	16.5	12.2	9.8	11.4	4.5	0.0	35.5	26.2	8.3	0.0	0.0	14.0	4.0	0.9
6. Transportation	12.5	12.2	12.9	12.4	13.8	12.0	0.0	0.0	48.4	32.4	7.6	0.6	0.0	16.0	4.6	0.0
7. Medication	14.1	11.8	16.5	13.9	15.9	12.0	4.5	0.0	48.4	33.8	10.2	0.0	0.0	18.2	4.0	0.0
8. Finances	21.2	19.8	22.7	20.3	22.2	23.4	13.6	0.0	67.7	51.0	15.5	0.0	0.0	25.0	16.6	1.9

Appendix 2 Logistic regression models for each item of the BI and LIADL scales.

Barthel Index		b-coefficients	SE	OR	95% confidence interval		R^2 H&L	R^2 C&S	R^2 Nagel-kerwke
					lower	upper			
1. Bowels	Gender	0.069	0.15	1.07	0.80	1.44	0.167	0.201	0.27
	Age	0.323**	0.09	1.38	1.15	1.65			
	Level ID	0.806**	0.09	2.24	1.88	2.67			
	Mobility	0.939**	0.12	**2.56**	2.02	3.25			
2. Bladder	Gender	0.561**	0.15	1.75	1.32	2.33	0.148	0.185	0.25
	Age	0.372**	0.09	1.45	1.21	1.74			
	Level ID	0.629**	0.08	1.88	1.59	2.22			
	Mobility	0.953**	0.13	**2.59**	2.02	3.33			
3. Grooming	Gender	-0.417*	0.16	0.66	0.48	0.91	0.202	0.224	0.32
	Age	0.076	0.10	1.08	0.88	1.32			
	Level ID	1.262**	0.12	**3.53**	2.82	4.43			
	Mobility	1.022**	0.19	2.78	1.94	3.99			
4. Toilet use	Gender	0.031	0.16	1.03	0.76	1.40	0.229	0.271	0.36
	Age	0.081	0.10	1.09	0.90	1.31			
	Level ID	0.999**	0.10	2.71	2.24	3.29			
	Mobility	1.446**	0.15	**4.25**	3.15	5.73			
5. Feeding	Gender	0.043	0.16	1.04	0.76	1.44	0.269	0.304	0.41
	Age	-0.009	0.10	0.99	0.82	1.21			
	Level ID	1.373**	0.11	**3.95**	3.16	4.92			
	Mobility	1.178**	0.14	3.25	2.47	4.27			
6. Transfer	Gender	0.303	0.20	1.35	0.92	1.98	0.345	0.327	0.48
	Age	-0.105	0.12	0.90	0.71	1.14			
	Level ID	0.857**	0.11	2.36	1.89	2.94			
	Mobility	2.083**	0.16	**8.03**	5.84	11.04			
7. Mobility	Gender	0.085	0.21	1.09	0.73	1.63	0.383	0.348	0.52
	Age	0.039	0.12	1.04	0.82	1.32			
	Level ID	0.532**	0.12	1.70	1.36	2.13			
	Mobility	2.377**	0.17	**10.77**	7.69	15.08			
8. Dressing	Gender	0.235	0.16	1.27	0.92	1.74	0.280	0.319	0.43
	Age	0.195	0.10	1.22	1.00	1.48			
	Level ID	1.331**	0.12	3.78	3.01	4.75			
	Mobility	1.462**	0.16	**4.31**	3.15	5.91			
9. Stairs	Gender	0.720**	0.20	2.05	1.40	3.02	0.143	0.152	0.22
	Age	0.311*	0.13	1.36	1.06	1.76			
	Level ID	0.705**	0.12	2.03	1.61	2.54			
	Mobility	2.259**	0.36	**9.57**	4.77	19.23			
10. Bathing	Gender	0.280	0.16	1.32	0.97	1.80	0.214	0.244	0.34
	Age	0.408**	0.10	1.50	1.23	1.84			

	Level ID	1.139**	0.11	3.12	2.53	3.85			
	Mobility	1.211**	0.19	**3.36**	2.33	4.83			
Lawton IADL Scale									
1. Telephone use	Gender	-0.067	0.18	1.07	0.76	1.51	0.268	0.262	0.39
	Age	-0.216	0.11	1.24	0.99	1.55			
	Level ID	1.749**	0.14	**5.75**	4.36	7.58			
	Mobility	0.781**	0.20	2.18	1.49	3.21			
2. Groceries	Gender	0.096	0.17	1.10	0.79	1.53	0.240	0.249	0.36
	Age	0.218*	0.11	1.24	1.00	1.54			
	Level ID	1.419**	0.12	**4.13**	3.24	5.27			
	Mobility	1.270**	0.22	3.56	2.31	5.49			
3. Food preparation	Gender	-0.143	0.22	0.87	0.57	1.32	0.207	0.144	0.27
	Age	0.102	0.14	1.11	0.84	1.45			
	Level ID	1.343**	0.15	3.83	2.86	5.13			
	Mobility	1.517**	0.39	**4.56**	2.11	9.83			
5. Laundry	Gender	-1.354**	0.25	0.26	0.16	0.42	0.232	0.147	0.30
	Age	0.153	0.15	1.17	0.87	1.56			
	Level ID	1.340**	0.16	3.82	2.78	5.24			
	Mobility	1.416**	0.38	**4.12**	1.97	8.61			
6. Transportation	Gender	-0.098	0.22	0.91	0.59	1.40	0.239	0.164	0.31
	Age	0.122	0.14	1.13	0.86	1.49			
	Level ID	1.532**	0.16	**4.63**	3.39	6.32			
	Mobility	1.513**	0.40	4.54	2.08	9.91			
7. Medication	Gender	-0.516*	0.21	0.60	0.39	0.91	0.239	0.177	0.32
	Age	0.107	0.14	1.11	0.85	1.45			
	Level ID	1.454**	0.15	4.28	3.18	5.77			
	Mobility	1.916**	0.43	**6.79**	2.90	15.89			
8. Finances	Gender	-0.101	0.19	0.90	0.63	1.31	0.258	0.232	0.36
	Age	0.042	0.12	1.04	0.83	1.31			
	Level ID	1.709**	0.15	**5.52**	4.16	7.33			
	Mobility	0.815**	0.22	2.26	1.47	3.47			

* = significant at p<0.05

** = significant at p<0.01

(Gender (man=0, woman=1), age (50-59=1, 60-69=2, 70-79=3, 80-89=4, 90-99=5), level of ID (ID) (borderline=0, mild=1, moderate=3, severe=4, profound=5), mobility (MOB) (0=no support, 1=support, 2=wheelchair). All items are rescaled into 0=independent or 1=dependent (in any form))

Chapter 11

General Discussion

PRINCIPAL FINDINGS

Although the importance of physical activity and fitness for daily functioning and health of ageing adults has been established consistently in research and practice [1], hardly any research had been conducted on these topics in older adults with intellectual disabilities (ID). To do so, instruments to measure these concepts in this particular population had to be selected, and tested for their feasibility and reliability. For physical activity, a pedometer that could measure reliably at 3.2 km/h (NL-1000) was the most cost-effective solution to measure physical activity objectively in a large sample, and a wearing period of any four days (not necessarily consecutively) proved to be sufficient for a valid measurement. Physical fitness is a multidimensional concept, consisting of multiple, interrelated components. A description of this concept specifically for older adults with ID was proposed, and comprised manual dexterity, reaction time, balance, muscle strength, muscle endurance, cardiorespiratory endurance and flexibility. The selected instruments to measure these components (Box and block test, Response time test, Berg Balance Scale, Walking speed, Grip strength, 30s Chair stand, 10m Incremental shuttle walking test and the Extended modified back saver sit and reach test) proved to be reliable and feasible for large-scale research, although feasibility for subgroups varied. With these instruments, physical activity and fitness were, for the first time worldwide, studied objectively in a large sample of older adults with ID (n=1050), varying in level of ID, residential setting, age, and level of mobility. This study provided useful information on the applicability of these measurements in this population, and which subgroups should be distinguished when formulating reference values.

Furthermore, this study generated shocking results regarding physical activity levels and physical fitness levels of older adults with ID. At least two-thirds of this population is not physically active enough to gain health benefits. Moreover, physical fitness of the older adults with ID in their 50s was comparable to that in older adults of the general population aged 75-80 years, or worse. Since their life expectancy is approaching that of the general population [2], the number of years spent at a low fitness level, with accompanying functional decline, motor impairments and high risk of adverse health outcomes, is 20 to 30 years longer than in the general population, thus resulting in lower quality of life, and generating high health care costs that are principally avoidable. This is supported by our finding of a strong association of level of mobility with aspects of daily functioning, in some cases even more so than level of ID. Promoting physical activity and a physically active lifestyle can be the key factor in reducing health care costs of the population of older adults with ID.

METHODOLOGICAL ISSUES

Bias

One of the methodological issues of this study is the large, and often selective, drop-out.

First, recruitment through care providers led to a selection bias regarding the population we invited to join, excluding all older adults with borderline or mild ID living independent from any kind of registered ID-specific support or care. Secondly, drop-out during the informed consent process led to some bias regarding the total HA-ID study population, with an underrepresentation of the most independent group of older adults with ID within the ID care services (living independently with ambulatory support). Thirdly, selective drop-out during the measurements caused an underrepresentation of older adults with a severe or profound intellectual disability and/or wheelchair-bound older adults with ID.

All of these biases are somewhat influencing the generalizability of our results to the total older population with ID, nevertheless, this study is the first to investigate such a large sample of (older) adults with ID worldwide. By reporting the drop-out for every step in the process, this study not only provides valuable insight into the reality of such a complex undertaking, it also makes transparent to which groups the results are applicable, and which part of the total population that group represents.

Evaluation of physical activity

Although cycling is very common in the general Dutch population, in a typically sedentary population such as older adults with ID, walking is the most frequent activity [3]. Pedometers were therefore the method of choice in the current study. This study clearly demonstrated that the used pedometer (NL-1000) was suitable only for the most able part of the population, and that a large part of the study population could not reliably participate in this measurement. Other, far more expensive motion sensors such as the Stepwatch, that can reliably monitor physical activity regardless of the walking velocity, could provide a solution for the part of the population that walks slower than 3.2 km/h (about 25% of the current study population). Questionnaires seem an attractive alternative because they can be completed by or for everybody, but they are likely to underestimate the physical activity levels, as walking time is unreliably recalled [4].

Submaximal performance

Motivation is a main issue when measuring physical fitness in this group [5-7]: how to motivate participants to perform to their maximum ability? In this study, the test observers, who had been trained to conduct the fitness tests and all had ample experience in working with people with ID as a physiotherapist, occupational therapist or physical activity instructor, were instructed to 'maximally motivate' participants. For the 10 meter Incremental shuttle walking test, effort was monitored by heart rate monitors, which showed that effort was quite low during the test, despite the verbal encouragements during the test. We hypothesize that the limited experience with exercise and physical signs of exertion, such as sweating or increased body temperature and heart rate, caused a large portion of the participants to stop further exertion the moment they felt such physical signs.

Most of the other tests were performance-based as well, and results might not always be a 'true' representation of the abilities of the participants. However, we suppose that measured performance during the tests does not exceed the required performance for daily tasks. If these persons have not been practicing fitness components at a more intense level regularly, it very well might be the best they can do.

From early development continuing throughout our lives, everybody needs to learn how to utilise fitness components in the execution of, for example, daily tasks. Previous experiences can be combined and applied to new tasks and contexts, thus facilitating the acquisition of new skills. This transfer of motor skills may be hampered in people with intellectual disabilities [8], and this is likely to influence the performance on tasks that are part of a test or test environment. Although test performance in our study did not change over three or four sessions with the same tests, we cannot rule out that performance was not yet maximal, and a longer learning period may be required.

Indirect measures

Taking the transfer problem into account, we chose to use field tests in this study. The advantage of field tests over laboratory testing is that they relate to daily tasks more than laboratory tests, and that they can be applied at sites close by and/or familiar to participants. The disadvantage is that they measure physical fitness components indirectly and give an approximation of the component intended to assess, in contrast with laboratory tests which (in some cases) measure specific physical components directly.

Reference problems

Another issue in the interpretation of the results is the assumption that in theory, the same physical performance levels are possible in adults with ID as in the general population [7]. In reality, performance might be hampered to some extent by the limited cognitive performance and accompanying physical limitations, as has been demonstrated for people with Down syndrome [9,10]. Many persons with ID, including those who are able to walk independently, may suffer from neurological dysfunctions which hamper a smooth motor control, possibly resulting in lower physical performance on fitness tests[11,12]. In the current study, level of ID indeed was related to performance in all tests, independent of physical activity levels. If this population is indeed not able to achieve similar results as the general population, this would justify developing norms for this population in particular. Intensive training regimes and maximal testing might provide insight into whether this is the case, but the burden of this kind of research for participants is substantial. Available research shows that large improvements in test performance of adults with ID and/or Down syndrome were indeed possible when adhering to an intensive exercise programme [6,13,14]. Research in younger athletes with ID showed that similar levels as in the general population were possible for some aspects of fitness, but not on the complete range of physical fitness components [6,15,16]. Further research is necessary to determine what reference values are most suitable, based on their maximum abilities, and more direct measures (such as measuring maximal oxygen uptake during exercise, or balance tasks with mobile gait analysis equipment) may be required to determine what levels of physical performance are possible in adults with ID. In addition to research into these maximum physical fitness abilities, fitness levels will need to be related to daily functioning and future health outcomes to determine the recommended level of performance.

IMPLICATIONS FOR POLICY AND PRACTICE

First and foremost, the very low physical activity levels in older adults with ID call for strong actions to improve these levels. In this population, physical inactivity is so common that future adverse health effects seem to be inevitable. Promoting physical activity could therefore not only enhance independence and well-being of the older adults with ID themselves, it could also diminish the increase in health care costs in the future. The often heard argument that more physical activity leads to a higher prevalence of injuries and should therefore not be recommended, does not balance out the many health advantages already shown in research [17].

We state that care services, trusted with the care for people with ID, need to make it their responsibility to incorporate at least a basic level of physical activity for every client as part of daily care, just like brushing teeth. Since physical activity comprises much more than just sports or other vigorous activities, and considering the very low physical activity levels for most older adults with ID, the emphasis should be on a physically active lifestyle first.

Policy changes at national level

In the Netherlands, the General Act on Special Medical Expenses provides many people with ID with financial support to use day care, ambulatory support, residential care, and if indicated, specialist treatment. For the most independent group (around 165.000 people with borderline or mild ID using ambulatory support or day care facilities), the responsibility for the allocation of these resources will be changed in 2013 by law from government-based to municipality-based, and possibly this will be extended in the future to more dependent groups. These municipalities are already entrusted with physical activity promotion for the general population, and in line with governmental guidelines [18], the emphasis is on the direct environment of inhabitants: community facilities, sports clubs and creating a public environment which elicits an active life-style. Since people with ID may experience practical as well as psychological thresholds to participate in, and benefit from such general facilities, a high risk exists that they do not receive any physical activity promotion, or support to live an active lifestyle, at all. For the municipalities, the resulting increasing need of care when this group ages, should provide sufficient grounds to implement physical activity promotion adapted to or designed specifically for adults with ID, using the experience that ID care providers already have in how to activate this group [6,19,20]. Given the low participation of groups with low socio-economic status in the general population in existing health promotion activities, such adapted programmes might be more effective in those groups, too.

Disparity between supply and demand of care professionals

We already stressed that the results of this study support the notion that by being physically inactive, a loss of fitness and a decline in daily functioning will be inevitable. Combined with the loss of functioning due to the primary ageing process, and the increasing number of older adults with ID, this may lead to increasing health care demands in the near future. In contrast, the number of potential professional caregiv-ers will decrease in the future, predominantly as a result from the current ageing effect in the general population.

Put together, these trends will lead to smaller absolute numbers of professional caregivers, responsible for the same or even a larger number of adults with ID, with an overrepresentation of older adults. This emphasizes the need to prevent unnecessary early decline in daily functioning. To this end, physical activity of a certain duration, frequency and intensity is required, instead of merely an active lifestyle [21]. The use of reliable and feasible tests to measure physical fitness, as applied in this study, and future research to formulate reference values for subgroups in this population, are essential to evaluate the effectiveness of physical activity interventions or to monitor physical fitness levels in (subgroups of) older adults with ID.

Physical activity expertise in practice and research

Lack of motivation, partly due to lack of experience with physical activity and exercise and to not understanding physical signs or the purpose of being active, is a major barrier in initiatives to increase physical activity levels in adults with ID [22-24]. Since several decades, physical activity experts have been working in ID care services in the Netherlands, equipped with knowledge and experience on how to activate people with ID in a positive way, whether it is by activating people with ID themselves, or coaching other care professionals in how to do this in the context of a living facility or day care centre. However, this group of experts is increasingly being dismissed due to cost considerations, while their expertise is indispensible to put physical activity into practice in this population.

Organising and evaluating complex physical activity interventions, which are much sought-after in this population, requires a scientific background, organisational qualities and expert knowledge of the wide range of aspects regarding physical activity, such as physiology, exercise programming, motivational strategies and strategies to facilitate behavioral changes in the client and his/her (professional) caregivers. Human movement scientists, to date still very scarce in ID care, are equipped with specifically these skills, and are essential for ID care services to deploy an effective physical activity policy.

Take home messages

- Adapted physical activity promotion and support to maintain an active lifestyle should be available to all (older) adults with ID.
- Exercise to maintain physical fitness, necessary for daily functioning, should be stimulated in all (older) adults with ID.
- Physical fitness tests should be used widely for structured evaluation of physical activity interventions and monitoring of fitness levels of (subgroups of) older adults with ID.
- Physical activity experts and human movement scientists are both essential to put physical activity promotion to practice.

DIRECTIONS FOR FUTURE RESEARCH

This study is a relevant first step towards healthy ageing in older adults with intellectual disabilities: by quantifying the size and severity of the problem of low physical activity and fitness, establishing first relationships with daily functioning and subgroup characteristics, and providing a well-evaluated set of diagnostic instruments, it provides a solid basis for future research, both within the HA-ID consort and by other research groups.

Associations between concepts

First of all, the data collected in this study can provide answers to more questions than could be addressed in one thesis, such as the exact nature of the relationship between physical fitness and daily functioning, the prevalence of physical-activity related health conditions in this population, and the relationship of physical fitness with sarcopenia and frailty. These questions might provide answers with which reference values can be formulated for this population, based on reference groups as well as on the association with daily functioning and health conditions. Also, the underlying theoretical model of this study (see Chapter 1) and the proposed combination of relevant physical fitness components for older adults with ID could be validated, which is beyond the results presented in this thesis. Furthermore, in the HA-ID study, other health topics have been investigated and the relationship of both physical activity and fitness with, for example, obesity, depression, sleep, nutritional intake or inflammatory processes can first be studied in a cross-sectional design.

Longitudinal research to confirm validity

Secondly, the predictive validity of low physical activity, low physical fitness, sarcopenia and frailty for future health problems, which has been demonstrated in the general population [6,25-28], needs to be confirmed for this population. To this end, a 3-year longitudinal follow-up in the HA-ID study population is now being set up, in which adverse health outcomes, such as falls, morbidity and decline in daily functioning, will be monitored.

Inactivity physiology: new directions of activity evaluation

In a population this inactive, one may wonder whether small improvements in physical activity, although still well below the guidelines, may provide health benefits. In 1994, Haskell described the shift during the last few decades in the American College of Sport Medicine from "exercise training to promote physical fitness" to "physical activity to promote health", and already mentioned that the greatest benefits occur when the least active become moderately active [29]. In 2007, Hamilton et al. took this view to a different level, stating that "recent observational epidemiological studies strongly suggest that daily sitting time or low non-exercise activity levels may have a significant direct relationship with each of these medical concerns (mortality, cardiovascular disease, type 2 diabetes, metabolic syndrome risk factors, and obesity). There is now a need for studies to differentiate between the potentially unique molecular, physiologic, and clinical effects of too much sitting (inactivity physiology) separate from the responses caused by structured exercise (exercise physiology)." This theory suggests that health benefits can be achieved just by reducing the time spent inactively. In other words, the theory focuses on the lower end of the fitness and activity curve, instead of on the higher end [30]. Research investigating this theory may provide useful insights for the population with ID, because achieving health benefits is possibly within reach by reducing inactivity rather than by enhancing moderate-to-vigorous activity.

Effectiveness of adapted physical activity interventions in people with ID

Finally, the results of this thesis strongly call for effective intervention programmes aimed at improvement of physical activity in adults with ID [6,19,20]. As part of the HA-ID study, a randomized controlled trial was conducted to investigate the effects of a 9-month intervention programme for older adults with ID in day-care centres. Intervention-mapping was used to design an intervention based on accepted theories of motivation and behavioral change, combined with experiences of physical activity experts and day care professionals. The combination of quantitive and qualitative effect evaluation with process evaluation promises to yield interesting results, much sought after in ID care services [20]. The results of that study are currently being analysed.

In the Netherlands, several national foundations support health promotion in adults with ID, such as Disability Sports Netherlands (in Dutch: Gehandicaptensport Nederland), with a special programme for ID care services to initiate physical activities for their clients and to incorporate physical activity into their policy and practice. Although this programme has resulted in a wide range of good practices and solutions to stimulate physical activity, a structured evaluation is lacking in most cases, thus hampering firm conclusions about the effectiveness on the short-term and the long-term of these initiatives. Following the current study and using a variety of physical activity solutions, Abrona, one of the care services involved in HA-ID, will conduct a study into what kind of physical activity programme to stimulate physical activity is appropriate and effective for what kind of situation, considering characteristics and preferences of clients, support system, living facility and environment. Following the choice of the appropriate solution, professional caregivers will be coached to implement this in their daily care, and effectiveness of this intervention will be monitored objectively.

Furthermore, in a world where care and support are increasingly cost-driven, longitudinal studies directed at cost-effectiveness and cost-benefit of lifestyle interventions are required as well.

Hopefully, this thesis is only the start of an expanding body of research into physical activity and fitness in people with ID, taking into account scientific as well as more practical research questions, aiming to positively influence individual quality of life of people with ID, as well as general quality and efficiency of care for this group, today and in the future.

REFERENCES

1. WHO, *Global recommendations on physical activity for health*. 2010, World Health Organization: Geneva.
2. Janicki M.P., Dalton A.J., Henderson C.M., et al., *Mortality and morbidity among older adults with intellectual disability: health services considerations.* Disabil Rehabil, 1999. 21(5-6): p. 284-94.
3. Draheim C.C., Williams D.P., and McCubbin J.A., *Prevalence of physical inactivity and recommended physical activity in community-based adults with mental retardation.* Ment Retard, 2002. 40(6): p. 436-44.
4. Tudor-Locke C.E. and Myers A.M., *Challenges and opportunities for measuring physical activity in sedentary adults.* Sports Med, 2001. 31(2): p. 91-100.
5. Pitetti K.H., Rimmer J.H., and Fernhall B., *Physical fitness and adults with mental retardation. An overview of current research and future directions.* Sports Med, 1993. 16(1): p. 23-56.
6. WHO. *International classification of functioning, disability and health*. 2001. Geneva.
7. Fernhall B., *Physical fitness and exercise training of individuals with mental retardation.* Med Sci Sports Exerc, 1993. 25(4): p. 442-50.
8. Mohan A., Singh A.P., and Mandal M.K., *Transfer and interference of motor skills in people with intellectual disability.* J Intellect Disabil Res, 2001. 45(Pt 4): p. 361-9.
9. Mendonca G.V., Pereira F.D., and Fernhall B., *Reduced exercise capacity in persons with Down syndrome: cause, effect, and management.* Ther Clin Risk Manag, 2010. 6: p. 601-10.
10. Rigoldi C., Galli M., and Albertini G., *Gait development during lifespan in subjects with Down syndrome.* Res Dev Disabil, 2011. 32(1): p. 158-63.
11. Agiovlasitis S., Yun J., Pavol M.J., et al., *Gait transitions of persons with and without intellectual disability.* Res Q Exerc Sport, 2008. 79(4): p. 487-94.
12. Carmeli E., Bar-Yossef T., Ariav C., et al., *Perceptual-motor coordination in persons with mild intellectual disability.* Disabil Rehabil, 2008: p. 1-7.
13. Mendonca G.V., Pereira F.D., and Fernhall B., *Effects of combined aerobic and resistance exercise training in adults with and without down syndrome.* Arch Phys Med Rehabil, 2011. 92(1): p. 37-45.
14. Calders P., Elmaghoub S., de Mettelinge T.R., et al., *Effect of combined exercise training on physical and metabolic fitness in adults with intellectual disability: a controlled trial.* Clin Rehabil, 2011.
15. van de Vliet P., Rintala P., Frojd K., et al., *Physical fitness profile of elite athletes with intellectual disability.* Scand J Med Sci Sports, 2006. 16(6): p. 417-25.
16. Frey G.C., McCubbin J.A., Hannigan-Downs S., et al., *Physical fitness of trained runners with and without mild mental retardation.* Adapt Phys Activ Q, 1999. 16(2): p. 126-137.
17. DHHS, *Physical Activity Guidelines Advisory Committee Report*. 2008, U.S. Department of Health and Human Services, : Rockville (MD).
18. Schippers E., *National document on health policy "Close to health" [In Dutch: Landelijke nota gezondheidsbeleid "Gezondheid dichtbij"]*, W.a.S.I.D.M.v.V. Department of Health, Welzijn en Sport], Editor. 2011.

19. Stanish H.I. and Frey G.C., *Promotion of physical activity in individuals with intellectual disability.* Salud Publica Mex, 2008. 50 Suppl 2: p. s178-84.
20. Bartlo P. and Klein P.J., *Physical activity benefits and needs in adults with intellectual disabilities: systematic review of the literature.* Am J Intellect Dev Disabil, 2011. 116(3): p. 220-32.
21. Cowley P.M., Ploutz-Snyder L.L., Baynard T., et al., *The effect of progressive resistance training on leg strength, aerobic capacity and functional tasks of daily living in persons with Down syndrome.* Disabil Rehabil, 2011. 33(23-24): p. 2229-36.
22. Messent P.R., Cooke C.B., and Long J., *Primary and secondary barriers to physically active healthy lifestyles for adults with learning disabilities.* Disabil Rehabil, 1999. 21(9): p. 409-19.
23. Rimmer J.H., Riley B., Wang E., et al., *Physical activity participation among persons with disabilities: barriers and facilitators.* Am J Prev Med, 2004. 26(5): p. 419-25.
24. Temple V.A., *Barriers, enjoyment, and preference for physical activity among adults with intellectual disability.* Int J Rehabil Res, 2007. 30(4): p. 281-7.
25. Cooper R., Kuh D., Cooper C., et al., *Objective measures of physical capability and subsequent health: a systematic review.* Age Ageing, 2011. 40(1): p. 14-23.
26. Abellan van Kan G., Rolland Y., Andrieu S., et al., *Gait speed at usual pace as a predictor of adverse outcomes in community-dwelling older people an International Academy on Nutrition and Aging (IANA) Task Force.* J Nutr Health Aging, 2009. 13(10): p. 881-9.
27. Rolland Y., Abellan van Kan G., Benetos A., et al., *Frailty, osteoporosis and hip fracture: causes, consequences and therapeutic perspectives.* J Nutr Health Aging, 2008. 12(5): p. 335-46.
28. Rolland Y., Czerwinski S., Abellan Van Kan G., et al., *Sarcopenia: its assessment, etiology, pathogenesis, consequences and future perspectives.* J Nutr Health Aging, 2008. 12(7): p. 433-50.
29. Haskell W.L., *J.B. Wolffe Memorial Lecture. Health consequences of physical activity: understanding and challenges regarding dose-response.* Med Sci Sports Exerc, 1994. 26(6): p. 649-60.
30. Hamilton M.T., Hamilton D.G., and Zderic T.W., *Role of low energy expenditure and sitting in obesity, metabolic syndrome, type 2 diabetes, and cardiovascular disease.* Diabetes, 2007. 56(11): p. 2655-67.

Summary

Chapter 1 General Introduction

The number of older adults with ID is growing, due to an ageing effect in the total population, as well as an increased life expectancy due to improved health care. For this expanding population, health care costs are growing as well, but information on the health of this group and risk groups for health problems is lacking. To answer questions regarding these topics, three ID care services (Abrona, Amarant and Ipse de Bruggen) and two academic institutes (Intellectual Disability Medicine, Erasmus Medical Center, and Human Movement Sciences, University Medical Centre Groningen) founded a consort, and started the study 'Healthy ageing and intellectual disability' (HA-ID). Health in older adults was to be investigated from a perspective of prevention: Physical activity & fitness, Nutrition & nutritional state and Mood & anxiety. After a description of the design and recruitment of the total HA-ID study, this thesis presents results of the first theme: Physical activity and fitness.

Chapter 2 Design and recruitment HA-ID study

At the start of this study, preparation of the measurements was started by carefully reviewing and selecting instruments to measure a wide set of health variables to answer the research questions. Specific demands of these instruments were that they could be executed efficiently and accurately on-site in a large sample of participants and that the burden of these measurements for participants as well as their caregivers was as minimal as possible. Then, preparation was continued by designing and executing a thorough communication plan for clients, legal representatives and staff of the care providers, preceding the informed consent procedure. In this plan, which had a top-down structure, specific attention was given to personal information and motivation of key stakeholders: the professional caregivers. This preparation led to a recruitment of 1050 out of 2320 participants (45.2%) and to high participation rates in key parts of the assessment. Physical activity was measured with pedometers, physical fitness was measured with objective tests to measure a wide range of different aspects of fitness, and daily functioning was measured with questionnaires (Barthel Index and Lawton IADL scale).

PHYSICAL ACTIVITY IN OLDER ADULTS WITH ID

Chapter 3 Measuring physical activity with pedometers

To measure physical activity with pedometers, it is necessary to know how many days participants need to wear the pedometer for a valid measurement, and if he responds to wearing the pedometer with more physical activity during the first days (reactivity). To investigate this, 268 participants with borderline to severe ID aged 50 years and older wore a pedometer (NL-1000, minimum required walking speed = 3.2 km/h) for 14 days. Outcome measure was steps/day. No reactivity was present. Any combination of four days of wearing a pedometer is sufficient to validly measure physical activity in this group.

Chapter 4 Low physical activity levels

While the purpose of the study was to measure physical activity in all 1050 participants of the HA-ID study, this proved to be impossible for the entire group. Largely due to physical limitations (n = 103), walking speed <3.2 km/h (n = 252), limited understanding or non-cooperation (n = 233), only 257 participants were able to participate in valid measurements with pedometers. Of these 257 participants, only 16.7% (95% CI 12.2–21.3) complied with the guideline of 10,000 steps/day, 36.2% (95% CI 30.3–42.1) took 7500 steps/day or more, and 39% (95% CI 32.6–44.5) was sedentary (<5000 steps/day). Because the measured sample was the more functionally able part of the total sample, this result is likely to be a considerable overestimation of the actual physical activity levels in this population.

PHYSICAL FITNESS IN OLDER ADULTS WITH ID

Chapter 5 Review instruments physical fitness

A certain level of physical fitness is a prerequisite for independent functioning and selfcare, but the level of physical fitness declines with ageing. This applies to older adults with intellectual disabilities too, but very little is known about their actual level of physical fitness. The search for and choice of instruments depends on the operationalization of the concept physical fitness, as relevant for this specific target population. A combination of seven components to describe physical fitness in older adults with intellectual disabilities is proposed: coordination, reaction time, balance, muscular strength, muscular endurance, flexibility and cardiorespiratory endurance. A literature search for all instruments to measure any of these components resulted in a large number of available instruments. These instruments were evaluated according to criteria of functionality, reliability and feasibility in this target population. The aim of this article was to propose a selection of instruments complying with these criteria, to advance widespread use and sharing and/or pooling of data. The proposed selection of tests to measure physical fitness in older adults with intellectual disabilities is: Box and Block test, Reaction time test with an auditive and visual signal, Berg balance scale, Walking speed comfortable and fast, Grip strength with a hand dynamometer, 30 s Chair stand, Extended modified back saver sit and reach and the 10m Incremental shuttle walking test.

Chapter 6 Pilot study physical fitness instruments

Before using the proposed selection of instruments in a large-scale study such as HA-ID, their feasibility, learning effect and test-retest reliability needed to be investigated. In a pilot study, 36 older adults with ID performed the eight tests: Box and Block test, Reaction time test with an auditive and visual signal, Berg balance scale, Walking speed comfortable and fast, Grip strength with a hand dynamometer, 30 s Chair stand, Extended modified back saver sit and reach and the 10m Incremental shuttle walking test. Feasibility was expressed in completion rates per test. Learning effect and test-retest reliability were investigated by looking at agreement between multiple, successive measurements within one day and two weeks apart.

All tests had moderate to excellent feasibility and sufficient test-retest reliability (ICCs 0.63 – 0.96). No statistically significant learning effects were found. Therefore, all tests were suitable to be used in large-scale epidemiological research, such as the HA-ID study.

Chapter 7 Feasibility physical fitness instruments

In the HA-ID study, trained test observers administered the physical fitness tests to the total sample of 1050 older adults with ID. This large sample provides more in-depth insight into the feasibility of these tests for subgroups of this population, which is useful information for clinical practice.

All tests had moderate to good feasibility in all subgroups, except for participants with profound ID (low for all tests), severe ID (low for Response time test and Berg balance scale), and wheelchair users (low for all tests that involve standing and walking).

Chapter 8 Low physical fitness levels

Results of comfortable walking speed, muscle strength (Grip strength), muscle endurance (30 second Chair stand) and cardiorespiratory endurance (10 meter Incremental shuttle walking test) were compared with reference values for the general older population. Across all age ranges, approximately two-thirds of the entire HA-ID study population scored 'below average' or 'impaired'. Even the youngest age groups (50-59 or 50-54 years) in this sample achieve similar to or even worse than age groups 20 to 30 years older in the general population. The found low physical fitness levels in older adults with ID demonstrate that this group is prone to unnecessary premature loss of functioning and health problems. Maintaining physical fitness should have priority in practice and policy.

Chapter 9 Subgroups low physical fitness

Fitness levels may differ across subgroups, and it is important to identify which subgroups need to be targeted specifically in physical activity and fitness interventions. For eight physical fitness tests, administered in the HA-ID sample (n=1050), subgroups associated with lower fitness levels were identified with multivariate regression analyses.

Although explained variance by the regression models varied widely, fixed personal characteristics such as older age, female gender, more severe ID and Down syndrome are associated with lower levels of physical fitness. These subgroups need to be taken into account when formulating reference values for this population. Lower physical fitness was associated as well with potentially modifiable or preventable factors such as walking with an aid or sitting in a wheelchair and/or being physically inactive, and living in a setting with more intensive care, which underline the importance of promoting physical activity across the entire older population with ID.

DAILY FUNCTIONING IN OLDER ADULTS WITH ID

Chapter 10 Association mobility and level of ID with daily functioning

Daily living skills are important for all ageing people in taking care of themselves and being able to live independently. The level of these skills and the influence of gender, age, level of ID and mobility on these skills in older adults with ID has been investigated with multivariate regression analyses. Daily living skills were measured with the Barthel Index (for Activities of Daily Living, ADL) and the Lawton IADL scale (for Instrumental Activities of Daily Living, IADL) in 989 adults with ID aged 50 years and over living in community-based and institutional settings. ADL and IADL scores in older adults with ID are comparable to those of vulnerable patient-groups in the general population. Total ADL score was mainly determined by mobility, while total IADL score was mainly determined by level of ID. Of all 18 separate items of these questionnaires, 11 were determined more by mobility than by level of ID. The Barthel Index and Lawton IADL scale are recommended for future use in research and clinical practice in this group. This study stresses the need to support mobility of older adults with ID as much as possible, in order to optimalize independency in this group.

DISCUSSION

Chapter 11 General discussion

Despite some methodological limitations, this thesis shows that physical activity and fitness levels are very low in older adults with ID, which poses a high risk of an unnecessary decline in daily functioning skills, health problems and high health care costs. Adapted physical activity promotion and support to maintain or develop an active lifestyle needs to be available to all (older) adults with ID, whereas exercise to maintain physical fitness, necessary for daily functioning, should be stimulated, too. Physical fitness tests, used in this study, can be used widely for structured evaluation of physical activity interventions and monitoring of fitness levels of (subgroups of) older adults with ID.

Nederlandse samenvatting

Hoofdstuk 1 Algemene inleiding

De laatste jaren neemt het aantal ouderen met een verstandelijke beperking steeds verder toe. Enerzijds wordt de zorg voor deze groep steeds beter, waardoor de levensverwachting hoger wordt, anderzijds vergrijst de totale bevolking, dus ook deze groep. De kosten van de gezondheidszorg voor mensen met een verstandelijke beperking zijn relatief hoog, en nemen verder toe als zij ouder worden. Tegelijkertijd is er erg weinig bekend over de gezondheid van deze ouderen met een verstandelijke beperking, of over subgroepen binnen die groep die een hoger risico lopen op bepaalde gezondheidsproblemen. Met deze vragen in gedachten, zijn drie grote zorgorganisaties (Abrona, Amarant en Ipse de Bruggen) en een universitaire instelling (Geneeskunde voor Verstandelijk Gehandicapten, Erasmus Medisch Centrum) een samenwerkingsverband aangegaan, en hebben zij in 2008 de studie 'Gezond ouder met een verstandelijke beperking (GOUD)' opgestart, waarbij het interfacultair centrum voor Bewegingswetenschappen van het Universitair Medisch Centrum Groningen ook betrokken werd. In deze studie wordt gezondheid van deze groep onderzocht rondom drie thema's: Lichamelijke activiteit & fitheid, Voeding & Voedingstoestand en Depressie & angst. Na een beschrijving van de opzet en toestemmingsprocedure van de GOUD-studie als geheel, beschrijft dit proefschrift de resultaten van het thema Lichamelijke activiteit en fitheid.

Hoofdstuk 2 Opzet en toestemmingsprocedure GOUD-studie

Volledige artikel: Study healthy ageing and intellectual disabilities: Recruitment and design. T.I. Hilgenkamp, L.P. Bastiaanse, H. Hermans, C. Penning, R. van Wijck, H.M. Evenhuis *Research in Developmental Disabilities* (2011)

De GOUD-studie startte in 2008 met een grondige inventarisatie en beoordeling van internationaal beschikbare meetinstrumenten om verschillende gezondheidskenmerken te meten bij ouderen met een verstandelijke beperking. De eisen aan deze meetinstrumenten waren dat ze efficient en betrouwbaar gebruikt konden worden op verschillende locaties, bij een grote groep ouderen met een verstandelijke beperking, en dat de belasting van deze metingen voor zowel de deelnemers als de begeleiders zo laag mogelijk bleef. Na selectie van de meetinstrumenten werd er een uitgebreid communicatieplan opgesteld en ingezet voor cliënten, wettelijk vertegenwoordigers, medewerkers en management van de drie betrokken zorgorganisaties, voorafgaand aan de toestemmingsprocedure. Dit communicatieplan had een top-down structuur, maar er werd specifieke aandacht besteed aan het persoonlijk informeren en motiveren van de sleutelpersonen in het slagen van het onderzoek: de begeleiders van de cliënten. Deze voorbereiding leidde in de toestemmingsprocedure tot een deelname van 1050 van de 2322 (45.2%) uitgenodigde cliënten van 50 jaar en ouder van de drie betrokken zorgorganisaties. Deze groep was redelijk representatief voor de totale uitgenodigde: de meest zelfstandige ouderen met een verstandelijke beperking (die alleen ambulante zorg ontvangen) bleken iets minder deel te nemen, en de groep met intensieve zorg en behandeling bleek iets oververtegenwoordigd in de studiepopulatie. Alle varianten woonvormen waren vertegenwoordigd, het grootste deel van de studiepopulatie woonde in woningen in de wijk of op centrale terreinen.

Binnen het thema Lichamelijke activiteit & Fitheid werden de volgende metingen gedaan: lichamelijke activiteit werd gemeten met stappentellers en fitheid werd gemeten met een serie objectieve testen, die elk een andere component van fitheid in kaart brachten. Het dagelijks functioneren van deelnemers, en de behoefte aan ondersteuning daarbij, werd geïnventariseerd met vragenlijsten over de (instrumentele) Activiteiten Dagelijks Leven (ADL en IADL) en mobiliteit, die door begeleiders werden ingevuld.

LICHAMELIJKE ACTIVITEIT BIJ OUDEREN MET EEN VERSTANDELIJKE BEPERKING

Hoofdstuk 3 Het meten van lichamelijke activiteit met stappentellers

Volledige artikel: Measuring physical activity with pedometers in older adults with ID: reactivity and number of days. T.I. Hilgenkamp, R. van Wijck, H.M. Evenhuis *Intellectual and Developmental Disabilities:* ter perse

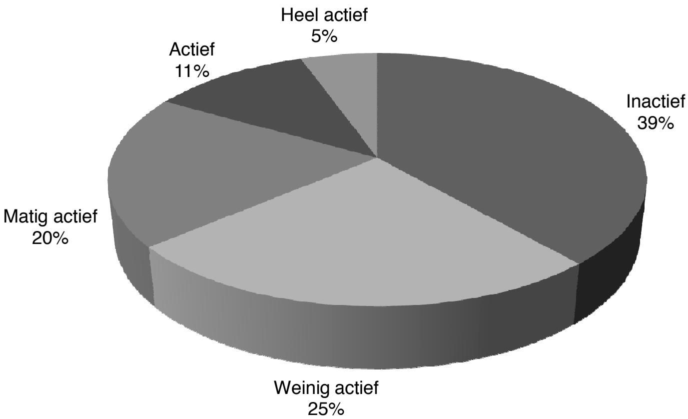
Om een goede meting van de lichamelijke activiteit te kunnen doen met behulp van stappentellers, is het nodig eerst te bepalen hoeveel dagen er gemeten moet worden voor een waarheidsgetrouwe meting[1]. Ook is het noodzakelijk te onderzoeken of er bij deze groep sprake is van 'reactiviteit', wat wil zeggen dat deelnemers in de eerste dagen dat ze een stappenteller dragen meer actief zijn dan normaal[2]. Om dit te onderzoeken, droegen 268 deelnemers van 50 jaar en ouder, variërend in mate van verstandelijke beperking van zwakbegaafd tot ernstig, 14 dagen lang een stappenteller (type New Lifestyles 1000, minimale benodigde wandelsnelheid voor een betrouwbare meting: 3,2 km/u[3-4]). Het aantal stappen per dag was in de eerste dagen niet anders dan in de latere dagen, en een meting van 4 dagen bleek voldoende voor een goede meting, ongeacht welke dagen, en ongeacht of deze dagen wel of niet aansluitend waren.

Hoofdstuk 4 Weinig lichamelijk actief

Volledige artikel: Extremely low physical activity levels in older adults with intellectual disabilities. T.I. Hilgenkamp, R. van Wijck, H.M. Evenhuis *Research in Developmental Disabilities* (2012) 33(2) 477-483

Bij te weinig lichamelijke activiteit loop je een verhoogd risico op gezondheidsaandoeningen en afname van vaardigheden voor het dagelijks functioneren [5]. De aanbevolen hoeveelheid lichamelijke activiteit is 30 minuten matig-intensief bewegen op minimaal 5 dagen per week (Nederlandse Norm Gezond Bewegen). In stappen per dag wordt vaak de '10.000 stappen'-norm gehanteerd, maar recent onderzoek laat zien dat 7500 stappen per dag ook voldoende lijken te zijn om gezondheid te onderhouden of te bevorderen [6-7]. Hoe actief ouderen met een verstandelijke beperking zijn, was nog niet eerder in kaart gebracht.

Hoewel het de bedoeling van de GOUD-studie was om lichamelijke activiteit met stappentellers te meten bij het merendeel van de totale groep van 1050 GOUD-deelnemers, bleek dit niet haalbaar. De redenen hiervoor waren met name: lichamelijke beperkingen (103 deelnemers), een wandelsnelheid lager dan 3,2 km/u (252 deelnemers) en het niet goed begrijpen wat de bedoeling was of niet mee willen doen (233 deelnemers). Dit leidde uiteindelijk tot een goede meting bij maar 257 deelnemers, en dit bleek de functioneel minst beperkte groep te zijn. Van deze 257 mensen haalde slechts 16,7% (95% betrouwbaarheidsinterval: 12,2-21,3) de 'richtlijn' van gemiddeld tenminste 10.000 stappen/dag, slechts 36,2% (95% betrouwbaarheidsinterval 30,3-42,1) haalde gemiddeld tenminste 7500 stappen/dag, en 39% (95% betrouwbaarheidsinterval 32,6-44,5) viel in de laagste categorie, inactief (gemiddeld minder dan 5000 stappen/dag) (zie ook Figuur 1)[6,8]. Omdat dit de resultaten van de functioneel minst beperkte groep zijn, is dit waarschijnlijk een overschatting van de werkelijke hoeveelheid lichamelijke activiteit van de groep ouderen met een verstandelijke beperking.



Figuur 1 Percentages GOUD-deelnemers in de verschillende categorieën van lichamelijke activiteit (gemeten aantal deelnemers =257)

FITHEID BIJ OUDEREN MET EEN VERSTANDELIJKE BEPERKING

Hoofdstuk 5 Bespreking van instrumenten om fitheid te meten

Volledige artikel: Physical fitness in older people with ID—Concept and measuring instruments: A review. T.I. Hilgenkamp, R. van Wijck, H.M. Evenhuis *Research in Developmental Disabilities (2010)* 31(5) 1027-1038

Fitheid is belangrijk om voor jezelf te kunnen zorgen en om zelfstandig te kunnen leven, maar fitheid neemt af als iemand ouder wordt [9-10]. Deze afname geldt ook voor ouderen met een verstandelijke beperking, maar hoe fit deze groep ouderen eigenlijk is, was nog niet eerder onderzocht. Om dit te kunnen doen, was het nodig eerst te benoemen welke componenten van fitheid relevant zijn voor deze doelgroep, voordat het zoeken naar meetinstrumenten voor deze componenten kon starten. Relevantie werd gerelateerd aan het kunnen uitvoeren van (Instrumentele) Activiteiten van het Dagelijks Leven (ADL en IADL), en de voorgestelde componenten waren: coördinatie, reactietijd, balans, kracht, krachtuithoudingvermogen, flexibiliteit en aëroob uithoudingsvermogen [11-12]. De zoekactie in de wetenschappelijke literatuur leverde een groot aantal meetinstrumenten op, die allemaal beoordeeld werden op 'functionaliteit' (hoe functioneel de taak was die in de test werd uitgevoerd), betrouwbaarheid en uitvoerbaarheid in specifiek deze doelgroep. Het doel hierbij was om tot een selectie te komen die geschikt was om breed te gebruiken, en die de mogelijkheden om data van verschillende populaties met elkaar te kunnen vergelijken, zou vergroten. Deze uiteindelijke selectie fitheidstesten is weergegeven in Tabel 1.

Tabel 1 Gekozen meetinstrumenten voor het meten van fitheid bij ouderen met een verstandelijke beperking

Te meten onderdeel van fitheid	Meetinstrument
Coördinatie	Box and block test [13]
Reactietijd	Reactietijd test op laptop [14]
Balans	Berg balans schaal [15]
	Wandelsnelheid (comfortabel en snel) [16]
Spierkrachtuithoudingsvermogen	30 seconden Chair stand [17]
Spierkracht	Knijpkracht [18]
Aëroob uithoudingsvermogen	10 meter Incremental shuttle walking test [19]
Flexibiliteit	Uitgebreide versie van modified back baver sit and reach [20-21]

Hoofdstuk 6 Pilot onderzoek fitheidstesten

Volledige artikel: Feasibility and reliability of tests for measuring physical fitness in older adults with intellectual disabilities. A pilot study. T.I. Hilgenkamp, R. van Wijck, H.M. Evenhuis *Journal of Intellectual & Developmental Disability:* ter perse.

Omdat de meeste van deze fitheidstesten nog niet eerder gebruikt waren bij ouderen met een verstandelijke beperking, was het nodig om eerst te onderzoeken hoe goed deze testen werken in deze groep. Daarom werd in een pilot-onderzoek bij 36 ouderen met een verstandelijke beperking gekeken naar de uitvoerbaarheid, de test-hertestbetrouwbaarheid en het leereffect van de meetinstrumenten uit tabel 1, met uitzondering van de Berg balans schaal. De uitvoerbaarheid werd uitgedrukt in de deelnamepercentages, en het leereffect en de test-hertest betrouwbaarheid werden onderzocht door te kijken in hoeverre opeenvolgende metingen op dezelfde dag, en twee weken later, overeenstemden. Dit werd statistisch getoetst met intraclass correlatie coëfficiënten (≥ 0.60 is acceptabel, ≥ 0.90 is uitstekend). Alle fitheidstesten bleken matig tot zeer goed uitvoerbaar te zijn (44% - 86%), en de test-hertestbetrouwbaarheid varieerde van acceptabel tot uitstekend (zie Tabel 2). Statistisch significante leereffecten zijn niet gevonden. Op basis van deze resultaten zijn de fitheidstesten geschikt bevonden voor gebruik in de GOUD-studie.

Tabel 2 Overeenstemming van verschillende meetmomenten (ICC=intraclass correlatie coefficiënt, B.I.=betrouwbaarheidsinterval, MBBSR = modified back saver sit and reach)

Test	Metingen op dezelfde dag		Metingen met twee weken er tussen	
	ICC (95% B.I.)	aantal	ICC (95% B.I.)	aantal
Box and block test	0.90 (0.79-0.95)	31	0.90 (0.81-0.95)	30
Reactietijd test op laptop: visueel	0.75 (0.41-0.90)	16	0.72 (0.38-0.89)	17
Reactietijd test op laptop: auditief	0.87 (0.69-0.95)	18	0.74 (0.43-0.90)	18
Comfortabele wandelsnelheid	0.96 (0.90-0.98)	26	0.93 (0.85-0.97)	26
Snelle wandelsnelheid	0.96 (0.90-0.99)	17	0.90 (0.70-0.96)	17
30 seconden Chair Stand	0.72 (0.32-0.91)	15	0.65 (0.19-0.87)	14
Knijpkracht	0.94 (0.87-0.97)	31	0.90 (0.80-0.95)	28
10 meter incremental shuttle walking test	0.90 (0.77-0.96)	21	0.76 (0.48-0.90)	18
Uitgebreide versie MBBSR: links	0.96 (0.91-0.98)	25	0.63 (0.29-0.83)	22
Uitgebreide versie MBBSR: rechts	0.95 (0.89-0.98)	23	0.71 (0.43-0.87)	22

Hoofdstuk 7 Uitvoerbaarheid fitheidstesten in de hele studiepopulatie

Volledige artikel: Feasibility of eight physical fitness tests in 1050 older adults with ID: results of the HA-ID study. T.I. Hilgenkamp**,** R. van Wijck, H.M. Evenhuis *Submitted*

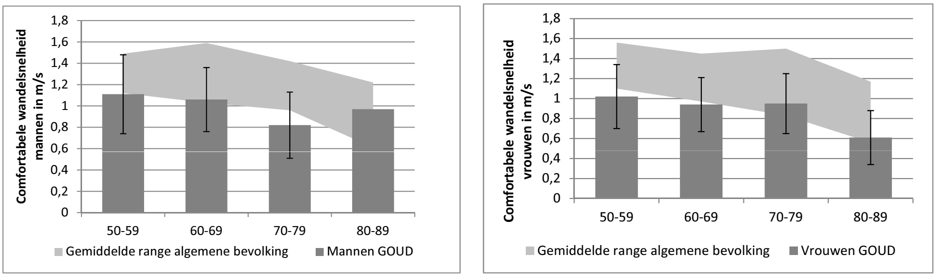
In de GOUD-studie hebben getrainde fysiotherapeuten, ergotherapeuten en bewegingsagogen de fitheidstesten afgenomen bij 1050 ouderen met een verstandelijke beperking. Met deze grote aantallen is de uitvoerbaarheid van deze fitheidstesten in meer detail te onderzoeken voor subgroepen, wat nuttige informatie oplevert voor gebruik van de testen in de praktijk. Ook hieruit bleek dat de gekozen fitheidstesten matig tot goed uitvoerbaar zijn voor deze doelgroep (48%-70%), met uitzondering van deelnemers met een zeer ernstige verstandelijke beperking (geen van de testen was voldoende uitvoerbaar, 1%-25%), deelnemers met een ernstige verstandelijke beperking (lage uitvoerbaarheid van de reactietijd test en de Berg Balans Schaal 16%-18%) en deelnemers in een rolstoel (lage uitvoerbaarheid van alle testen waarbij je je benen nodig hebt).

Hoofdstuk 8 Lage mate van fitheid

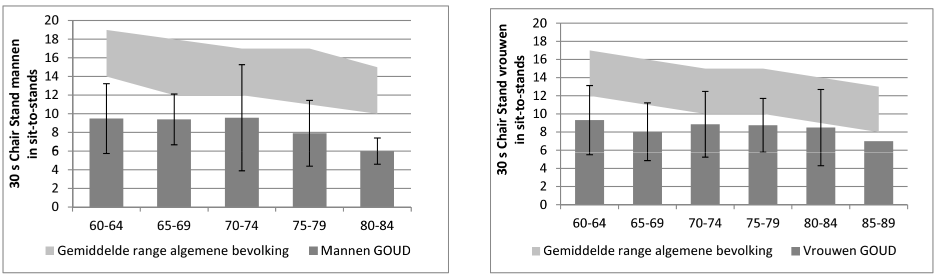
Volledige artikel: Low physical fitness levels in older adults with ID. Results of the HA-ID study. T.I. Hilgenkamp, R. van Wijck, H.M. Evenhuis *Research in Developmental Disabilities (2012) 33(4) 1048–1058*

Om fitheid van ouderen met een verstandelijke beperking te kunnen vergelijken met fitheid van ouderen in het algemeen, zijn grote datasets van de algemene bevolking van dezelfde leeftijdsgroepen nodig, bij voorkeur met normwaarden waaronder een score 'ondergemiddeld' of 'beperkt' is. Deze waren beschikbaar voor de comfortabele wandelsnelheid [22], knijpkracht [23-24], 30 seconden Chair Stand [25] en de 10 meter Incremental shuttle walking test (VO2max) [26-27]. Vergeleken met deze normwaarden scoorde circa tweederde van de GOUD-groep onder de norm (geldt voor alle leeftijdsgroepen binnen GOUD). Zelfs de 'jongste' GOUD-deelnemers (groep van 50-54 of 50-59 jaar) scoorden ongeveer even laag als, of zelfs slechter dan groepen van 20 tot 30 jaar ouder in de algemene populatie. Zie hiervoor ook Figuren 2, 3 en 4. Wat betreft de VO2max: van de 654 deelnemers aan de 10 meter Incremental shuttle walking test, haalden slechts 81 deelnemers een inspanningsniveau dat voldoende was voor een geldige test (85% van de hartslagreserve). Al die 81 deelnemers scoorden ondergemiddeld. Daarbij moet aangetekend worden dat de vergelijking wat betreft VO2max onder discussie staat: ten eerste omdat de referentiegegevens bestaan uit een relatief fitte subgroep van de algemene bevolking, en ten tweede vanwege de aannames die gemaakt moeten worden bij de berekening van VO2max uit de 10 meter Incremental shuttle walking test [26-28].

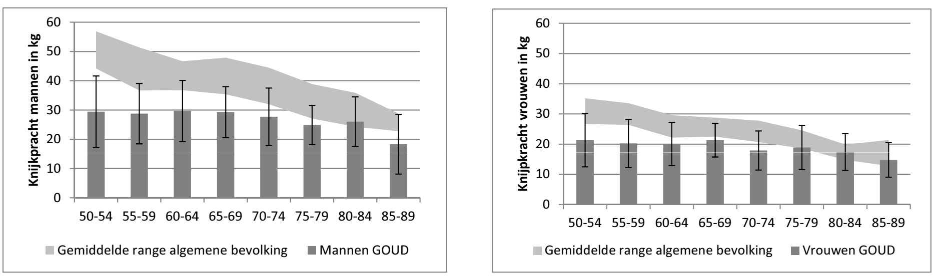
Als gevolg van deze lage fitheidsniveaus gaan de zelfstandigheid en gezondheid van ouderen met een verstandelijke beperking onnodig achteruit [29]. Het onderhouden en behouden van fitheid zou daarom een hogere prioriteit moeten krijgen in zorgbeleid en zorgpraktijk.



Figuur 2a en 2b Vergelijking resultaten comfortabele wandelsnelheid algemene bevolking (lichtgrijze band) en deelnemers GOUD (donkergrijze balken)



Figuur 3a en 3b Vergelijking resultaten beenkrachtuithoudingsvermogen algemene bevolking (lichtgrijze band) en deelnemers GOUD (donkergrijze balken)



Figuur 4a en 4b Vergelijking resultaten knijpkracht algemene bevolking (lichtgrijze band) en deelnemers GOUD (donkergrijze balken)

Hoofdstuk 9 Subgroepen met een lagere fitheid

Volledige artikel: Subgroups associated with lower physical fitness in older adults with ID: results of the HA-ID study. T.I. Hilgenkamp, R. van Wijck, H.M. Evenhuis *Ingediend*

Het is mogelijk dat bepaalde subgroepen binnen de groep ouderen met een verstandelijke beperking extra laag scoren op fitheid, en het is belangrijk deze subgroepen te identificeren, zodat hier specifieke bewegings- en fitheidsprogramma's voor ingezet kunnen worden. Voor elk van de 8 fitheidstesten die bij de 1050 GOUD-deelnemers zijn afgenomen, werd met multivariate regressie analyse onderzocht welke kenmerken samenhangen met een lage fitheidsscore.

De persoonlijke kenmerken die samenhangen met een lage fitheid zijn: oudere leeftijd, vrouwelijk geslacht, ernstige of zeer ernstige verstandelijke beperking en Down syndroom. Omdat dit onveranderlijke kenmerken zijn, moet met deze subgroepen rekening gehouden worden bij het opstellen van doelgroepspecifieke normwaarden. Kenmerken die samenhangen met een lage fitheid en die als aangrijpingspunt kunnen dienen bij de inzet van bewegings- en fitheidsprogramma's zijn: lopen met een hulpmiddel of in een rolstoel zitten, inactiviteit, en wonen op een locatie waar intensieve zorg geboden wordt. Omdat een lage fitheid wel in het bijzonder, maar niet uitsluítend in deze subgroepen wordt geconstateerd, blijft het belangrijk om fitheid te stimuleren in de gehele groep ouderen met een verstandelijke beperking.

DAGELIJKS FUNCTIONEREN VAN OUDEREN MET EEN VERSTANDELIJKE BEPERKING

Hoofdstuk 10 Samenhang van mobiliteit en mate van verstandelijke beperking met dagelijks functioneren

Volledige artikel: (Instrumental) activities of daily living in older adults with intellectual disability. T.I. Hilgenkamp, R. van Wijck, H.M. Evenhuis *Research in Developmental Disabilities* (2011) 32(5) 1977–198

Vaardigheden in het uitvoeren van Activiteiten van het Dagelijks Leven (ADL) zijn nodig om voor jezelf te kunnen zorgen (eten, toiletgebruik etc.), en vaardigheden in Instrumentele Activiteiten van het Dagelijks Leven (IADL) zijn nodig om zelfstandig te kunnen leven (huishouden doen, omgaan met geld etc.) [30-31]. Mensen met een verstandelijke beperking ervaren per definitie vaak al een afhankelijkheid van hun omgeving, juist vanwege hun verstandelijke beperking. Maar in hoeverre mobiliteit (d.w.z. of mensen zelfstandig kunnen lopen, een rollator nodig hebben of in een rolstoel zitten) daarnaast ook een rol speelt, is voor deze doelgroep niet bekend. Het dagelijks functioneren is bij 989 GOUD-deelnemers gemeten met de Barthel Index (vragenlijst voor ADL) [32] en de Lawton IADL scale (vragenlijst voor IADL) [33], ingevuld door de begeleiders. De ADL en IADL resultaten van deze groep waren vergelijkbaar met de resultaten van kwetsbare patientengroepen uit de algemene bevolking, zoals ouderen die na een ziekenhuisopname ontslagen worden [34-35]. De totaalscore op ADL bleek meer samen te hangen met mobiliteit dan met de mate van verstandelijke beperking, en bij de totaalscore op IADL was het andersom. Van de in totaal 18 onderdelen van deze twee vragenlijsten, hingen de scores van 11 onderdelen meer samen met de mobiliteit dan met de mate van verstandelijke beperking (zie Tabel 3). Deze uitkomsten onderstrepen het belang van het zo lang mogelijk onderhouden en stimuleren van het zelfstandig blijven lopen van ouderen met een verstandelijke beperking, om daarmee ook hun vaardigheden om dagelijks te kunnen functioneren te behouden. De twee gebruikte vragenlijsten bleken goed bruikbaar en worden aangeraden voor toekomstig gebruik in onderzoek en in de zorgpraktijk.

Tabel 3 Overzicht van de kenmerken die een significante bijdrage leveren aan de score op elk item van de vragenlijsten ('Ja'), met in donker grijs het kenmerk met de grootste bijdrage

	Significante bijdrage aan item?			
	Geslacht	Leeftijd	Mate van VB	Mobiliteit
Barthel Index totaalscore		Ja	Ja	Ja
1. Continentie darmen		Ja	Ja	Ja
2. Continentie blaas	Ja	Ja	Ja	Ja
3. Gezichtsverzorging	Ja		Ja	Ja
4. Toiletgebruik			Ja	Ja
5. Eten			Ja	Ja
6. Transfer bed-stoel			Ja	Ja
7. Lopen			Ja	Ja
8. Aankleden			Ja	Ja
9. Traplopen	Ja	Ja	Ja	Ja
10. Douchen		Ja	Ja	Ja
Lawton's IADL Scale totaalscore		Ja	Ja	Ja
1. Telefoon gebruiken			Ja	Ja
2. Boodschappen doen		Ja	Ja	Ja
3. Eten klaarmaken			Ja	Ja
5. De was doen	Ja		Ja	Ja
6. Vervoer			Ja	Ja
7. Omgaan met medicatie	Ja		Ja	Ja
8. Omgaan met geld			Ja	Ja

ALGEMENE DISCUSSIE

Hoofdstuk 11 Algemene discussie

Deze studie toont aan dat het overgrote deel van de ouderen met een verstandelijke beperking lichamelijk inactief en niet fit is. Dit kan leiden tot een verhoogd risico op onnodige afname van vaardigheden voor het dagelijks functioneren en op gezondheidsproblemen, en uiteindelijk tot hogere kosten van de gezondheidszorg voor deze groep [5]. De geselecteerde meetinstrumenten voor lichamelijke activiteit, fitheid, ADL en IADL kunnen breed ingezet worden voor het monitoren van ouderen met een verstandelijke beperking en voor evaluatie van effecten van behandelingen en bewegingsstimuleringsprogramma's.

Deze studie heeft ook methodologische beperkingen. De gemeten groep deelnemers was niet geheel representatief voor de populatie ouderen met een verstandelijke beperking, wat de generalisatie van deze resultaten naar de totale populatie ouderen met een verstandelijke beperking enigszins beperkt. Verder bracht het gebruik van de instrumenten, en het verzamelen van een grote set van gegevens bij deze doelgroep, verschillende beperkingen aan het licht, die nieuwe richtingen aangeven voor verder onderzoek.

De implicaties van de resultaten van dit onderzoek zijn groot. Door de geringe hoeveelheid lichamelijke activiteit en fitheid, is er een grote kans op onnodig vroegtijdige beperkingen in het dagelijks functioneren als mensen met een verstandelijke beperking ouder worden. Dit heeft niet alleen gevolgen voor de gemeentes, die een deel van deze doelgroep onder hun hoede krijgen de komende jaren, maar ook voor de organisaties die ondersteuning en zorg bieden.

Daarnaast zal, door de vergrijzing, het aantal medewerkers in de zorg de komende jaren afnemen, terwijl we zien dat het aantal ouderen met een verstandelijke beperking, die toenemend zorg nodig hebben, groeit. Ook worden ze steeds ouder, waardoor er een discrepantie zal ontstaan tussen zorgbehoefte en zorgaanbod. Om meer bewegen te stimuleren in deze doelgroep, is expertise nodig van bewegingsagogen wat betreft de keuze van activiteiten, motivatie en veiligheid. Daarnaast zijn bewegingswetenschappers nodig in deze zorg, om goed onderbouwde bewegingsprogramma's op te zetten, toe te passen in de dagelijkse zorgpraktijk en structureel te evalueren op effecten.

Aanbevelingen worden gedaan voor verder onderzoek naar de samenhang van lichamelijke activiteit en fitheid met andere kenmerken van gezondheid, en naar de consequenties op de lange termijn voor gezondheid en dagelijks functioneren van de inactiviteit en lage fitheid in deze groep. Fundamenteel onderzoek naar de mechanismen die de gezondheid beïnvloeden bij inactiviteit is ook nodig [36], net als onderzoek naar de fysieke prestaties van mensen met een verstandelijke beperking: zijn ze wel in staat om dezelfde scores te halen als mensen zonder een verstandelijke beperking?

Het is nodig dat er aangepaste programma's ontworpen en structureel geëvalueerd worden om lichamelijke activiteit te bevorderen en ondersteuning te bieden voor een actieve leefstijl, zodat inactiviteit drastisch verminderd wordt. Daarnaast moet ook het stimuleren van onderhoud, of zelfs opbouw, van fitheid hoger op de agende komen.

Hopelijk is dit proefschrift de aftrap van een groeiende hoeveelheid onderzoek naar de lichamelijke activiteit en fitheid bij mensen met een verstandelijke beperking, waarin zowel wetenschappelijke vragen als praktijkvragen een plek krijgen. Dit met als doel om niet alleen de individuele kwaliteit van leven van mensen met een verstandelijke beperking positief te beïnvloeden, maar ook de algemene kwaliteit en efficiëntie van zorg voor deze doelgroep, nu en in de toekomst.

Take home messages

- Aangepaste bewegingsstimuleringsprogramma's en ondersteuning voor een actieve leefstijl moeten beschikbaar zijn voor alle (oudere) volwassenen met een verstandelijke beperking.
- Het trainen van fitheid, zodat je niet afhankelijk(er) wordt bij het dagelijks functioneren, zou gestimuleerd moeten worden in alle (oudere) volwassenen met een verstandelijke beperking.
- Fitheidstesten moeten breed ingezet worden voor de gestructureerde evaluatie van beweegprogramma's en/of voor het monitoren van (subgroepen van) ouderen met een verstandelijke beperking.
- Bewegingsagogen en bewegingswetenschappers zijn beiden essentieel in de vormgeving van doelmatige bewegingsstimulering voor mensen met een verstandelijke beperking.

REFERENTIES

1. Temple V.A. and Stanish H.I., *Pedometer-measured physical activity of adults with intellectual disability: predicting weekly step counts.* Am J Intellect Dev Disabil, 2009. **114**(1): p. 15-22.
2. Clemes S.A. and Parker R.A., *Increasing our understanding of reactivity to pedometers in adults.* Med Sci Sports Exerc, 2009. **41**(3): p. 674-80.
3. Grant P.M., Dall P.M., Mitchell S.L., et al., *Activity-monitor accuracy in measuring step number and cadence in community-dwelling older adults.* J Aging Phys Act, 2008. **16**(2): p. 201-14.
4. Crouter S.E., Schneider P.L., and Bassett D.R., Jr., *Spring-levered versus piezo-electric pedometer accuracy in overweight and obese adults.* Med Sci Sports Exerc, 2005. **37**(10): p. 1673-9.
5. DHHS, *Physical Activity Guidelines Advisory Committee Report*. 2008, U.S. Department of Health and Human Services, : Rockville (MD).
6. Marshall S.J., Levy S.S., Tudor-Locke C.E., et al., *Translating physical activity recommendations into a pedometer-based step goal: 3000 steps in 30 minutes.* Am J Prev Med, 2009. **36**(5): p. 410-5.
7. Rowe D.A., Kemble C.D., Robinson T.S., et al., *Daily walking in older adults: day-to-day variability and criterion-referenced validity of total daily step counts.* J Phys Act Health, 2007. **4**(4): p. 434-46.
8. Tudor-Locke C., Hatano Y., Pangrazi R.P., et al., *Revisiting "how many steps are enough?".* Med Sci Sports Exerc, 2008. **40**(7 Suppl): p. S537-43.
9. Bouchard C., Shephard R.J., and Stephens T., *Physical activity, fitness, and health: International proceedings en consensus statement*. 1994, Champaign: Human Kinetics Publishers.
10. *Physical Activity and Health. A report of the Surgeon General. Older Adults*, US Department of Health and Human Services, Editor. 1996.
11. Bouchard C. and Shephard R.J., *Physical Activity, Fitness, and Health: The model and key concepts*, in *Physical Activity, Fitness and Health. International Proceedings and Consensus Statement*. 1994, Human Kinetics Publishers: Champaign.
12. ACSM, *ACSM's Health-Related Physical Fitness Assessment Manual* 1st ed, ed. G.B. Dwyer and S.E. Davis. 2005, Baltimore, Lippincott: Williams & Wilkins. 180 p.
13. Mathiowetz V., Volland G., Kashman N., et al., *Adult norms for the Box and Block Test of manual dexterity.* Am J Occup Ther, 1985. **39**(6): p. 386-91.
14. Dunn J.M., *Reliability of selected psychomotor measures with mentally retarded adult males.* Percept Mot Skills, 1978. **46**(1): p. 295-301.
15. Berg K.O., Wood-Dauphinee S.L., Williams J.I., et al., *Measuring balance in the elderly: validation of an instrument.* Can J Public Health, 1992. **83 Suppl 2**: p. S7-11.
16. Bohannon R.W., *Comfortable and maximum walking speed of adults aged 20-79 years: reference values and determinants.* Age Ageing, 1997. **26**(1): p. 15-9.
17. Rikli R.E. and Jones C.J., *Development and validation of a functional fitness test for community-residing older adults.* J Aging Phys Act, 1999. **7**: p. 129-161.
18. Mathiowetz V., Kashman N., Volland G., et al., *Grip and pinch strength: normative data for adults.* Arch Phys Med Rehabil, 1985. **66**(2): p. 69-74.
19. Singh S.J., Morgan M.D., Scott S., et al., *Development of a shuttle walking test of disability in patients with chronic airways obstruction*. Thorax, 1992. **47**(12): p. 1019-24.
20. Hui S.S. and Yuen P.Y., *Validity of the modified back-saver sit-and-reach test: a comparison with other protocols.* Med Sci Sports Exerc, 2000. **32**(9): p. 1655-9.
21. Hilgenkamp T.I., van Wijck R., and Evenhuis H.M., *Physical fitness in older people with ID-Concept and measuring instruments: a review.* Res Dev Disabil, 2010. **31**(5): p. 1027-38.

22. Bohannon R.W. and Williams Andrews A., *Normal walking speed: a descriptive meta-analysis.* Physiotherapy, 2011. **97**(3): p. 182-9.
23. Bohannon R.W., Bear-Lehman J., Desrosiers J., et al., *Average grip strength: a meta-analysis of data obtained with a Jamar dynamometer from individuals 75 years or more of age.* J Geriatr Phys Ther, 2007. **30**(1): p. 28-30.
24. Bohannon R.W., Peolsson A., Massy-Westropp N., et al., *Reference values for adult grip strength measured with a Jamar dynamometer: a descriptive meta-analysis.* Physiotherapy, 2006. **92**(1): p. 11-15.
25. Rikli R.E. and Jones J., *Functional fitness normative scores for community-residing older adults, ages 60-94.* J Aging Phys Act, 1999. **7**: p. 162-181.
26. Singh S.J., Morgan M.D., Hardman A.E., et al., *Comparison of oxygen uptake during a conventional treadmill test and the shuttle walking test in chronic airflow limitation.* Eur Respir J, 1994. **7**(11): p. 2016-20.
27. ACSM, *ACSM's Guidelines for exercise testing and prescription*. 8th edition ed. 2010, Philadelphia, PA: Lippincott Williams & Wilkins.
28. Fernhall B., McCubbin J.A., Pitetti K.H., et al., *Prediction of maximal heart rate in individuals with mental retardation.* Med Sci Sports Exerc, 2001. **33**(10): p. 1655-60.
29. Brach J.S., Simonsick E.M., Kritchevsky S., et al., *The association between physical function and lifestyle activity and exercise in the health, aging and body composition study.* J Am Geriatr Soc, 2004. **52**(4): p. 502-9.
30. Ward G., Jagger C., and Harper W., *A review of instrumental ADL assessments for use with elderly people.* Reviews in clinical gerontology, 1998(8): p. 65-71.
31. Kane R.A. and Kane R.L., *Assessment of older people: self maintaining and instrumental activities of daily living.* 1981, Toronto: Lexington Books.
32. Mahoney F.I. and Barthel D.W., *Functional Evaluation: the Barthel Index.* Md State Med J, 1965. **14**: p. 61-5.
33. Lawton M.P. and Brody E.M., *Assessment of older people: self-maintaining and instrumental activities of daily living.* Gerontologist, 1969. **9**(3): p. 179-86.
34. Guerini F., Frisoni G.B., Morghen S., et al., *Clinical instability as a predictor of negative outcomes among elderly patients admitted to a rehabilitation ward.* J Am Med Dir Assoc, 2010. **11**(6): p. 443-8.
35. Luk J.K., Chiu P.K., and Chu L.W., *Rehabilitation of older Chinese patients with different cognitive functions: how do they differ in outcome?* Arch Phys Med Rehabil, 2008. **89**(9): p. 1714-9.
36. Vis J.C., de Bruin-Bon R.H., Bouma B.J., et al., *'The sedentary heart': Physical inactivity is associated with cardiac atrophy in adults with an intellectual disability.* Int J Cardiol, 2011.

Dankwoord

DANKWOORD

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Dank natuurlijk ook aan de mede-onderzoekers van het eerste uur: Heidi, Luc en Marieke. Hoe hadden we het zonder elkaar moeten doen! Wat ben ik ongelooflijk gelukkig geweest jullie te treffen als mede-onderzoekers in dit project, ik had me geen beter team kunnen voorstellen om in te mogen werken. Heidi, naast jouw ongelooflijke deskundigheid en genuanceerdheid in je inhoudelijke vakgebied, ben je ook een kei in methodologie en statistiek, en ben je voor mij en de andere collega's vaak een steun en toeverlaat geweest bij lastige vraagstukken. Bovenal ben je echt een lieve, fijne, open collega en vriendin, met wie ik alle vragen, klaagmomenten, dipjes en successen heb mogen delen afgelopen vier jaar, en hopelijk nog een poos langer. Luc, grote waardering heb ik voor jouw betrokkenheid en deskundigheid als Arts voor Verstandelijk Gehandicapten, en hoe je professionele verantwoordelijkheid combineert met een toegankelijke vriendelijkheid en sensitiviteit. Schijnbaar gemakkelijk en relaxed weet jij de moeilijkste problemen tot een goed einde te brengen, en daarin ben je een lichtend voorbeeld in onderzoek en zorg. Voor mij ben jij de lijm van ons onderzoeksteam, waar ik altijd terecht kon voor vragen, problemen of twijfels, en die altijd klaar stond met een grapje of positief woord, waardoor ik het weer zag zitten. Ik hoop dat ook voor jou te kunnen doen tijdens jouw laatste loodjes! En dan Marieke, jij hebt mij regelmatig aan het denken gezet over mijn onderwerpen of aanpak, door jouw grondigheid, volledigheid en goed doordachte keuzes. Je denkt net zo gemakkelijk overstijgend over de lijn waar we mee bezig zijn als over de kleinste details in de uitvoering van je project, en alles met groot gevoel voor nuance en de verschillende kanten van een verhaal. Je persoonlijke betrokkenheid bij medewerkers en cliënten is inspirerend voor elk onderzoek in de zorg, en ik hoop nog vaak met je te sparren over toekomstige projecten!

Ook de andere onderzoekers binnen de Leerstoel Geneeskunde voor Verstandelijk Gehandicapten (Michael, Ellen, Josje, Sandra, Sonja, Fleur, en van wat eerder Ymie, Rob en natuurlijk Corine) wil ik hartelijk bedanken voor hun enthousiasme, humor, support en het meedenken over inhoud en uitvoering: door jullie en met jullie is dit onderzoek gelukt, en heb ik ontzettend genoten van de afgelopen vier jaar! Dank ook aan de onderzoekers van Huisartsengeneeskunde voor de kritische vragen bij de werkbesprekingen en de gezelligheid tijdens de lunch en uitjes.

Gerdien, Caroline, Ellen, Ruben, Debora, Petra en de korter aanwezige studenten, bedankt voor jullie inzet en enthousiasme voor dit onderzoek, jullie brachten leven in de brouwerij en hebben met jullie kritische vragen en afzonderlijke vraagstellingen een grote bijdrage geleverd aan de kwaliteit van GOUD!

En last but not least wil ik ook mijn vrienden en familie bedanken. Lieve vriendinnen, jullie hebben mij altijd gesteund in mijn keuzes, en tijd gemaakt om daar met mij over te sparren, en ondanks de soms overheersende drukte en grotere afstand zijn jullie onverminderd vriendinnen gebleven, waarvoor mijn grote dank!

Lieve paps en mams, door jullie vertrouwen in mij en jullie ondersteuning in de afgelopen 30 jaar heb ik de beslissingen durven en kunnen maken die ervoor hebben gezorgd dat ik hier nu sta! Ik ben dankbaar voor alles wat jullie mij gegeven hebben en voor mij mogelijk gemaakt hebben, maar ik ben vooral dankbaar dat ik dit moment gewoon met jullie allebei kan delen. Ik hoop dat er nog 60 jaar met mooie momenten samen voor de deur staan, ik hou ook van jullie! Hannes en Florien, ook jullie bedankt voor het meedenken, de steun, de gezelligheid en leuke momenten in de verschillende thuizen! En dan Radzies, mijn grote lieverd, jij hebt het wel het meeste te verduren gehad in de laatste periode, maar je was altijd bereid te luisteren en met me mee te denken, waardoor ik steeds nieuwe invalshoeken mee kon nemen in mijn keuzes of interpretaties. Dankjewel voor je geduld, je ondersteuning en je liefde.

Curriculum Vitae

CURRICULUM VITAE

Thessa Irena Maria Hilgenkamp is op 3 januari 1982 geboren te Dalfsen. Na het afronden van het gymnasiumdiploma aan het Gymnasium Celeanum in Zwolle in 2000, startte zij in datzelfde jaar met de opleiding Bewegingswetenschappen aan de Rijksuniversiteit Groningen. Hoewel zij de afstuurrichting 'Arbeid' heeft gevolgd, ging haar afstudeeronderzoek over het objectief meten van fysieke veranderingen die duiden op een grotere mate van ontspanning, tijdens een driedaagse leefstijltraining voor mensen met aspecifieke klachten als vermoeidheid en hoofdpijn. Na een wereldreis van vijf maanden na haar afstuderen, kon zij bij haar voormalige afstudeerdocent starten als onderzoeksassistent op een nieuw onderzoek 'Actigrafie en Alzheimer bij mensen met Down syndroom'.

Door de positieve ervaringen met onderzoek bij mensen met verstandelijke beperkingen en het afnemen van fitheidstesten bij deze groep, solliciteerde zij eind 2007 voor een promotieplek bij het onderzoek 'Gezond ouder met een verstandelijke beperking (GOUD). Dit onderzoek, met ondersteuning van een subsidie van ZonMw, werd opgezet vanuit een consortium bestaande uit de Leerstoel Geneeskunde voor Verstandelijk Gehandicapten van het Erasmus Medisch Centrum te Rotterdam en drie zorgaanbieders (Abrona, Amarant en Ipse de Bruggen), en hierbij was ook Bewegingswetenschappen Groningen betrokken. Vervolgens verrichtte zij van 1 januari 2008 tot aan het einde van 2011 werkzaamheden voor het promotietraject dat beschreven is in dit proefschrift.

Per 1 januari 2012 is zij deels werkzaam als projectleider om zowel bewegen als het benutten van wetenschap te stimuleren bij zorgaanbieder Abrona, en deels als postdoc bij de Leerstoel Geneeskunde voor Verstandelijk Gehandicapten.

PhD Portfolio

Erasmus MC
Universitair Medisch Centrum Rotterdam

PHD PORTFOLIO

SUMMARY OF PHD TRAINING AND TEACHING

Name PhD student: drs. Thessa Hilgenkamp Erasmus MC Department: Intellectual Disability Medicine, Department of General Practice	PhD period: 2008-2011 Promotor(s): Prof. dr. H.M. Evenhuis Supervisor: Prof. dr. H.M. Evenhuis

1. PhD training		
	Year	**Workload (Hours/ ECTS)**
General courses		
- Project management in health care – PRINCE2	2011	70
- BROK ('Basiscursus Regelgeving Klinisch Onderzoek'	2011	1
- Biomedical English Writing and Communication	2008	4
Specific courses (NIHES Research School)		
- Epidemiologic Data Analysis	2011	0.7
- Regression Analysis	2010	1.9
- Regression Analysis for Clinicians	2010	1.9
- Basic principles of Epidemiology	2009	0.7
- Introduction to Data-analysis	2009	1.0
Presentations		
- Seminar Dutch Association of Intellectual Disability Physiotherapists (oral presentation)	2011	1.0
- Seminar Dutch Association of Intellectual Disability Physiotherapists (2 oral presentations)	2010	1.0
- Symposium opening Health centre Abrona (oral presentation)	2010	1.0
(Inter)national conferences		
- Dutch Congress 'Focus on Research' (oral presentation)	2011	2.0
- 7th Congress of EUGMS (poster presentation)	2011	1.0
- 3rd European congress IASSID, Rome (2 oral presentation)	2010	3.0
- Roundtable SIRGAID IASSID, Prato (oral presentation)	2010	2.0
- Roundtable SIRGAID IASSID, Edinburgh (poster presentation	2009	1.0
2. Teaching		
Lecturing		
- Guest lecturer Human Movement Sciences,UMCG (3 lectures)	2008-2010	18
- Guest lecturer Intellectual Disability Medice, Erasmus MC (2 lectures)	2009-2011	12
Supervising Master's theses		
- 4 Master Medical Science student research projects	2008-2011	320
- 2 Master Physiotherapy student research projects	2008-2011	80
Other		
- Advisor other student projects	2008-2010	24
- Two day course Physical fitness tests for physiotherapists 5x	2009-2010	120

List of publications

LIST OF PUBLICATIONS

INTERNATIONAL PUBLICATIONS (PEER REVIEWED JOURNALS)

1. Subgroups associated with lower physical fitness in older adults with ID: results of the HA-ID study. **T.I. Hilgenkamp,** R. van Wijck, H.M. Evenhuis *Submitted*
2. Low physical fitness levels in older adults with ID. Results of the HA-ID study. **T.I. Hilgenkamp,** R. van Wijck, H.M. Evenhuis *Research in Developmental Disabilities (2012) 33(4) 1048–1058 (Rank: 1/36 Special Education,1/62 Rehabilitation)*
3. Feasibility of eight physical fitness tests in 1050 older adults with ID: results of the HA-ID study. **T.I. Hilgenkamp,** R. van Wijck, H.M. Evenhuis *Submitted*
4. Measuring physical activity with pedometers in older adults with ID: reactivity and number of days. **T.I. Hilgenkamp,** R. van Wijck, H.M. Evenhuis *Intellectual and Developmental Disabilities:* in press (Rank: 14/36 Special Education, 23/62 Rehabilitation)
5. Feasibility and reliability of tests for measuring physical fitness in older adults with intellectual disabilities. A pilot study. **T.I. Hilgenkamp,** R. van Wijck, H.M. Evenhuis *Journal of Intellectual & Developmental Disability:* in press (Rank: 12/36 Special Education, 22/62 Rehabilitation)
6. Extremely low physical activity levels in older adults with intellectual disabilities. **T.I. Hilgenkamp,** R. van Wijck, H.M. Evenhuis *Research in Developmental Disabilities* (2012) 33(2) 477-483 (Rank: 1/36 Special Education,1/62 Rehabilitation)
7. Overweight and obesity in older people with intellectual disability. C.F. de Winter, L.P. Bastiaanse, **T.I. Hilgenkamp**, H.M. Evenhuis, M.A. Echteld *Research in Developmental Disabilities* (2012) 33 (2) 398-405 (Rank: 1/36 Special Education,1/62 Rehabilitation)
8. (Instrumental) activities of daily living in older adults with intellectual disability. **T.I. Hilgenkamp,** R. van Wijck, H.M. Evenhuis *Research in Developmental Disabilities* (2011) 32(5) 1977–198 (Rank: 1/36 Special Education,1/62 Rehabilitation)
9. Exploring the use of actigraphy to investigate sleep problems in older people with intellectual disability. E. van Dijk, **T.I. Hilgenkamp**, H.E. Evenhuis, M.A. Echteld *Journal of Intellectual Disability Research* (2011) Epub ahead of print (Rank: 9/36 Special Education,15/62 Rehabilitation)
10. Study healthy ageing and intellectual disabilities: Recruitment and design. **T.I. Hilgenkamp**, L.P. Bastiaanse, H. Hermans, C. Penning, R. van Wijck, H.M. Evenhuis *Research in Developmental Disabilities* (2011) 32(3):1097-106 (Rank: 1/36 Special Education,1/62 Rehabilitation)

11. Physical fitness in older people with ID—Concept and measuring instruments: A review. **T.I. Hilgenkamp,** R. van Wijck, H.M. Evenhuis *Research in Developmental Disabilities (2010)* 31(5) 1027-1038 (Rank: 1/36 Special Education,1/62 Rehabilitation)

CONFERENCE PROCEEDINGS

1. Physical activity in older adults with intellectual disabilities. **T. Hilgenkamp**, R. van Wijck, H. Evenhuis *European Geriatric Medicine* (2011) 2S 90-90 Meeting abstract 7th Congress of the EUGMS
2. Feasibility and reliability of tests to measure physical fitness in older adults with ID. **T. Hilgenkamp**, R. van Wijck, C. Penning, H. Evenhuis *Journal of applied research in intellectual disabilities* (2010) 23(5) 412-412 Meeting abstract 3rd European congress IASSID (Rank: 28/50 Educational psychology, 33/62 Rehabilitation)
3. Preliminary results of physical fitness assessment in older adults with ID. **T. Hilgenkamp**, R. van Wijck, H. Evenhuis *Journal of applied research in intellectual disabilities* (2010) 23(5) 412-412 Meeting abstract 3rd European congress IASSID (Rank: 28/50 Educational psychology, 33/62 Rehabilitation)

Het onderzoek *'Gezond ouder met een verstandelijke beperking (GOUD)'* is mogelijk gemaakt door:

ZonMw

Erasmus MC
Universitair Medisch Centrum Rotterdam

rijksuniversiteit groningen

Abrona
met elkaar | voor elkaar

Amarant

IPSE DE BRUGGEN

Het aantal ouderen met een verstandelijke beperking is de afgelopen jaren gegroeid door de vergrijzing. Daarnaast worden ze steeds ouder doordat de zorg voor deze groep steeds beter wordt. Toch is er nog maar weinig bekend over de gezondheid van ouderen met een verstandelijke beperking, over mogelijke gezondheidsrisico's die ze lopen in dit verouderingsproces, en over de rol van lichamelijke activiteit en fitheid hierin. Om hier meer over te weten te komen, is het nodig eerst te weten wat de huidige stand van zaken is. Dit proefschrift beschrijft het proces dat is doorlopen om hier antwoord op te geven. Van het stellen van de vraag, het zoeken naar geschikte meetinstrumenten, het testen van deze meetinstrumenten, tot het antwoord op de vraag: hoe actief en fit zijn ouderen met een verstandelijke beperking eigenlijk?