19.6% (142 participants) fell one or two times and 5.9% (43 participants) fell more than two times. The personal characteristics and medical information are shown in Table 1, for the three categories of fallers. Due to missing data, the number of participants differed per variable. Fallers had more often mobility impairments (χ^2 [4, $n = 694$] = 17.26, $p = 0.002$) and epilepsy (χ^2 [2, $n = 636$] = 17.27, $p < 0.001$).

Falls at baseline was significantly correlated to falls at follow-up ($r_s = 0.13$, $p < 0.001$). At baseline, 22.6% experienced at least one fall in three months. Compared to falls at baseline, 107 participants (15.5%) fell more often at follow-up and 94 participants (13.6 %) fell less often at follow-up. The remaining 488 participants (70.8%) were in the same category of falls at follow-up as they were at baseline.

The results of the baseline physical fitness assessment for the three categories of fallers are presented in the final part of Table 1. Because not all participants performed all physical fitness tests the number of participants differed across the tests. Comfortable gait speed (GSC) (F [2, 503] = 5.71, $p = 0.004$) was significantly different across the three categories. Post hoc tests revealed that GSC was significantly lower in participants that fell three times or more than in participants that did not fall ($p = 0.005$).

Predictive value of physical fitness for falls

Simple logistic regression analyses showed that a slower comfortable gait speed was a significant predictor for falls, with an odds ratio of 0.47, 95% CI [0.24, 0.95] (model 1, Table 2). None of the other physical fitness components significantly predicted falls.

Older age ($r_s = 0.10$, $p = 0.008$), epilepsy ($r_s = 0.13$, $p = 0.001$), polypharmacy ($r_s = 0.11$, $p = 0.005$) and falls at baseline ($r_s = 0.31$, $p < 0.001$) were significantly positively correlated with falls at follow-up. Having DS ($r_s = -0.12$, $p = 0.004$) was significantly negatively correlated with falls at follow-up. Together with gender, these characteristics were entered as confounders in the multiple logistic regression models. Multiple logistic regression analyses revealed that gait speed did not significantly add to the prediction of falls after adjustments for confounders (model 2, Table 2). Falls at baseline was a significant predictor for falls. Not having DS was a significant predictor in the regression models with comfortable walking speed and muscular endurance as physical fitness component. The Cox & Snell explained variances of the final multiple logistic regression models ranged from 6.8% to 11.5%, and the Nagelkerke explained variance ranged from 10.4% to 17.3% (Table 2).

DISCUSSION

We assessed the predictive value of balance, gait speed, strength, and muscular endurance for falls, over a 3-year period, in 724 older adults with intellectual disabilities (ID).

Falls at follow-up occurred in 25.5% of the participants. Gait speed was a significant predictor for falls, however, after adjustment for confounders, gait speed did not significantly add to the prediction of falls. Only falls at baseline and not having Down syndrome (DS) were significant predictors for falls.

One-fourth of the participants experienced a fall in the three months prior to the follow-up fall assessment, of whom 19.6% fell one or two times and 5.9% fell three times or more. Other studies regarding falls in the population of ID found percentages of fallers, ranging from 25% to 46% during one year [1, 3, 5, 9] and 70% during five years [48].

Table 2. Results of the simple (model 1) and multiple (model 2) logistic regression analyses for the predictive value of physical fitness for falls.

		B (SE)	*Exp(B)* [95% CI]	Model characteristics
Balance				
Model 1				
	BBS	-0.01 (0.01)	0.10 [0.97, 1.02]	*n* = 271, C&S R^2 = 0.001,
	Constant	-1.00 (0.62)	0.37	Nagelkerke R^2 = 0.001, χ^2 = 0.145
Model 2				
Block 1	Age	0.01 (0.02)	1.01 [0.97, 1.06]	*n* = 271, C&S R^2 = 0.068,
	Female	0.30 (0.31)	1.35 [0.73, 2.46]	Nagelkerke R^2 = 0.104, χ^2 = 19.21**
	Down syndrome	-0.25 (0.54)	0.78 [0.27, 2.25]	
	Epilepsy	0.58 (0.41)	1.79 [0.80, 4.03]	
	Polypharmacy	0.18 (0.32)	1.20 [0.64, 2.23]	
	Falls at baseline	1.15 (0.34)**	3.14 [1.63, 6.07]	
Block 2	BBS	0.01 (0.01)	1.01 [0.98, 1.04]	
	Constant	-3.00 (1.64)	0.05	
Comfortable gait speed				
Model 1				
	GSC	-0.75 (0.36)*	0.47 [0.24, 0.95]	*n* = 409, C&S R^2 = 0.011,
	Constant	-0.50 (0.34)	0.60	Nagelkerke R^2 = 0.016, χ^2 = 4.47*
Model 2				
Block 1	Age	-0.01 (0.02)	0.99 [0.96, 1.03]	*n* = 409, C&S R^2 = 0.115,
	Female	0.09 (0.26)	1.09 [0.66, 1.80]	Nagelkerke R^2 = 0.173, χ^2 = 49.86**
	Down syndrome	-1.38 (0.51)**	0.25 [0.09, 0.69]	
	Epilepsy	0.51 (0.32)	1.66 [0.88, 3.12]	
	Polypharmacy	0.24 (0.27)	1.27 [0.75, 2.14]	
	Falls at baseline	1.32 (0.28)**	3.73 [2.14, 6.40]	
Block 2	GSC	-0.49 (0.41)	0.62 [0.28, 1.37]	
	Constant	-0.57 (1.30)	0.56	

		B (SE)	*Exp(B)* [95% CI]	Model characteristics
Muscular endurance				
Model 1				
	30sCS	-0.01 (0.04)	0.99 [0.91, 1.08]	*n* = 301, C&S $R^2 < 0.001$,
	Constant	-1.16 (0.42)**	0.31	Nagelkerke $R^2 < 0.001$, $\chi^2 = 0.05$
Model 2				
Block 1	Age	-0.001 (0.02)	1.00 [0.96, 1.04]	*n* = 301, C&S $R^2 = 0.096$,
	Female	0.11 (0.30)	1.12 [0.63, 2.01]	Nagelkerke $R^2 = 0.146$, $\chi^2 = 30.29$**
	Down syndrome	-1.26 (0.58)*	0.28 [0.09, 0.89]	
	Epilepsy	0.29 (0.40)	1.33 [0.61, 2.90]	
	Polypharmacy	0.19 (0.31)	1.20 [0.65, 2.22]	
	Falls at baseline	1.43 (0.33)**	4.17 [2.17, 8.01]	
Block 2	30sCS	-0.01 (0.05)	0.99 [0.91, 1.09]	
	Constant	-1.53 (1.49)	0.22	
Grip strength				
Model 1				
	GS	-0.01 (0.01)	0.99 [0.96, 1.01]	*n* = 405, C&S $R^2 = 0.003$,
	Constant	-0.92 (0.30)**	0.40	Nagelkerke $R^2 = 0.004$, $\chi^2 = 1.04$
Model 2				
Block 1	Age	0.00 (0.02)	1.00 [0.97, 1.04]	*n* = 405, C&S $R^2 = 0.076$,
	Female	0.05 (0.28)	1.05 [0.61, 1.81]	Nagelkerke $R^2 = 0.116$, $\chi^2 = 32.12$**
	Down syndrome	-0.55 (0.44)	0.58 [0.25, 1.36]	
	Epilepsy	0.50 (0.32)	1.65 [0.89, 3.07]	
	Polypharmacy	0.15 (0.27)	1.16 [0.69, 1.96]	
	Falls at baseline	1.21 (0.27)**	3.34 [1.96, 5.70]	
Block 2	GS	-0.01 (0.02)	0.99 [0.96, 1.02]	
	Constant	-1.46 (1.21)	0.23	

Model 1: simple logistic regression excluding potential confounders; model 2: multiple logistic regression including potential confounders.
Age (in years), gender (male = 0, female = 1), Down syndrome (no = 0, yes = 1), epilepsy (no = 0, yes = 1), polypharmacy (no = 0, yes = 1), falls at baseline (non-faller = 0, faller = 1).
B = unstandardized coefficient; *SE* = standard error; *Exp(B)* = odds ratio; CI = confidence interval; R^2 = explained variance; C&S R^2 = Cox & Snell explained variance; χ^2 = model chi-square statistic; BBS = Berg Balance Scale; GSC = comfortable gait speed; 30sCS = 30s Chair stand; GS = grip strength.
* $p < 0.05$
** $p < 0.01$

Our lower percentage of fallers may be due to the shorter time period and/or a possible underestimation due to retrospective data collection [49].

Participants with DS fell less. This is in line with the results of Finlayson et al. (2010), who found a lower risk for falls and related injuries for people with DS. A possible explanation may be the stability-enhancing gait pattern of people with DS, implying an effective strategy. However, we only found this result in the regression models with comfortable walking speed and muscular endurance as the physical fitness component. This limits the generalizability of this result to other subgroups than those performing these tests.

In our study, falls at baseline were an important predictor for future falls. This has also been found to be an important predictor for falls in the general population [12, 14, 17, 18]. It is therefore important to provide fall prevention programs for people who have already fallen once, to limit the risk of recurrent falls. Unfortunately, to date no fall prevention guidelines are available for the population of adults with ID. However, a recent study showed that a 10-session obstacle exercise training was effective in reducing the number of falls, alongside with improvements in balance, gait capacity and speed, in adults with mild to profound ID with a high fall risk [50]. This result implies that, although physical fitness was not predictive for falls in this study, it can be effective in reducing fall risk. More research is needed to establish the beneficial effects of exercise training on falls and develop fall prevention guidelines for adults with ID.

Gait speed was lowest in participants who fell three times or more at follow-up. However, gait speed did not remain a significant predictor after correcting for confounders. Therefore, the predictive value of physical fitness for falls found in the general population [12-18], and the relation between physical fitness and falls found in retrospective studies with people with ID [2, 3, 6], was not confirmed in our study. This result is in line with the results of Enkelaar et al. (2013b), who also found that balance and gait measures (Berg Balance Scale, Timed up and go test, Functional reach, Single leg stance, Ten meter walking test, Comfortable gait speed) did not predict falls in older adults with ID. However, in the study of Enkelaar et al. (2013b), the participants who fell indoors were significantly older and performed significantly worse on the balance and gait tests than those who fell outdoors.

Possible explanations for the limited predictive value of physical fitness for falls are described below. In order to find a predictive value of physical fitness for falls, the number of falls should increase with age along with a decrease in physical fitness. We found that the number of fallers did not increase with age. In addition, physical fitness of people with ID seems to be low across the lifespan. In previous studies, we found that the balance, strength, muscular endurance, and gait speed of older adults with ID were comparable to, or even worse than, that of age groups 20 to 30 years older in the general population [10, 11]. Low fitness levels are seen at younger ages as well [51-53]. Due to these lifelong low physical fitness levels, the age-related decrease in physical fitness and (related) increase in falls may be less pronounced in older adults with ID than in the general population. This may limit the predictive value of physical fitness for falls in this population, which is in line with our results. Nevertheless, an exercise program may reduce the risk of falling.

In addition, the predictive value of physical fitness for falls may be limited in people with ID because they may have developed compensation strategies to deal with their low physical fitness. For example, it has been found that people with DS and Williams syndrome have slower gait speed, shorter step and stride lengths, wider base of support, and a longer stance and double support phase than people with normal intelligence, which may be a compensatory strategy to maintain stability and postural control [54-57]. Further research is needed to establish the relationship between these gait patterns of people with ID and falls. This would provide information about the effectiveness of these compensation strategies and identify areas for fall prevention.

This study had some limitations. First, our power to find significant effects of personal, medical, and physical fitness factors in predicting falls may have been limited because the number of participants who fell three times or more at follow-up was relatively small. This could be an alternative explanation for the fact that risk factors for falls found in other studies with people with ID, were not identified as risk factors in our study. Second, it was recommended in previous studies to make a distinction between fallers and recurrent fallers [46], while this study combined both fallers and recurrent fallers in one group (one or two time fallers). Unfortunately, we could not split this group in to fallers and recurrent fallers due to the structure of the questionnaire used in this study. Third, we retrospectively collected falls, which is less reliable than prospectively monitoring falls [49]. Last, because not all participants performed all physical fitness tests, the selection of participants differed for each regression analysis (with that specific test as independent variable). The selection of participants that performed the physical fitness tests was the functionally more able part of the study sample [10, 11]. This limits the generalizability of our results to the entire population of older adults with ID. However, to keep our sample size as large as possible, we chose to not only select those participants who performed all tests.

In conclusion, we found that balance, comfortable gait speed, strength, and muscular endurance were not significant predictors for falls in older adults with ID. Non age-related increase in falls, extremely low physical fitness levels, and possible strategies to compensate for these low levels, may explain the limited predictive value of physical fitness found in this study. The low explained variance of our regression models show that more research is needed regarding the role of physical fitness and other risk factors for falls. This will help in developing fall prevention programs for older adults with ID.

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Chapter 7

Physical fitness is predictive for a decline in daily functioning in older adults with intellectual disabilities: Results of the HA-ID study

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ABSTRACT

A high incidence of limitations in daily functioning is seen in older adults with intellectual disabilities (ID), along with poor physical fitness levels. The aim of this study was to assess the predictive value of physical fitness for daily functioning after 3 years, in 602 older adults with borderline to profound ID (≥ 50 years). At baseline, physical fitness levels and daily functioning (operationalized as basic activities of daily living [ADL] and mobility) were assessed. After 3 years, the measurements of daily functioning were repeated. At follow-up, 12.6% of the participants were completely independent in ADL and 48.5% had no mobility limitations. More than half of the participants (54.8%) declined in their ability to perform ADL and 37.5% declined in their mobility. Manual dexterity, visual reaction time, balance, comfortable and fast gait speed, muscular endurance, and cardiorespiratory fitness were significant predictors for a decline in ADL. For a decline in mobility, manual dexterity, balance, comfortable and fast walking speed, grip strength, muscular endurance, and cardiorespiratory fitness were all significant predictors. This proves the predictive validity of these physical fitness tests for daily functioning and stresses the importance of using physical fitness tests and implementing physical fitness enhancing programs in the care for older adults with ID.

INTRODUCTION

The life expectancy of people with intellectual disabilities (ID) is increasing [1, 2]. With increasing age, daily functioning has been found to decrease in adults with ID [3, 4]. In older adults with ID (≥ 50 years), a high incidence (86%) of limitations in performing basic activities of daily living (ADL) was seen [5].

One's ability to perform ADL determines the level of independence and need for care, and is an important predictor for hospital admission and mortality in older adults of the general population [6, 7]. Loss of independence affects quality of life, and increases the burden placed on family, caregivers, and health care facilities [8, 9]. Maintaining as much independence in daily functioning as possible is especially important for people with ID, who already experience a lifelong dependency on others due to their cognitive impairment and other comorbidities.

The ability to perform ADL is, amongst other things, affected by one's health condition (disorders or diseases). Physical fitness affects one's health condition, and thereby indirectly affects daily functioning [10, 11]. For example, cardiovascular diseases can lead to limitations in performing ADL [11, 12], and cardiorespiratory fitness is an important risk factor for cardiovascular diseases [12, 13].

Next to this indirect effect of physical fitness on daily functioning, physical fitness also directly influences daily functioning because a certain level of physical fitness is required to perform ADL [11, 14-18]. For example, a maximal oxygen uptake below 20 $ml{\cdot}kg^{-1}{\cdot}min^{-1}$ and leg strength below 2.5 $N{\cdot}m$ / ($kg{\cdot}m^{-1}$) have been associated with an increased risk of limitations in ADL [17]. In the same line, physical fitness determines one's ability to stand and walk. For example, a normal gait requires the ability to safely maintain an upright posture, bear bodyweight, and propel forward while determining one's position in space [19, 20]. This requires adequate balance, strength, muscular endurance, gait speed, and reaction time. Cardiorespiratory fitness is important to keep walking for a certain amount of time [19]. In this way, high physical fitness levels can be protective against developing dependency in daily functioning by providing enough physical reserve, and thereby a safety margin to attenuate limitations in daily functioning [21].

Due to the relation between physical fitness and daily functioning, physical fitness tests may be an important tool in identifying people at risk for developing, or worsening of, limitations in daily functioning. In the general population, physical fitness components such as gait speed, strength, muscular endurance, balance, cardiorespiratory fitness, and manual dexterity have indeed been found to be predictive for limitations in daily functioning [15, 22-24]. This has not yet been investigated in the population with ID.

This is an important area for research for older adults with ID, because older adults with ID have low physical fitness levels (gait speed, strength, muscular endurance, balance, and cardiorespiratory fitness), as well as a high incidence of limitations in ADL and mobility [25, 26]. These low physical fitness levels may be a cause for the high incidence of limitations in daily functioning. If this is the case, exercise to improve physical fitness may reduce limitations in daily functioning.

However, only a few cross-sectional studies have looked at the association between physical fitness and daily functioning in adults with ID. In young adults with Down syndrome (DS), knee extensor strength and cardiorespiratory fitness were found to be associated to functional daily living tasks as rising from a chair and walking up and down stairs [27]. In addition, progressive resistance training (two times a week for 10 weeks) was effective in improving leg strength and the ability to walk up and down stairs [28]. In a small study with older adults with ID, low quadriceps strength was correlated with limitations in ADL and stair climbing and descending [29]. Grip strength did not significantly correlate with ADL, in contrast to the general population [22, 29, 30]. In another small study with older adults with ID, balance, gait, and cardiorespiratory fitness were significantly correlated to daily functioning [31]. Longitudinal studies regarding the predictive value of physical fitness for limitations in daily functioning are needed to provide insight in the relation between physical fitness and daily functioning in older adults with ID. This will provide the information needed for implementation of physical fitness tests and fitness improving programs in the routine care for older adults with ID.

Therefore, the aim of this study was to assess the predictive value of physical fitness for daily functioning, over a 3-year period, in a large sample of older adults with ID. In addition, if the physical fitness tests are predictive for a decline in daily functioning, this will prove the predictive validity of these tests.

METHODS

Study design and participants

This study was part of the large 'Healthy ageing and intellectual disabilities' (HA-ID) study by three ID care organizations and two university departments in the Netherlands. All clients aged 50 years and over, receiving care or support by one of the three participating care organizations were invited to participate (n = 2150), resulting in a near-representative sample of 1050 clients. No exclusion criteria were applied. Details about design, recruitment, and representativeness of the sample have been presented elsewhere [32]. Baseline data collection took place between February 2009 and July 2010. Follow-up data were collected three years after baseline data collection.

The Medical Ethical Committee of the Erasmus Medical Center (MEC 2008-234 and MEC 2011-309) and the ethical committees of the ID care organizations approved this study. All participants or their legal representatives provided informed consent. This study was conducted in accordance to the guidelines of the Declaration of Helsinki [33].

Baseline measurements

The measurements performed at baseline are described below.

Personal characteristics

Age and gender were retrieved from the administrative systems of the care organizations. Level of ID was obtained from behavioral therapists' or psychologists' files and was classified as borderline (IQ = 70 – 84), mild (IQ = 50 – 69), moderate (IQ = 35 – 49), severe (IQ = 20 – 34), or profound (IQ < 20) [34]. The presence of Down syndrome (DS) was retrieved from the medical files.

Physical fitness

Manual dexterity was measured with the Box and Block test (BBT) [35]. Participants had to move as many colored blocks (of 2.5 cm^3) from one side of a box to the other side, in one minute. A wooden plank separated sides. The number of blocks moved was the result of the test. Results were only recorded if the test instructor was convinced the participant understood the 'as fast as possible' instruction of the test. Validity and reliability in the general population was good [36, 37]. In older adults with ID, test-retest reliability was good, with an ICC of 0.90 for both the same-day and 2-week interval [38].

Reaction time was measured with an auditive (doorbell) and a visual (white dot on the screen) reaction time task [39, 40]. Participants had to press a key on a laptop as quickly as possible. Each task had 15 trials, with a random duration of presenting the signal (between 1.0 and 9.0 seconds). First the auditive reaction time task (RTA) was performed, followed by the visual reaction time task (RTV). Time (in milliseconds) between the presentation of the stimulus and pushing the button was recorded. The median of the 15 scores was the result of the test. Results were only recorded if the test instructor was convinced the participant understood the action-reaction and the 'as fast as possible' parts of the instruction. Validity and reliability in the general population was good [41, 42]. In older adults with ID, test-retest reliability was also good. For RTA, the ICC for the same-day interval was 0.87 and 0.74 for the 2-week interval, for RTV this was 0.75 and 0.72, respectively [38].

Balance was measured with the Berg Balance Scale (BBS), consisting of 14 static and dynamic functional balance tasks [40, 43]. The original test instructions were followed with some aids to enhance understanding of the tasks: two carpet feet and a carpet circle on the floor to point out where the participant had to stand or turn around on. All items were scored on a 5-point scale from 0 (unable to complete the task) to 4 (completion of the task) points, with a maximum of 56 points. Walking aids were not allowed. Validity and reliability was confirmed in the general population [44-46], as well as inter-rater and test-retest reliability in the population with ID (ICC = 0.98 – 0.96) [47, 48].

Gait speed was measured at comfortable speed (GSC) and fast speed (GSF) over a 5-meter distance, after 3 meters for acceleration [49]. Participants walked three times for each condition. For GSC the three trials were averaged to get the result (in m/s). For GSF the fastest trial was the result (in m/s). To avoid influencing the speed and balance of the participants, participants walked without someone walking alongside or physically supporting them. Walking aids were allowed. Validity and reliability in the general population was good [23, 50-53]. In older adults with ID, test-retest reliability was also good. For GSC, the ICC for the same-day interval was 0.96 and 0.93 for the 2-week interval, for GSF the ICC for the same-day interval was 0.96 and 0.90 for 2-week interval [38].

Grip strength (GS) was measured with the Jamar Hand Dynamometer (#5030J1, Sammons Preston Rolyan, USA) in seated position, according to the recommendations of The American Society of Hand Therapists [54]. First, participants could squeeze a rubber ball, to assure understanding of the task. Subsequently, participants squeezed the dynamometer with maximum force; three times with both hands, with one-minute rest between attempts. Results were only recorded if the test instructor was convinced the participant had squeezed with maximum effort. The maximal produced force was the test result (in kg). Validity and reliability in the general population was good [55, 56]. In older adults with ID, test-retest reliability was good, with an ICC of 0.94 for a same-day interval and 0.90 for a 2-week interval [38].

Muscular endurance was measured with the 30s Chair stand (30sCS) [57]. Participants were instructed to stand up and sit down again as often as possible in 30 seconds, without using their hands. The total number of complete stances was the result of the test. In the general population, validity and reliability was good [58]. In older adults with ID, test-retest reliability was moderate to good, with an ICC of 0.72 for a same-day interval and 0.65 for a 2-week interval [38].

Flexibility was measured with an extended version of the modified back saver sit and reach test (EMBSSR) [59, 60]. Participants sat on a chair with one leg stretched forward on to a second chair, while bending forward reaching toward their foot. The distance from the distal point of the distal phalanx of the digitus medius to the malleolus lateralis was measured (in cm). The score was given a negative sign if the digitus medius did not pass the malleolus lateralis. This test was executed for both legs. The furthest reach was the result of the test. Validity and reliability was good in the general population [59, 61]. In older adults with ID, test-retest reliability was moderate to good, with an ICC of 0.95 – 0.96 for a same-day interval and 0.63 – 0.71 for a 2-week interval [38].

Cardiorespiratory fitness was measured with the 10-meter incremental shuttle walking test (ISWT) [62]. Participants walked up and down a 10 m course at increasing pace. An instructor who walked along with the participant set the pace. The starting speed was 0.50 m/s and increased every minute by 0.17 m/s. The test ended when either the participant failed to complete a 10 m shuttle within the allowed time or was too breathless to maintain the required pace. Heart rates were monitored during the test with wireless heart-rate monitors (Suunto T6c). The covered distance was the test results. The ISWT was performed twice, because earlier studies suggested the need for a practice session to obtain valid results [62-64]. Results from the best test, defined as the test in which the participant reached the highest heart rate, were used in the analyses. Test-retest reliability was confirmed in patients with chronic airway construction ($r \geq 0.98$) [62] and patients attending cardiac rehabilitation (ICC = 0.94) [63]. Validity has also been confirmed in patients with chronic airway construction [65]. In older adults with ID, test-retest reliability was good, with an ICC of 0.90 for the same-day interval and 0.76 for the 2-week interval [38].

The physical fitness assessment was conducted at locations familiar or close to participants. Test instructors were all physiotherapists, physical activity instructors, or occupational therapists with several years of experience in working with people with ID. Before the data collection, test instructors received an instruction manual and a 2-day training for the execution of all tests. In the training, test instructors practiced the assessment of the physical fitness tests, and test results were compared between different instructors to assure similarity of the results. It was emphasized that test instructors had to be convinced that participants understood the task and performed with maximal effort; otherwise test results should not be recorded.

Standardized encouragement provided by test instructions for testing individuals with normal intelligence is unsuitable for individuals with ID. To keep the 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 tests by constant verbal encouragement and verbal rewarding, in other cases the test instructor had to remain very calm and quiet to motivate the participant as much as possible and to prevent stress or anxiety. The background, knowledge, and experience of the test instructors were important for ensuring the most suitable 'maximal motivation' for every participant, while regarding safety as well.

Daily functioning

Daily functioning was operationalized in basic activities of daily living (ADL) and mobility.

ADL was measured with the Barthel index [66]. The Barthel index consists of the following ten items: bowel control, bladder control, grooming, toilet use, feeding, transfer, walking, dressing, stair climbing, and bathing. Scoring categories ranged from two to four categories, with a total score ranging from 0 (completely dependent) to 20 (completely independent) [67, 68]. The Barthel index was filled in by the professional caregivers of the participants, which has been found to be as reliable as testing the participant himself [68]. Psychometric properties (validity, test-retest reliability, sensitivity, and clinical utility) of the Barthel index are good [67, 69-71].

Mobility is usually divided into the categories independent, walking with an aid, and wheelchair-bound. Since mobility is an important aspect of daily functioning in older adults with ID [5], and walking is one of the main activities of people with ID [72], we wanted to assess mobility in more detail. Therefore, professional caregivers provided information about if and the kind of aids the participants used in the following situations: walking inside the house, walking at work or school, walking outside in a protected area (distances within 50 meters), walking outside in a protected area (distances over 50 meters), and walking outside in an unprotected area. Each situation had the following answer categories: no aids, furniture for support, a cane, a walker, a wheelchair and moves forward by using his/her legs, a wheelchair and moves forward by using his/her arms, a wheelchair and needs someone else to move him/her forward, an electrical wheelchair, or bedridden. The scoring ranged from 0 (completely independent) to 40 (bedridden).

Follow-up daily functioning

At follow-up, 3 years later, the professional caregivers of the participants again filled in the Barthel index and mobility scale.

Missing data

Missing items on the Barthel index (ADL) and mobility scale were imputed using the mean of each respondent on the other ADL or mobility items. For example, if a participant had one missing response on the ADL scale, the missing value for that item was filled with the average of the remaining nine items. No more than 30% missing values were accepted for each participant. Follow-up data from four participants were omitted from the analyses because of the suspicion that they were filled in incorrectly.

Statistical analyses

Baseline personal characteristics and physical fitness results were described for the group of participants who had performed at least one physical fitness measurement and had follow-up data available. Baseline and follow-up ADL and mobility results are presented for the total group as means with standard deviations and medians with the 1st and 3rd quartile, to provide insight in the range of the results. Differences between baseline and follow-up were analyzed with paired *t* tests. Bonferroni correction was used to correct for multiple testing. *P*-values smaller than 0.025 (0.05/2) were considered statistical significant.

Simple and multiple linear regression analyses were used to assess the predictive value of each physical fitness component for ADL and mobility at follow-up.

First, the predictive value of each physical fitness component for ADL and mobility at follow-up was assessed with a simple linear regression, with each physical fitness component as the independent variable and follow-up ADL or mobility as the dependent variable.

Second, the predictive value of each physical fitness component for a decline in ADL and mobility at follow-up was assessed with multiple linear regression adjusted for age (in years), gender (male = 0, female = 1), level of ID, DS (no = 0, yes = 1), and baseline score [73, 74]. Level of ID was recoded into three categories (borderline-mild, moderate, severe-profound), because the group of participants with borderline and mild ID did not differ from each other on the physical fitness tests, and neither did the severe and profound ID groups [73]. Subsequently, dummy variables were constructed for level of ID. The confounders were entered in the first block, and the physical fitness component was entered in the second block. An interaction term between baseline score and the physical fitness component was forwarded in the third block, and therefore only remained in the final model if it significantly added to the predictive power of the model. A significant interaction term represents the difference in physical fitness slopes for different baseline scores. Multicollinearity was checked with the Variance Inflation Factor (VIF), which had to be below 10 for all independent variables, except for the interaction terms [75]. Results are presented as the unstandardized coefficients (*B*), representing the strength of the relation between each independent variable and the outcome in units of the independent variable; its standard error (SE *B*), the standardized beta (β), representing the strength of the relation between each independent variable and the outcome in standardized units; the explained variance (adjusted R^2), and the model *F*-ratio, representing the fit of the model [75]. A summary table of the results of the simple and multiple regression analyses is presented in the results section, with the sample size and adjusted R^2 of model 1 and 2, and the standardized betas (β) of each physical fitness component and interaction term of model 2, for both ADL and mobility as an outcome measure. The full results are presented in Appendices 1 and 2. Statistical significance was set at 5% ($p < 0.05$).

Analyses were performed with the Statistical Package for Social Sciences (SPSS) version 21 (IBM Corporation, New York).

RESULTS

Baseline personal characteristics and physical fitness

Of the 1050 participants in the HA-ID study, 602 participants performed at least one physical fitness test and had follow-up data available. The mean age of the study sample was 60.9 years (*sd* = 7.6), and 49.2% was female. Most participants had mild or moderate ID, and 13.3% of the study sample had Down syndrome (DS). The baseline personal characteristics and physical fitness results are presented in Table 1.

Table 1. Baseline personal characteristics and physical fitness results.

		Total (*n* = 602)
Personal characteristics		
Age (years)	*m* ± *sd*	60.9 ± 7.6
	50 – 59	301 (50.0%)
	60 – 69	206 (34.2%)
	70 – 79	86 (14.3%)
	80 plus	9 (1.5%)
Gender	Females	296 (49.2%)
	Males	306 (50.8%)
Level of ID	Borderline	18 (3.0%)
	Mild	132 (21.9%)
	Moderate	309 (51.3%)
	Severe	103 (17.1%)
	Profound	25 (4.2%)
	Unknown	15 (2.5%)
Down syndrome	Yes	80 (13.3%)
	No	432 (71.8%)
	Unknown	90 (15.0%)
Physical fitness		
Manual dexterity (*n* = 522)	*m* ± *sd*	28.8 ± 12.3
Auditive reaction time (*n* = 395)	ms (*m* ± *sd*)	1060.7 ± 1080.1
Visual reaction time (*n* = 390)	ms (*m* ± *sd*)	1063.8 ± 797.7
Balance (*n* = 356)	*m* ± *sd*	47.1 ± 10.0
Comfortable gait speed (*n* = 510)	m/s (*m* ± *sd*)	0.97 ± 0.35
Fast gait speed (*n* = 403)	m/s (*m* ± *sd*)	1.85 ± 0.87
Grip strength (*n* = 515)	kg (*m* ± *sd*)	24.2 ± 10.3
Muscular endurance (*n* = 385)	*m* ± *sd*	9.4 ± 3.3
Flexibility (*n* = 447)	cm (*m* ± *sd*)	-5.1 ± 13.8
Cardiorespiratory fitness (*n* = 433)	meters (*m* ± *sd*)	245.2 ± 178.0

m = mean; *sd* = standard deviation; *n* = number of participants; ID = intellectual disability.

Daily functioning

Results of the ADL and mobility scales at baseline and follow-up are presented in Table 2. ADL at follow-up was significantly worse than ADL at baseline ($t(587) = 8.86$, $p < 0.001$). At baseline, 91 out of 602 participants (15.1%) were completely independent in ADL. At follow-up, 76 participants (12.6%) were completely independent. Over the 3-year follow-up period, 54.8% of the participants deteriorated in their ability to perform ADL (a range of 1 to 17 points deterioration on the Barthel index), 21.6% was stable, and 23.6% improved in their ability to perform ADL (a range of 1 to 20 points improvement on the Barthel index).

Table 2. Results of the activities of daily living and mobility scale at baseline and follow-up.

	m* ± *sd	***mdn* (1st quartile – 3rd quartile)**
ADL at baseline (*n* = 588)[a]	15.0 ± 4.7	16.0 (13.0 – 19.0)
ADL at follow-up (*n* = 602)[a]	13.9 ± 5.3	15.0 (11.0 – 18.0)
Mobility at baseline (*n* = 588)[b]	6.0 ± 9.3	0.0 (0.0 – 12.0)
Mobility at follow-up (*n* = 597)[b]	9.1 ± 10.8	1.0 (0.0 – 18.0)

m = mean; *sd* = standard deviation; mdn = median; ADL = basic activities of daily living.
[a] = A higher score representing a better ADL.
[b] = A lower score representing a better mobility.

Mobility of the participants was significantly worse at follow-up than at baseline ($t(583) = -12.19$, $p < 0.001$). At baseline, 373 out of 602 participants (62.0%) had no mobility limitations in comparison to 292 participants (48.5%) at follow-up. Over the 3-year follow-up period, 37.5% of the participants deteriorated in their mobility (a range of 1 to 30 points deterioration on the mobility scale), 56.0% was stable, and 6.5% improved in their mobility (a range of 1 to 18 points on the mobility scale).

Predictive value of physical fitness for activities of daily living and mobility

For ADL, simple linear regression revealed that all physical fitness components predicted ADL at follow-up, except flexibility (Table 3, model 1). A better score on the physical fitness tests predicted a higher ADL score at follow-up. The explained variance of the significant simple linear regression models for ADL at follow-up ranged from 7.2% (auditive reaction time) to 40.7% (balance).

Multiple linear regression analyses showed that after adjustment for confounders, all physical fitness components, except auditive reaction time, grip strength, and flexibility, were significant predictors for a decline in ADL (Table 3, model 2). The explained variance of the final regression models for follow-up ADL scores ranged from 45.4% (muscular endurance) to 69.1% (manual dexterity). The full results of the simple and multiple regression analyses are presented in Appendix 1. A higher baseline ADL score was an

Table 3. Summary of the results of the simple (model 1) and multiple (model 2) linear regression analyses for the predictive value of physical fitness for ADL and mobility.

	Model 1 (*n* and R^2)	Model 2 (*n* and R^2)	β fitness component[a]	β baseline x fitness component[b]
Manual dexterity				
ADL	$n = 418, R^2 = 0.367$**	$n = 418, R^2 = 0.691$**	0.69**	-0.68**
Mobility	$n = 415, R^2 = 0.168$**	$n = 415, R^2 = 0.725$**	-0.09*	ns
Auditive reaction time				
ADL	$n = 308, R^2 = 0.072$**	$n = 308, R^2 = 0.610$**	-0.06	ns
Mobility	$n = 306, R^2 = 0.026$**	$n = 306, R^2 = 0.743$**	0.01	ns
Visual reaction time				
ADL	$n = 301, R^2 = 0.112$**	$n = 301, R^2 = 0.606$**	-0.34**	0.28*
Mobility	$n = 299, R^2 = 0.019$**	$n = 299, R^2 = 0.732$**	-0.01	ns
Balance				
ADL	$n = 270, R^2 = 0.407$**	$n = 270, R^2 = 0.574$**	0.37**	ns
Mobility	$n = 267, R^2 = 0.475$**	$n = 267, R^2 = 0.695$**	-0.53**	0.42**
Comfortable gait speed				
ADL	$n = 411, R^2 = 0.315$**	$n = 411, R^2 = 0.604$**	0.66**	-0.63**
Mobility	$n = 407, R^2 = 0.317$**	$n = 407, R^2 = 0.668$**	-0.18**	0.15*
Fast gait speed				
ADL	$n = 319, R^2 = 0.217$**	$n = 319, R^2 = 0.539$**	1.03**	-1.01**
Mobility	$n = 315, R^2 = 0.232$**	$n = 315, R^2 = 0.564$**	-0.17**	ns
Grip strength				
ADL	$n = 408, R^2 = 0.194$**	$n = 408, R^2 = 0.625$**	0.07	ns
Mobility	$n = 404, R^2 = 0.125$**	$n = 404, R^2 = 0.717$**	-0.08*	0.14*
Muscular endurance				
ADL	$n = 302, R^2 = 0.227$**	$n = 302, R^2 = 0.454$**	0.74**	-0.68*
Mobility	$n = 299, R^2 = 0.146$**	$n = 299, R^2 = 0.557$**	-0.12**	ns
Flexibility				
ADL	$n = 353, R^2 = -0.002$	$n = 353, R^2 = 0.582$**	0.03	ns
Mobility	$n = 350, R^2 = -0.002$	$n = 350, R^2 = 0.712$**	-0.02	ns
Cardiorespiratory fitness				
ADL	$n = 351, R^2 = 0.201$**	$n = 351, R^2 = 0.539$**	0.55*	-0.48*
Mobility	$n = 349, R^2 = 0.211$**	$n = 349, R^2 = 0.593$**	-0.15**	ns

Model 1: simple logistic regression excluding potential confounders; model 2: multiple logistic regression including potential confounders.

β = standardized beta; R^2 = adjusted explained variance; ns = non-significant; ADL = activities of daily living.

[a] The standardized betas of the physical fitness component of model 2 for each physical fitness component.

[b] The standardized betas of the interaction term (baseline x physical fitness component) of model 2 for each physical fitness component.

* $p < 0.05$

** $p < 0.01$

important predictor for a higher ADL score at follow-up, with often the highest standardized beta. However, in the multiple regression models with balance, fast gait speed, and muscular endurance as the physical fitness components, the standardized betas of these physical fitness components were the highest, instead of those of baseline ADL. The standardized betas of comfortable walking speed and cardiorespiratory fitness were also large and close to those of baseline ADL. A significant negative interaction term was found between baseline ADL and visual reaction time, comfortable walking speed, fast walking speed, muscular endurance, and cardiorespiratory fitness, representing a decrease in the influence of physical fitness on follow-up ADL for people with better baseline ADL scores. Finally, older age, being female, having moderate and severe-profound ID, and having DS were negatively related to ADL performance at follow-up (Appendix 1). However, gender and severe-profound ID were not significant predictors across all regression models.

For mobility, simple linear regression showed that all physical fitness components predicted mobility at follow-up, except flexibility (Table 3, model 1), with a better score on the physical fitness tests predicting a better mobility at follow-up. The explained variance from the significant simple linear regression models for follow-up mobility scores ranged from 1.9% (visual reaction time) to 47.5% (balance).

After adjustment for confounders, all physical fitness components, except flexibility, auditive and visual reaction time, were significant predictors for a decline in mobility (Table 3, model 2). The explained variance of the final regression models for follow-up mobility scores ranged from 55.7% (muscular endurance) to 74.3% (auditive reaction time). The full results of the simple and multiple regression analysis are presented in Appendix 2. Again, a better baseline mobility score was an important predictor for a better mobility score at follow-up. In the multiple regression model with balance as the physical fitness component, the standardized beta of balance was the highest, instead of the standardized beta of the baseline mobility score. A significant positive interaction term was found between baseline mobility and balance, comfortable gait speed, and grip strength, representing a decrease in the influence of physical fitness on follow-up mobility for people with better baseline mobility. Finally, older age, being female, and having DS were negatively related to mobility at follow-up (Appendix 2). However, older age was not a significant predictor across all regression models.

DISCUSSION

We assessed the predictive value of physical fitness for daily functioning (basic activities of daily living [ADL] and mobility), over a 3-year period, in 602 older adults with intellectual disabilities (ID). This first longitudinal study shows that more than half of the participants (54.8%) declined in their ability to perform ADL over the 3-year follow-up period, with only 12.6% being completely independent in performing ADL at follow-up. In addition, 37.5% of the participants declined in their mobility, with 48.5% being free of mobility limitations at follow-up. All physical fitness components, except flexibility, auditive reaction time, and grip strength, significantly predicted a decline in ADL. All physical fitness components, except flexibility and auditive and visual reaction time, significantly predicted a decline in mobility. These results prove the predictive validity of the physical fitness tests for these components.

The percentage of older adults with ID that declined in their daily functioning was higher than that found in studies in the general older population. In a 3-year follow-up study with 897 older adults (65 – 102 years), 10.8% declined in their ability to perform ADL [76], in comparison to 54.8% in our study. In another study with 625 middle-aged and older adults (mean age 62.3 [*sd* = 8.9]), 76.5% of the participants were independent in performing ADL at baseline [77]. After a 10-year follow-up period, 67.7% of the participants were still independent in performing ADL. In our study the percentage of participants that were independent in their daily functioning was considerably lower, both at baseline and follow-up. This suggests that in older adults with ID both the percentage of participants that decline in their daily functioning over a 3-year period is larger, as well as the amount that is dependent in their ADL.

Our finding that physical fitness was predictive for a decline in daily functioning in older adults with ID, is in line with findings of studies in the general population [22-24]. It is also in line with the associations found between physical fitness and daily functioning in the few cross-sectional studies in the population with ID [27, 29, 31]. The multiple linear regression models showed that manual dexterity, visual reaction time, balance, comfortable and fast gait speed, muscular endurance, and cardiorespiratory fitness were significant predictors for a decline in ADL. Grip strength, however, was not a significant predictor for ADL in our study, at least not after adjustment for confounders. Carmeli et al. (2012) also found that grip strength did not significantly correlate with ADL, whereas in the general population grip strength is often raised as an important predictor for a decline in daily functioning [22, 78]. Grip strength, however, was a significant predictor for mobility, along with manual dexterity, balance, comfortable and fast walking speed, muscular endurance, and cardiorespiratory fitness.

The explained variance of the simple linear regression models for ADL and mobility differed largely between the physical fitness components. Of all fitness components, balance explained most of the variance of ADL and mobility. Looking at the multiple regression models, baseline ADL and mobility scores were important predictors for follow-up ADL and mobility scores. However, in the multiple regression models with balance, fast gait speed, and muscular endurance as the physical fitness components, these physical fitness components were the main predictors for ADL, with higher standardized betas than baseline ADL scores and the other confounders (see Appendix 1). For mobility, this was the case in the multiple regression model with balance as the physical fitness component (see Appendix 2). For ADL, comfortable gait speed and cardiorespiratory fitness had standardized betas close to the standardized betas of baseline ADL scores, indicating also the importance of these physical fitness components for ADL. This shows that, across all the regression models, each with a single physical fitness component as independent variable, the physical fitness components with the highest betas were balance, comfortable and fast gait speed, muscular endurance, and cardiorespiratory fitness. These results stress the need for interventions to improve physical fitness levels of older adults with ID, which should especially focus on these physical fitness components.

The significant interaction terms between physical fitness and daily functioning show that physical fitness is a better predictor for daily functioning in older adults with ID who have lower baseline scores. This finding is in line with the idea that high physical fitness levels provide a physical reserve for daily functioning and that a certain level of physical fitness is required to perform ADL without any limitations [17, 18, 21, 79]. With high physical fitness levels, physical fitness can deteriorate without leading to limitations in daily functioning. Only if physical fitness levels drop below the required level, daily functioning will start to deteriorate, resulting in a ceiling effect for detecting limitations in daily functioning with physical fitness tests. This thereby limits the predictive value of physical fitness for relatively independent people. However, the interaction terms were not significant for balance and ADL, manual dexterity and mobility, fast gait speed and mobility, muscular endurance and mobility, and cardiorespiratory fitness and mobility, which may mean that the required fitness levels to remain free from limitations in daily functioning is higher for these physical fitness components.

In the better functioning group, physical fitness may be predictive for limitations in instrumental activities of daily living (IADL), because the ability to perform IADL usually declines prior to the loss of ability to perform ADL [80]. Impairments in physical fitness may therefore lead to impairments in IADL ahead of ADL. In addition to our study, it will therefore be useful to look at the predictive value of physical fitness for limitations in IADL in older adults with ID.

Even though older adults with ID more or less encounter a lifelong dependency on others due to their cognitive limitations and other comorbidities, this study shows that physical fitness is also an important aspect of daily functioning in this population. It is therefore important to improve the physical fitness of older adults with ID. In the general population, physical exercise programs have successfully improved daily functioning [15]. However, physical exercise programs developed for the general population may not be applicable for people with ID because of their cognitive limitations, need of support, sensory and mobility impairments, and other health conditions [81-83]. Therefore, physical exercise programs need to be developed or tailored specifically for this population [84]. Physical exercise programs have been found successful in improving physical fitness in people with ID [85-87]. However, whether this transfers to benefits in daily functioning has not been thoroughly investigated. Cowley et al. (2011) found that progressive resistance training was effective in improving leg strength and also the ability to walk up and down stairs. However, more research is needed regarding the effectiveness of exercise programs for improving the daily functioning of older adults with ID and to provide guidelines for the content of these exercise programs.

Physical fitness tests are an important tool for the care of older adults with ID, because they both can be used to assess the effectiveness of interventions and may help in identifying people at risk for developing, or worsening of, limitations in daily functioning. The next important step for this use of physical fitness tests is to identify test scores associated with certain levels of daily functioning (criterion-referenced values) for the interpretation of the physical fitness test results.

This study had some limitations. First, the results may not be representative for the entire population of older adults with ID because of selection bias; adults with severe or profound ID and wheelchair users were underrepresented in the physical fitness assessment [26]. In addition, the HA-ID study sample did not include older adults with ID who did not use any form of registered care or support, and older adults with ID that only receive ambulatory care or only visit a day-care center were underrepresented in the sample [32]. Therefore, our results are not generalizable to these groups. Second, a ceiling effect was present for the mobility scale, which may have limited the reliability of the regression models for the maximum scores of the mobility scale and thereby the results regarding the interaction terms. For the Barthel index (ADL) a minimal ceiling effect was present at baseline, with 15.1% being completely independent. However, this is very close to the 15% cut-off for floor and ceiling effects [88, 89]. Third, for a linear regression analysis the outcome measures need to be continuous, but the mobility scale may not be entirely continuous because it is not possible to have equal differences between response categories. However, by taking as many small steps as possible, we tried to measure each small deterioration or improvement in mobility. In addition, the direction of the scale is consistent, with a higher score representing worse mobility, which is especially important for the linear regression analyses. Last, the range of improvement and deterioration on the ADL and mobility scale was large. Because we did not assess ADL and mobility within the 3-year period, we do not know the pattern of improvement or deterioration over the follow-up period to explain these large changes during the follow-up period. However, the ADL and mobility scores of outliers were doubly checked with the professional caregivers of the participants to ensure correctness. We do not think that not knowing the pattern of improvement or deterioration has influenced our results.

In conclusion, we found that physical fitness significantly predicts a decline in daily functioning in older adults with ID, providing predictive validity for physical fitness tests for daily functioning. This stresses the importance of using physical fitness tests in the care of older adults with ID. Identifying criterion-referenced values is needed to improve interpretation of the test results and support decision making for treatment and interventions.

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Appendix 1 Results of the simple (model 1) and multiple (model 2) linear regression analyses for the predictive value of physical fitness for ADL.

			B (SE)	***β***	**Model characteristics**
Manual dexterity					
Model 1		BBT	0.26 (0.02)**	0.61	*n* = 418, adjusted R^2 = 0.367,
		Constant	6.74 (0.51)**		*F* = 242.65**
Model 2	*Block1*	Age	-0.10 (0.02)**	-0.15	*n* = 418, adjusted R^2 = 0.691,
		Female	-0.82 (0.30)**	-0.08	*F* = 117.46**
		Moderate ID Severe/profound ID	-0.93 (0.39)* -0.91 (0.55)	-0.09 -0.07	
		Down syndrome	-1.97 (0.46)**	-0.13	
		Baseline ADL	0.99 (0.07)**	0.86	
	Block 2	BBT	0.30 (0.04)**	0.69	
	Block 3	Baseline ADL x BBT	-0.01 (0.003)**	-0.68	
		Constant	4.28 (1.73)*		
Auditive reaction time					
Model 1		RTA	-0.001 (0.000)**	-0.27	*n* = 308, adjusted R^2 = 0.072,
		Constant	16.40 (0.37)**		*F* = 24.82**
Model 2	*Block1*	Age	-0.10 (0.03)**	-0.15	*n* = 308, adjusted R^2 = 0.610,
		Female	-0.62 (0.35)	-0.06	*F* =69.53**
		Moderate ID Severe/profound ID	-1.38 (0.40)** -0.61 (0.77)	-0.14 -0.03	
		Down syndrome	-2.60 (0.54)**	-0.18	
		Baseline ADL	0.78 (0.04)**	0.67	
	Block 2	RTA	0.00 (0.00)	-0.06	
	Block 3	Baseline ADL x RTA	ns		
		Constant	10.14 (1.86)**		
Visual reaction time					
Model 1		RTV	-0.002 (0.00)**	-0.34	*n* = 301, adjusted R^2 = 0.112,
		Constant	17.32 (0.43)**		*F* = 38.69**
Model 2	*Block1*	Age	-0.09 (0.02)**	-0.14	*n* = 301, adjusted R^2 = 0.606,
		Female	-0.76 (0.35)*	-0.08	*F* =58.64**
		Moderate ID Severe/profound ID	-1.56 (0.40)** -0.85 (0.78)	-0.16 -0.05	
		Down syndrome	-2.79 (0.55)**	-0.20	
		Baseline ADL	0.61 (0.08)**	0.53	
	Block 2	RTV	-0.002 (0.001)**	-0.34	
	Block 3	Baseline ADL x RTV	0.00 (0.00)*	0.28	
		Constant	12.88 (2.12)**		

			B (SE)	β	Model characteristics
Balance					
Model 1		BBS	0.26 (0.02)**	0.64	*n* = 270, adjusted R^2 = 0.407,
		Constant	3.39 (0.92)**		*F* = 185.53**
Model 2	*Block1*	Age	-0.09 (0.02)**	-0.16	*n* = 270, adjusted R^2 = 0.574,
		Female	-0.53 (0.36)	-0.06	*F* = 52.75**
		Moderate ID Severe/profound ID	-0.83 (0.40)* -2.04 (0.70)**	-0.09 -0.13	
		Down syndrome	-3.19 (0.56)**	-0.24	
		Baseline ADL	0.42 (0.07)**	0.34	
	Block 2	BBS	0.15 (0.02)**	0.37	
	Block 3	Baseline ADL x BBS	ns		
		Constant	8.56 (1.98)**		
Comfortable gait speed					
Model 1		GSC	7.67 (0.56)**	0.56	*n* = 411, adjusted R^2 = 0.315,
		Constant	7.36 (0.56)**		*F* = 189.38**
Model 2	*Block1*	Age	-0.09 (0.02)**	-0.15	*n* = 411, adjusted R^2 = 0.604,
		Female	-0.51 (0.30)	-0.06	*F* = 79.19**
		Moderate ID Severe/profound ID	-1.56 (0.37)** -2.66 (0.48)**	-0.17 -0.23	
		Down syndrome	-2.27 (0.43)**	-0.18	
		Baseline ADL	0.90 (0.10)**	0.73	
	Block 2	GSC	8.96 (1.59)**	0.66	
	Block 3	Baseline ADL x GSC	-0.39 (0.10)**	-0.63	
		Constant	5.67 (2.19)*		
Fast gait speed					
Model 1		GSF	2.41 (0.26)**	0.47	*n* = 319, adjusted R^2 = 0.217,
		Constant	10.99 (0.51)**		*F* = 89.08**
Model 2	*Block1*	Age	-0.09 (0.03)**	-0.15	*n* = 319, adjusted R^2 = 0.539,
		Female	-0.64 (0.36)	-0.07	*F* = 47.40**
		Moderate ID Severe/profound ID	-1.50 (0.41)** -2.79 (0.57)**	-0.17 -0.25	
		Down syndrome	-2.89 (0.49)**	-0.25	
		Baseline ADL	0.90 (0.11)**	0.72	
	Block 2	GSF	5.27 (1.11)**	1.03	
	Block 3	Baseline ADL x GSF	-0.25 (0.06)**	-1.01	
		Constant	6.46 (2.61)*		

			B (SE)	β	Model characteristics
Grip strength					
Model 1		GS	0.23 (0.02)**	0.44	n = 408, adjusted R^2 = 0.194,
		Constant	8.95 (0.59)**		F = 99.11**
Model 2	*Block1*	Age	-0.11 (0.02)**	-0.16	n = 408, adjusted R^2 = 0.625,
		Female	-0.43 (0.37)	-0.04	F = 98.09**
		Moderate ID Severe/profound ID	-1.51 (0.39)** -2.14 (0.57)**	-0.15 -0.15	
		Down syndrome	-2.40 (0.47)**	-0.17	
		Baseline ADL	0.73 (0.04)**	0.64	
	Block 2	GS	0.04 (0.02)	0.07	
	Block 3	Baseline ADL x GS	ns		
		Constant	10.64 (1.75)**		
Muscular endurance					
Model 1		30sCS	0.62 (0.07)**	0.48	n = 302, adjusted R^2 = 0.227,
		Constant	10.03 (0.63)**		F = 89.50**
Model 2	*Block1*	Age	-0.01 (0.03)**	-0.17	n = 302, adjusted R^2 = 0.454,
		Female	-1.01 (0.35)**	-0.13	F = 32.23**
		Moderate ID Severe/profound ID	-1.29 (0.43)** -2.12 (0.61)**	-0.16 -0.19	
		Down syndrome	-2.81 (0.51)**	-0.26	
		Baseline ADL	0.72 (0.15)**	0.60	
	Block 2	30sCS	0.96 (0.29)**	0.74	
	Block 3	Baseline ADL x 30sCS	-0.04 (0.02)*	-0.68	
		Constant	9.08 (3.09)**		
Flexibility					
Model 1		EMBSSR	0.01 (0.02)	0.02	n = 353, adjusted R^2 =-0.002,
		Constant	14.95 (0.27)**		F = 0.18
Model 2	*Block1*	Age	-0.11 (0.02)**	-0.18	n = 353, adjusted R^2 = 0.582,
		Female	-1.22 (0.34)**	-0.13	F = 71.11**
		Moderate ID Severe/profound ID	-1.48 (0.39)** -2.85 (0.60)**	-0.16 -0.20	
		Down syndrome	-2.43 (0.51)**	-0.19	
		Baseline ADL	0.70 (0.04)**	0.61	
	Block 2	EMBSSR	0.01 (0.01)	0.03	
	Block 3	Baseline ADL x EMBSSR	ns		
		Constant	12.99 (1.74)**		

			B (SE)	β	Model characteristics
Cardiorespiratory fitness					
Model 1		ISWT	0.01 (0.001)**	0.45	*n* = 351, adjusted R^2 = 0.201,
		Constant	11.84 (0.38)**		*F* = 88.96**
Model 2	*Block1*	Age	-0.10 (0.03)**	-0.15	*n* = 351, adjusted R^2 = 0.539,
		Female	-0.83 (0.35)*	-0.09	*F* = 52.15**
		Moderate ID Severe/profound ID	-1.37 (0.44)** -3.02 (0.57)**	-0.15 -0.28	
		Down syndrome	-2.21 (0.51)**	-0.17	
		Baseline ADL	0.68 (0.07)**	0.58	
	Block 2	ISWT	0.02 (0.01)*	0.55	
	Block 3	Baseline ADL x ISWT	-0.001 (0.00)*	-0.48	
		Constant	11.19 (2.13)**		

Model 1: simple logistic regression excluding potential confounders; model 2: multiple logistic regression including potential confounders.
Age (in years), gender (male = 0, female = 1), level of ID (borderline-mild = 0, moderate = 1, severe-profound = 1), Down syndrome (no = 0, yes = 1).
B = unstandardized coefficient; *SE* = standard error; β = standardized beta; adjusted R^2 = adjusted explained variance; *F* = model *F*-ratio; ns = non-significant; ADL = activities of daily living; BBT = Box and Block test; RTA = reaction time auditive; RTV = reaction time visual; BBS = Berg Balance Scale; GSC = comfortable gait speed; GSF = fast gait speed; GS = grip strength; 30sCS = 30s Chair stand; EMBSSR = extended modified back saver sit and reach test; ISWT = 10-meter incremental shuttle walking test.
* $p < 0.05$
** $p < 0.01$

Appendix 2 Results of the simple (model 1) and multiple (model 2) linear regression analyses for the predictive value of physical fitness for mobility.

			B (SE)	*β*	Model characteristics
Manual dexterity					
Model 1		BBT	-0.37 (0.04)**	-0.41	*n* = 415, adjusted R^2 = 0.168,
		Constant	19.86 (1.22)**		*F* = 84.48**
Model 2	*Block1*	Age	0.13 (0.04)**	0.09	*n* = 415, adjusted R^2 = 0.725,
		Female	1.65 (0.59)**	0.07	*F* = 159.41**
		Moderate ID Severe/profound ID	-0.36 (0.75) -1.11 (1.08)	-0.02 -0.04	
		Down syndrome	3.58 (0.90)**	0.11	
		Baseline mobility	0.90 (0.04)**	0.78	
	Block 2	BBT	-0.08 (0.03)*	-0.09	
	Block 3	Baseline mobility x BBT	ns		
		Constant	-3.23 (2.89)		
Auditive reaction time					
Model 1		RTA	0.002 (0.001)**	0.17	*n* = 306, adjusted R^2 = 0.026,
		Constant	6.93 (0.86)**		*F* = 9.00**
Model 2	*Block1*	Age	0.19 (0.05)**	0.13	*n* = 306, adjusted R^2 = 0.743,
		Female	1.26 (0.65)	0.06	*F* = 126.81**
		Moderate ID Severe/profound ID	-0.10 (0.72) -0.10 (1.41)	-0.004 -0.002	
		Down syndrome	4.33 (1.00)**	0.14	
		Baseline mobility	0.97 (0.04)**	0.81	
	Block 2	RTA	0.000 (0.000)	0.01	
	Block 3	Baseline mobility x RTA	ns		
		Constant	-9.68 (2.90)**		
Visual reaction time					
Model 1		RTV	0.002 (0.001)**	0.15	*n* = 299, adjusted R^2 = 0.019,
		Constant	6.23 (1.02)**		*F* = 6.87 **
Model 2	*Block1*	Age	0.17 (0.05)**	0.12	*n* = 299, adjusted R^2 = 0.732,
		Female	1.51 (0.66)*	0.07	*F* = 117.21**
		Moderate ID Severe/profound ID	-0.13 (0.74) 0.13 (1.47)	-0.01 0.003	
		Down syndrome	4.39 (1.02)**	0.14	
		Baseline mobility	0.96 (0.04)**	0.80	
	Block 2	RTV	0.00 (0.00)	-0.01	
	Block 3	Baseline mobility x RTV	ns		
		Constant	-8.14 (2.93)**		
Balance					

			B (SE)	β	Model characteristics
Model 1		BBS	-0.64 (0.04)**	-0.69	*n* = 267, adjusted R^2 = 0.475,
		Constant	37.02 (1.95)**		*F* = 241.42**
Model 2	*Block1*	Age	0.09 (0.05)	0.07	*n* = 267, adjusted R^2 = 0.695,
		Female	1.05 (0.68)	0.05	*F* = 76.88**
		Moderate ID Severe/profound ID	-0.82 (0.78) -1.77 (1.38)	-0.04 -0.05	
		Down syndrome	3.96 (1.10)**	0.13	
		Baseline mobility	0.05 (0.17)	0.04	
	Block 2	BBS	-0.49 (0.09)**	-0.53	
	Block 3	Baseline mobility x BBS	0.02 (0.003)**	0.42	
		Constant	21.44 (5.82)**		
Comfortable gait speed					
Model 1		GSC	-16.3 (1.19)**	-0.57	*n* = 407, adjusted R^2 = 0.317,
		Constant	23.04 (1.20)**		*F* = 189.69**
Model 2 *Block1*		Age	0.12 (0.04)**	0.10	*n* = 407, adjusted R^2 = 0.668,
		Female	1.50 (0.60)*	0.08	*F* = 103.03**
		Moderate ID Severe/profound ID	0.06 (0.71) -0.74 (0.90)	0.003 -0.03	
		Down syndrome	3.45 (0.84)**	0.13	
		Baseline mobility	0.65 (0.09)**	0.51	
	Block 2	GSC	-5.18 (1.14)**	-0.18	
	Block 3	Baseline mobility x GSC	0.31 (0.13)*	0.15	
		Constant	-0.07 (3.25)		
Fast gait speed					
Model 1		GSF	-5.12 (0.52)**	-0.48	*n* = 315, adjusted R^2 = 0.232,
		Constant	15.24 (1.04)**		*F* = 95.77**
Model 2	*Block1*	Age	0.12 (0.05)*	0.09	*n* = 315, adjusted R^2 = 0.564,
		Female	2.00 (0.73)**	0.11	*F* = 59.00**
		Moderate ID Severe/profound ID	-0.09 (0.81) -0.93 (1.10)	-0.01 -0.04	
		Down syndrome	4.46 (0.98)**	0.19	
		Baseline mobility	0.83 (0.06)**	0.58	
	Block 2	GSF	-1.84 (0.48)**	-0.17	
	Block 3	Baseline mobility x GSF	ns		
		Constant	-1.74 (3.78)		
Grip strength					

			B (SE)	β	Model characteristics
Model 1		GS	-0.40 (0.05)**	-0.36	*n* = 404, adjusted R^2 = 0.125,
		Constant	18.40 (1.31)**		*F* = 58.80**
Model 2	*Block1*	Age	0.16 (0.04)**	0.11	*n* = 404, adjusted R^2 = 0.717,
		Female	1.18 (0.69)	0.05	*F* = 128.51**
		Moderate ID Severe/profound ID	0.08 (0.73) 0.02 (1.05)	0.004 0.001	
		Down syndrome	4.05 (0.89)**	0.13	
		Baseline mobility	0.75 (0.08)**	0.64	
	Block 2	GS	-0.08 (0.04)*	-0.08	
	Block 3	Baseline mobility x GS	0.01 (0.004)*	0.14	
		Constant	-5.33 (3.08)		
Muscular endurance					
Model 1		30sCS	-1.11 (0.15)**	-0.39	*n* = 299, adjusted R^2 = 0.146,
		Constant	16.19 (1.47)**		*F* = 52.11**
Model 2	*Block1*	Age	0.14 (0.06)*	0.11	*n* = 299, adjusted R^2 = 0.557,
		Female	2.76 (0.71)**	0.15	*F* = 54.49**
		Moderate ID Severe/profound ID	-0.30 (0.85) -0.92 (1.20)	-0.02 -0.04	
		Down syndrome	4.14 (1.02)**	0.17	
		Baseline mobility	0.87 (0.07)**	0.59	
	Block 2	30sCS	-0.35 (0.13)**	-0.12	
	Block 3	Baseline mobility x 30sCS	ns		
		Constant	-3.46 (3.77)		
Flexibility					
Model 1		EMBSSR	0.02 (0.04)	0.02	*n* = 350, adjusted R^2 =-0.002,
		Constant	8.37 (0.59)**		*F* = 0.17
Model 2	*Block1*	Age	0.18 (0.05)**	0.12	*n* = 350, adjusted R^2 = 0.712,
		Female	1.89 (0.63)**	0.09	*F* = 124.07**
		Moderate ID Severe/profound ID	0.32 (0.72) 1.02 (1.08)	0.02 0.03	
		Down syndrome	3.55 (0.95)**	0.12	
		Baseline mobility	0.96 (0.04)**	0.78	
	Block 2	EMBSSR	-0.02 (0.02)	-0.02	
	Block 3	Baseline mobility x EMBSSR	ns		
		Constant	-9.31 (2.82)**		
Cardiorespiratory fitness					

			B (SE)	β	Model characteristics
Model 1		ISWT	-0.03 (0.003)**	-0.46	n = 349, adjusted R^2 = 0.211,
		Constant	12.64 (0.74)**		F = 93.98**
Model 2	*Block1*	Age	0.14 (0.05)**	0.11	n = 349, adjusted R^2 = 0.593,
		Female	1.89 (0.67)**	0.10	F = 73.55**
		Moderate ID Severe/profound ID	-0.12 (0.82) -0.38 (0.99)	-0.01 -0.02	
		Down syndrome	3.66 (0.95)**	0.14	
		Baseline mobility	0.84 (0.05)**	0.63	
	Block 2	ISWT	-0.01 (0.002)**	-0.15	
	Block 3	Baseline mobility x ISWT	ns		
		Constant	-4.05 (3.38)		

Model 1: simple logistic regression excluding potential confounders; model 2: multiple logistic regression including potential confounders.
Age (in years), gender (male = 0, female = 1), level of ID (borderline-mild = 0, moderate = 1, severe-profound = 1), Down syndrome (no = 0, yes = 1).
B = unstandardized coefficient; *SE* = standard error; β = standardized beta; adjusted R^2 = adjusted explained variance; *F* = model *F*-ratio; ns = non-significant; BBT = Box and Block test; RTA = reaction time auditive; RTV = reaction time visual; BBS = Berg Balance Scale; GSC = comfortable gait speed; GSF = fast gait speed; GS = grip strength; 30sCS = 30s Chair stand; EMBSSR = extended modified back saver sit and reach test; ISWT = 10-meter incremental shuttle walking test.
* $p < 0.05$
** $p < 0.01$

Chapter 8

General discussion

Being physically fit is an essential factor in healthy ageing [1-4], and physical fitness tests can therefore be an important tool in the optimal care for the ageing population with intellectual disabilities. Unfortunately, suitable physical fitness tests for the (ageing) population with intellectual disabilities are not yet available for clinical practice, and more research regarding this topic was needed. This thesis addressed a number of gaps in the knowledge required for using physical fitness tests in clinical practice (Table 1). After an overview of the principal findings, the methodological issues are discussed, followed by implications and recommendations for practice and directions for future research.

Table 1. Remaining gaps, after this thesis, in the required knowledge for the use of physical fitness tests in clinical practice for older adults with intellectual disabilities.

Criteria	Coordination *(Box and Block test)*	Reaction time *(Reaction time task)*	Balance *(Berg Balance scale)*	Speed *(Gait speed)*	Strength *(Grip strength)*	Muscular endurance *(30s Chair stand)*	Flexibility *(Back saver sit and reach)*	Cardiorespiratory fitness *(Shuttle walking test)*
Feasibility								
Completion rates	✓	✓	✓	✓	✓	✓	✓	✓
Clarity of instructions	✓	✓	✓	✓	✓	✓	✓	✓
Reliability in older adults with ID								
Test-retest reliability	✓	✓	✓	✓	✓	✓	✓	✓
Inter-rater reliability	✓	✓	✓	✓	✓	✓	✓	✓
Validity in older adults with ID								
Criterion (predictive) validity	✓	✓	✓	✓	✓	✓	✓	✓
Responsiveness to change	FR	FR	FR	FR	FR	FR	FR	FR
Comparability to normative data								
Norm-referenced values of the general population available	FR	FR	FR	✓	✓	✓	FR	✓
Norm-referenced values of older adults with ID available	FR	FR	✓	✓	✓	✓	FR	✓
Criterion-referenced values of older adults with ID available	FR	FR	FR	FR	FR	FR	FR	FR

✓= knowledge available; FR = further research required; ID = intellectual disabilities.
Bold boxes were addressed in this thesis.

PRINCIPAL FINDINGS

Issues regarding the feasibility, the lack of normative data, and the lack of validity research were addressed in this thesis. The principal findings will be discussed here.

To improve the clarity of instructions for the grip strength measurement, we assessed the effect of handedness on grip strength. The dominant hand was not always the strongest hand. In 34.5% of the participants the non-dominant hand was stronger. Therefore, we recommended to measure both hands to get a valid grip strength result.

In the HA-ID study, the balance capacities of older adults with ID were assessed with the Berg Balance Scale, however, the completion rates were low for the subgroups with severe to profound ID and wheelchair users [5]. To address this feasibility problem we described the reasons for drop-out on the separate items of the Berg Balance Scale. The main reasons were difficulties understanding the task and physical limitations. Next, feasible subtests were composed with only the feasible items of the Berg Balance Scale, for each subgroup. Finally, we provided the scores on the Berg Balance Scale of the participants who completed all 14 items, which was the functionally more able part of the study sample. On the condition that the characteristics of the study sample are taken into account, these results can be used as norm-referenced values for older adults with ID.

It appeared in the 'Healthy ageing and intellectual disabilities' (HA-ID) study that the feasibility of the 10-meter incremental shuttle walking test (cardiorespiratory fitness) was a problem, because 61% of the participants did not reach the required peak heart rate during the test, which was a criterion to validly estimate maximal oxygen uptake [6, 7]. Therefore, we performed a literature review to provide an overview of published information concerning the validity and reliability of cardiorespiratory fitness testing in people with intellectual disabilities. We found that laboratory assessment with maximal treadmill protocols provides valid and reliable results of cardiorespiratory fitness levels of people with intellectual disabilities. However, laboratory testing is not suited for clinical practice. Several field tests have also been found reliable for cardiorespiratory fitness testing in people with intellectual disabilities. Comparisons of the results from field tests with maximal oxygen uptake results obtained from laboratory testing showed that field tests were valid indicators of cardiorespiratory fitness levels. However, estimating maximal oxygen uptake from field tests has been found problematic, due to the lack of appropriate equations for the population with intellectual disabilities and the requirements regarding high peak heart rates to validly estimate maximal oxygen uptake. The available equations are not generalizable to the entire population because of the small and selected samples they are based on. This limits the comparison of results against normative data of maximal oxygen uptake values.

Next, to bypass requirements regarding high peak heart rates and the problems with appropriate equations to estimate maximal oxygen uptake, we assessed the usefulness of heart rate recovery as an outcome measure of cardiorespiratory fitness testing. Heart rate recovery is the change from peak heart rate during the test to heart rate measured after passive recovery. It is an objective, non-invasive measurement, not requiring difficult equations, and requirements regarding high peak heart rates may be less important for heart rate recovery than for estimating maximal oxygen uptake [8, 9]. Heart rate recovery also reflects the activity of the autonomic nervous system [10], which may be of particular interest for the population with intellectual disabilities, since an altered autonomic modulation of heart rate is considered as one of the possible determinants for the low cardiorespiratory fitness levels found in this population [11-14]. We found that heart rate recovery was positively related to peak heart rates attained during the 10-meter incremental shuttle walking test. Therefore, using heart rate recovery as an outcome measure for cardiorespiratory fitness testing did not solve the problem of low numbers of participation due to too little exertion. Heart rate recovery was also related to the level of intellectual disability and the presence of Down syndrome, but not to gender and age as it is in the general population. This supports the idea that the autonomic control of heart rate is different in people with intellectual disabilities. So, although high peak heart rates are still required, heart rate recovery is a potentially relevant outcome measure for cardiorespiratory fitness testing in older adults with intellectual disabilities.

To address the lack of population specific validity research, we investigated the predictive (criterion) validity of the physical fitness tests for daily functioning (basic activities of daily living and mobility) and falls over a 3-year period. More than half of the participants (54.8%) declined in their ability to perform basic activities of daily living, and 37.5% declined in their mobility. Coordination (Box and Block test), visual reaction time (visual reaction time task), balance (Berg Balance Scale), comfortable and fast gait speed, muscular endurance (30s Chair stand), and cardiorespiratory fitness (10-meter incremental shuttle walking test) were significant predictors for a decline in the ability to perform activities of daily living. Coordination, balance, comfortable and fast walking speed, grip strength, muscular endurance, and cardiorespiratory fitness were significant predictors for a decline in mobility. These results prove the predictive validity of these physical fitness tests for daily functioning and stress the importance of using physical fitness tests and implementing physical fitness enhancing programs in the care of older adults with intellectual disabilities.

On the other hand, the physical fitness tests were not predictive for falls. Possible explanations for this result are the lifelong low physical fitness levels of people with intellectual disabilities [6, 15-17], possible strategies to compensate for these low fitness levels, and the finding that falls did not increase with age. The finding that physical fitness was not predictive for falls, but it was predictive for daily functioning may be explained by the fact that the relation between physical fitness and daily functioning is more direct than the relation between physical fitness and falls. Compensation strategies for low fitness levels may therefore not be effective for daily functioning. Another possible explanation is that the level of physical fitness required for daily functioning may be lower than that required to prevent falling, and the low physical fitness levels of older adults with intellectual disabilities [6] are therefore already too low to be able to find a predictive relationship between physical fitness and falls.

In conclusion, this thesis provided an additional instruction for grip strength testing, norm-referenced values of the Berg Balance Scale and subtests for subgroups with low completion rates, more knowledge regarding cardiorespiratory fitness testing and finally information regarding the predictive (criterion) validity of physical fitness tests for falls an daily functioning.

METHODOLOGICAL ISSUES

Bias

One methodological issue of this study is the selective drop-out. First, there was a selection bias regarding the recruitment of the HA-ID study sample through care organizations. This led to a study sample excluding older adults with intellectual disabilities not using any form of registered care or support (Appendix).

Second, drop-out during the informed consent procedure led to an underrepresentation of older adults with intellectual disabilities that only receive ambulatory support or only visit a day-activity center, thus the most independent group. There was also an underrepresentation of 80 to 84 year-olds, and a slight overrepresentation of women (Appendix).

And last, drop-out during the physical fitness assessment led to an underrepresentation of older adults with severe to profound intellectual disabilities and/or wheelchair users, due to difficulties executing the physical fitness tests. Drop-out differed between the physical fitness tests, as was an issue in the analyses regarding the predictive validity of the physical fitness tests for daily functioning and falls. Here, the selection of participants in the analysis varied across physical fitness test.

Thereby, the generalizability of our results to the entire population of older adults with intellectual disabilities is limited due to selection bias. More specifically, because of the drop-out during the physical fitness assessment, most of our results are reflecting the functionally more able part of the study sample and may not be directly applicable to the severely disabled groups.

Difficulties with exercise intensity

Some of the physical fitness tests required maximal performance. However, motivating people with an intellectual disability to perform maximally is a known issue in physical fitness testing [18, 19]. We prescribed the test instructors to provide 'maximal motivation'. In some cases, this meant that participants were motivated to engage in the tests by constant verbal encouragement and verbal rewarding, in other cases this meant that the test instructor had to remain very calm and quiet to motivate the participant as much as possible and prevent stress and anxiety. Test instructors were all physiotherapists, physical activity instructors, or occupational therapists with experience with exercising with people with intellectual disabilities, which was an important aspect in ensuring the most appropriate 'maximal motivation'.

Next to motivating the participants, test instructors had to assess if the participants indeed performed at their best. Test instructors subjectively evaluated this by looking for signs of effort associated with each test. In addition, peak heart rates, as a percentage of predicted maximal heart rate, were measured as an objective criterion to assess maximal performance on the cardiorespiratory fitness test. However, it is difficult to objectively identify maximal performance in older adults with intellectual disabilities on the basis of peak heart rates, because other studies found low peak heart rates during laboratory maximal exercise tests when maximal effort was assured with other objective criteria, such as respiratory exchange ratio [11, 20-22]. Due to these low peak heart rates, available equations to estimate maximal heart rates may not be suitable for older adults with intellectual disabilities. The low peak heart rates of people with intellectual disabilities may not necessarily be a sign of low effort, but might as well be caused by an altered physiological response to exercise, associated with the intellectual disability. This impedes the evaluation of maximal performance.

IMPLICATIONS AND RECOMMENDATIONS FOR PRACTICE

The implications and recommendations for practice of the results presented in this thesis can be divided into the topics 'improving physical fitness' and 'physical fitness testing'. The implications will be discussed here.

Improving physical fitness

Our finding that physical fitness is predictive for a decline in daily functioning (both basic activities of daily living and mobility) in older adults with intellectual disabilities, demonstrates that not just stimulating physical activity, but specifically improving physical fitness needs to become a basic part of the care of adults with intellectual disabilities. Even though this study was limited to older adults with intellectual disabilities, we think that this implication applies for people with intellectual disabilities of all ages, because of the low physical fitness levels seen across the lifespan [6, 15-17]. Putting great focus on improving physical fitness to prevent disability, or at least reduce a decline in disability, is in line with the policy of governments worldwide, as well as the Dutch Ministry of Health, Welfare, and Sport, who put a great focus on prevention [23, 24].

To enhance the physical fitness of people with intellectual disabilities, it is important to get them physically active at a certain intensity. Previous studies have shown that inactivity is a common finding in the population with intellectual disabilities [25-27], and physical activity has been found to successfully improve physical fitness levels of people with intellectual disabilities, across all ages [28-30]. As part of the HA-ID study, the 'Healthy Ageing – Physical Activity Programme' was developed and executed at day-activity centers of the participating care organizations [31]. This was an 8-month program consisting of a physical activity part and an education part. The physical activity part was performed three times a week and consisted of activities regarding physical fitness components cardiorespiratory fitness, strength, balance, and flexibility. The education part focused on increasing the awareness of normal bodily reactions to physical activity, the importance of physical activity for health, and making healthy lifestyle choices. The results are currently being analyzed, and preliminary results show positive effects on physical fitness levels. Since positive effects of physical activity on physical fitness fade out when one becomes inactive (again) [32, 33], promoting physical activity for people with intellectual disabilities and improving their physical fitness levels should become a high and continuing priority.

Getting people with intellectual disabilities structurally physically active is easier said than done. There are several barriers that limit the opportunities of people with intellectual disabilities to participate in sport and fitness-related activities organized for the general population. Important barriers are the low physical fitness starting levels and cognitive limitations of people with intellectual disabilities, which require adjusted sporting activities and specialized education regarding bodily reactions to physical activity and the importance of physical activity for health. Along with environmental and organizational barriers such as a lack of transportation, unqualified staff to adapt activities, and costs, these barriers limit the opportunities for people with intellectual disabilities to participate in sport and fitness-related activities designed for the general population [34].

These barriers need to be addressed to create opportunities for people with intellectual disabilities to become physically active. This is in line with article 30 of the Convention on the Rights of Persons with Disabilities, that states that people with disabilities should be able to participate on an equal basis with others in recreational, leisure, and sporting activities and thereby have access to services from those involved in organization of recreational, sporting, and leisure activities [35]. In the Netherlands, the municipalities are responsible for physical activity promotion for the general population. Since 2013, the financial resources for the care of people with intellectual disabilities, at least for the most independent groups, are gradually transferred from the government to the municipalities. The municipalities should therefore also make it their responsibility to promote physical activity for people with intellectual disabilities, and thereby address the abovementioned barriers.

Care organizations also have an essential role in getting people with intellectual disabilities physically active. They should emphasize on incorporating, at the very least, a basic level of physical activity for clients as part of their daily care, promoting a physically active lifestyle. In addition, they can collaborate with the municipalities in addressing the abovementioned barriers for participation in sport and fitness activities.

Physical fitness testing

Physical fitness tests are an important tool for clinical practice to evaluate the current fitness status of clients and the effect of physical activity and other therapeutic interventions on physical fitness levels. Even though this thesis did not address all gaps in knowledge (Table 1), among which the responsiveness of tests to change, we developed a first version of a standardized physical fitness test battery with the acquired knowledge so far from this thesis and previous results from the HA-ID study [5, 6, 36], to address the need for physical fitness tests in practice. The developed physical fitness test battery is called the VB-fitscan (VB is the Dutch abbreviation for intellectual disability), and an important footnote is thus that it is unknown how responsive it is to change. So far, around fifty physiotherapists have requested the VB-fitscan (www.onbeperktgezond.nl) and are working with it, demonstrating the need for it.

For physical fitness tests to be included in the VB-fitscan they had to be feasible and reliable in (older) adults with intellectual disabilities, and had to be valid and allow for comparisons with normative data of at least the general population and preferably the population with intellectual disabilities. Table 2 presents for each test whether the criteria were sufficiently fulfilled. Due to feasibility limitations in people with severe or profound intellectual disabilities, and wheelchair users, the VB-fitscan is suitable for adults with borderline to moderate intellectual disabilities, with at least some mobility.

The tests used in the HA-ID study that sufficiently met the criteria, and are therefore part of the VB-fitscan, are gait speed (dynamic balance), grip strength (strength), and the 30s chair stand (muscular endurance) (in grey in Table 2). To allow for optimal comparison with normative data of the general population, and due to limited available normative data for the population with intellectual disabilities, we chose to incorporate the Short Physical Performance Battery (SPPB) [37] in the VB-fitscan, which is only a minimal expansion of the test battery. The SPPB consists of a gait speed measurement (already in the VB-fitscan), three stances (side by side stance, semi-tandem stance, tandem stance),

Table 2. Overview of the criteria for the use of physical fitness tests in practice and whether they are sufficient fulfilled.

Criteria	Coordination (Box and Block test)	Reaction time (Reaction time task)	Balance (Berg Balance scale)	Speed (Gait speed)	Strength (Grip strength)	Muscular endurance (30s Chair stand)	Flexibility (Back saver sit and reach)	Cardiorespiratory fitness (Shuttle walking test)
Feasibility								
Completion rates*	✓	✓	✓	✓	✓	✓	✓	X
Clarity of instructions	✓	✓	✓	✓	✓	✓	✓	✓
Reliability in older adults with ID								
Test-retest reliability	✓	✓	✓	✓	✓	✓	✓	✓
Inter-rater reliability	✓	✓	✓	✓	✓	✓	✓	✓
Validity in older adults with ID								
Predictive validity for falls	X	X	X	X	X	X	X	X
Predictive validity for activities of daily living	✓	✓	✓	✓	X	✓	X	✓
Predictive validity for mobility	✓	X	✓	✓	✓	✓	X	✓
Responsiveness to change								
Comparability to normative data								
Norm-referenced values of the general population available				✓	✓	✓		X
Norm-referenced values of older adults with ID available			✓	✓	✓	✓		X
Criterion-referenced values of older adults with ID available								

✓= criterion sufficiently fulfilled; X = criterion insufficiently fulfilled; empty boxes = unaddressed gaps; ID = intellectual disabilities.

* Sufficient completion rates except for people with severe intellectual disabilities (reaction time test and Berg Balance Scale), profound intellectual disabilities (all tests), and wheelchair users (all tests involving the legs).

and the 5 times chair stand. The SPPB is a strong predictor for disability, institutionalization, and mortality, and is widely used to assess physical fitness of older adults in the general population [37-39]. The 5 times chair stand from the SPPB was added to muscular endurance testing, and the three stances of the SPPB replaced the Berg Balance Scale, thereby discarding less feasible items of the Berg Balance Scale, reducing the time investment, and allowing for comparison to normative data of the general population. A fourth stance, the one-leg stance, was added to reduce the ceiling effect. Even though the 5 times chair stand and the semi-tandem stance (the only stance that is not part of the Berg Balance scale) were not investigated in this thesis, they are very similar to the 30s chair stand and parts of the Berg Balance scale, respectively. We are therefore convinced that they are suitable for adults with ID. Finally, we added measures of height, weight, and waist circumference to measure the physical fitness component body composition. From previous research, it is known that these measures can be used in (older) adults with ID [40].

The tests for the other physical fitness components (cardiorespiratory fitness, flexibility, and reaction time) used in the HA-ID study, did not meet the criteria regarding feasibility and/or possibilities for comparison with normative data (Table 2). It is intended to add tests for the remaining physical fitness components as soon as they meet all criteria. At the same time, alternative or adapted tests to make the VB-fitscan suitable for subgroups with more severe disabilities, visual impairments, and children need to be added. More research is needed for this. To this end, a study regarding how to measure physical fitness in children with intellectual disabilities has recently started at the department of Intellectual Disability Medicine at the Erasmus MC.

Physiotherapists working with people with intellectual disabilities can play an important role in this further research, because of their expertise with activities and training with people with intellectual disabilities. Continuing to improve standardized physical fitness testing in people with intellectual disabilities is important for the profession of physiotherapists. With the current budget cuts and allocation of financial resources, physiotherapists need to be pro-active in evaluating their therapies and thereby providing evidence for the effectiveness of their therapies.

At the organizational level, care organizations for people with intellectual disabilities can use these physical fitness tests to evaluate how fit their clients are, and set care goals regarding these fitness results. In this way, care organizations can strengthen their position by showing that they emphasize the importance of the physical fitness of their clients by making it part of routine care.

DIRECTIONS FOR FUTURE RESEARCH

The directions for future research can be divided into two topics. First, directions related to the remaining gaps in knowledge for the use of physical fitness tests in clinical practice (Table 1). Second, falling seems to be a big problem in people with intellectual disabilities, and requires more research regarding risk factors. Directions for future research regarding these topics will be discussed here.

Remaining gaps in knowledge regarding physical fitness testing

The physical fitness tests were predictive for a decline in daily functioning, which represents one's independence in self-care. It is unknown if physical fitness tests are also predictive for a decline in instrumental activities of daily living (more complex skills, such as preparing a meal, telephone use, and managing finances [41]), which are also important for one's independence. Since the ability to perform instrumental activities of daily living usually declines prior to the loss of ability to perform basic activities of daily living [42], it is worthwhile to assess the predictive value of physical fitness tests for a decline in instrumental activities of daily living. Although the relation between physical fitness and instrumental activities of daily living may be less direct, this relation has been demonstrated in the general population [43-45]. If this relation also exists in people with intellectual disabilities, people at increased risk for developing or deteriorating in their daily functioning can be identified earlier on. This is currently being investigated with the longitudinal data of the HA-ID study. With these results, scores (criterion-referenced values) related to an increased risk for disability can be identified for people with intellectual disabilities. These scores will help with the interpretation of the physical fitness tests, and allow for the identification of people at risk for developing or deteriorating in their daily functioning.

In addition, the predictive validity of physical fitness for medical conditions and chronic diseases, such as metabolic syndrome, cardiovascular diseases, and all-cause mortality also needs to be confirmed in this population, to identify the role of physical fitness in improving and preventing medical conditions.

As mentioned before, the responsiveness to change of the physical fitness tests has not yet been investigated. This is an important aspect to be addressed in future research to identify in what amount changes in the physical fitness levels of clients can be identified with the physical fitness tests. This is essential for the evaluation of therapeutic interventions.

Finally, for the physical fitness components cardiorespiratory fitness, flexibility, coordination, and reaction time, no suitable tests for the use in practice could be identified. Further research should especially focus on a suitable cardiorespiratory fitness field test for clinical practice, since our review showed that low cardiorespiratory fitness levels have repeatedly been found in people with intellectual disabilities, and this was an important predictor for daily functioning in this population. There are valid and reliable field tests available. Nevertheless, there are no appropriate equations available to estimate maximal oxygen uptake and maximal heart rates of adults with intellectual disabilities, which makes it difficult to identify the endpoint of a field test. Due to the possibly altered autonomic control of heart rate [11-14] and lower maximal heart rates [11, 20-22] of people with intellectual disabilities, the endpoints for submaximal and maximal exercise field testing available for the general population may not be applicable to this population.

Falls

We did not find physical fitness to be predictive for falls in older adults with intellectual disabilities, and to date there is no consensus regarding risk factors for falls in the population with intellectual disabilities. Neither are there fall prevention guidelines available. However, a recent study showed positive results of obstacle course training in preventing falls [46]. Since falling is a big issue in people with intellectual disabilities, with a high incidence of fall related injuries [47-51], this is an important area for research to focus on.

One of the causes for falls may be the abnormal gait pattern of people with intellectual disabilities that is often seen in clinical practice. A normal gait is the result of an optimal shock absorption, stability, propulsion, and energy conservation. It requires the ability to stand up straight, bear one's body weight, and propel oneself forward at varying speeds, while determining one's position in space [52, 53]. People with intellectual disabilities have multiple factors that can disturb their gait. First, their low physical activity and fitness levels [6, 25, 26], because a certain amount of physical fitness is required for a normal gait. For example one needs enough strength and balance to maintain an upright posture, bear bodyweight, and propel forwards. The second factor is the high medication use of people with intellectual disabilities, and especially antipsychotics [54], which can negatively affect gait [55, 56]. In the HA-ID study, 40% of the study sample used 5 or more chronic medications [57]. Finally, the cognitive impairment is a possibly disturbing factor, since cognitive control is an essential part of gait, and gait abnormalities are seen with a decline in cognitive functioning [58-61].

In the general population, abnormalities in gait have been found to be related to falls [61-64]. So far, little research has been performed about the kind of gait abnormalities of people with intellectual disabilities and its relation to falls. To this end, a study regarding the gait abnormalities of adults with intellectual disabilities and the relation of these abnormalities with falls is now being set up.

CONCLUDING REMARKS

Gaps in the required knowledge for the use of physical fitness tests suitable for older adults with intellectual disabilities in clinical practice have been addressed in this thesis. Along with previous knowledge from the HA-ID study, this resulted in a standardized physical fitness test battery. Although further research is needed, (improving) physical fitness and using physical fitness tests should become a focus and part of the routine care of people with intellectual disabilities.

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Appendix

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 individualized 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 multicentre 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 that 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 participating 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 that 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.

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.

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)

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%).

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.

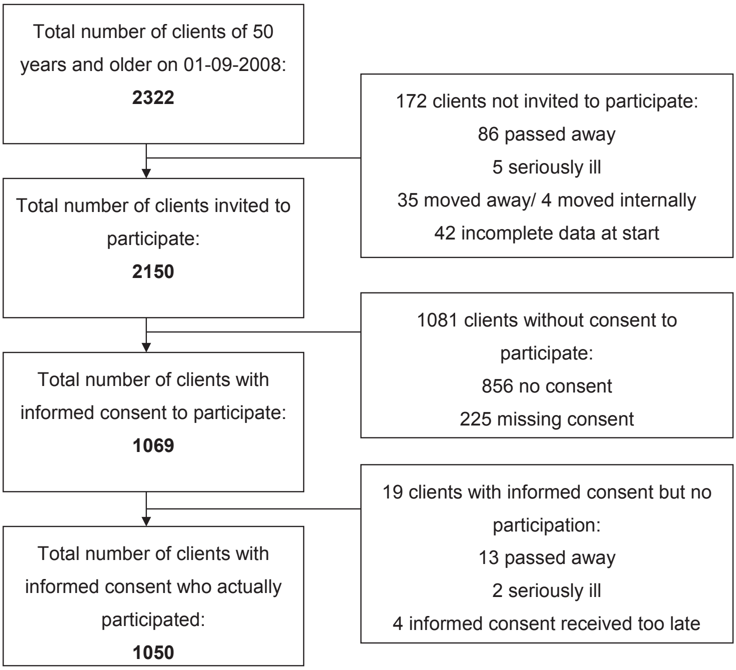

Figure 1. Flow chart inclusion of the HA-ID study.

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 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].

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	

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

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%

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.

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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]

Type	Outcome	Details
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].

Summary

Chapter 1 General Introduction

This thesis is about measuring physical fitness in older adults with intellectual disabilities. Physical fitness is a set of attributes or characteristics individuals have or achieve, that relate to their ability to perform physical activity. Physical fitness is strongly related to health and disability, and being physically fit is an essential factor for healthy ageing. People with intellectual disabilities are particularly at risk for low levels of physical fitness, due to a high prevalence of physical inactivity, sensory and mobility impairments, obesity, and chronic health conditions. As in the general population, the life expectancy of people with intellectual disabilities is increasing, and physical fitness tests can be an important tool in optimizing the care of this ageing population. Unfortunately, physical fitness tests suitable for this population are not yet available, and more research regarding this topic was needed. In the 'Healthy ageing and intellectual disabilities' (HA-ID) study, a first step has been made regarding investigating physical fitness tests for older adults with intellectual disabilities.

In the general introduction of this thesis we provided criteria for the use of physical fitness tests in clinical practice and identified the gaps in knowledge regarding these criteria. The criteria are categorized in feasibility, reliability, validity, responsiveness to change, and comparability to normative data. In this thesis we addressed the gaps in knowledge regarding feasibility, validity, and comparability to normative data.

FEASIBILITY

Chapter 2 Review cardiorespiratory fitness levels and testing

The feasibility of cardiorespiratory fitness testing (with the 10-meter incremental shuttle walking test) in the HA-ID study was limited due to the majority of participants being unable to reach the required peak heart rates to validly estimate maximal oxygen uptake. To address the feasibility problems regarding cardiorespiratory fitness testing, we first performed a literature review to provide an overview of the available literature regarding cardiorespiratory fitness levels and testing in people with intellectual disabilities. Our literature review showed that people with intellectual disabilities have low levels of cardiorespiratory fitness, and cardiorespiratory fitness levels are already low at young ages. Physical inactivity and chronotropic incompetence (inability of the heart to increase its rate proportional with increased activity or demand) are the most likely determinants for these low cardiorespiratory fitness levels.

Field tests have been found to be valid and reliable indicators of cardiorespiratory fitness. However, estimating maximal oxygen uptake from field tests has been found problematic due to the lack of appropriate equations for this population, due to often small and selected study samples. For a more precise measurement of cardiorespiratory fitness levels, valid and reliable maximal treadmill protocols for laboratory assessment are available for people with mild to moderate intellectual disabilities, after allowing for familiarization protocols.

Chapter 3 Heart rate recovery after the shuttle walking test

To bypass the problems with estimating maximal oxygen uptake after a cardiorespiratory fitness field test, we assessed the usefulness of heart rate recovery as an outcome measure of the 10-meter incremental shuttle walking test. Heart rate recovery is the rate of decline in heart rate after exercise, back to resting levels. Heart rate recovery is an objective, non-invasive measurement, not requiring difficult equations, and requirements regarding high peak heart rates may be less important for heart rate recovery than for estimating maximal oxygen uptake. In addition, heart rate recovery reflects the activity of the autonomic nervous system, which may be of particular interest for the population with ID, since an altered autonomic modulation of heart rate is considered as one of the possible determinants for the low cardiorespiratory fitness levels found in this population.

We defined heart rate recovery as the change from peak heart rate during the test, to heart rate measured after 1, 2, 3, 4, and 5 minutes of passive recovery. The largest decrease in heart rate was found in the first minute of recovery, leveling off towards the fifth minute of recovery. After the fifth minute of recovery, the heart rates of 69.4% of the participants with Down syndrome, and of 61.4% of the participants with intellectual disabilities by other causes returned to resting levels. Peak heart rate and distance walked on the 10-meter shuttle walking test were positively related to heart rate recovery. This indicates that heart rate recovery may be underestimated if participants do not exert themselves fully, and therefore peak heart rate is important for heart rate recovery. Finally, we found that heart rate recovery was related to level of intellectual disability and the presence of Down syndrome, but not to gender and age, as it is in the general population. This finding supports the idea that the autonomic control of heart rate is different in people with intellectual disabilities.

Although using heart rate recovery as an outcome measure does not solve the feasibility problems regarding inabilities to attain high peak heart rates, heart rate recovery is an objective, non-invasive measurement, not requiring difficult equations, and a potentially relevant outcome measure for cardiorespiratory fitness testing of older adults with intellectual disabilities.

Chapter 4 Handedness and grip strength

To improve the clarity of instructions for grip strength measurement we assessed the effect of handedness on grip strength in older adults with intellectual disabilities. Twenty-six percent of the study sample was left-handed; this percentage is about twice as high as in the general population. In right-handed participants the dominant (right) hand was on average 8.7% stronger than the non-dominant hand. For left-handed participants, there was no significant difference between the dominant and non-dominant hand. More detailed analyses revealed that the dominant hand was not always the strongest hand. In 34.5% of the participants the non-dominant hand was stronger, on average 16.6% stronger for right-handed participants and 16.3% stronger for left-handed participants. Because of the large strength differences found in this study, distributed in favor of both the dominant as the non-dominant hand, it is important that both hands are measured to get a valid result of the grip strength of older adults with intellectual disabilities.

FEASIBILITY AND NORMATIVE DATA

Chapter 5 Feasibility and outcomes Berg Balance Scale

In the HA-ID study, the balance capacities of older adults with intellectual disabilities were assessed with the Berg Balance Scale. The Berg Balance Scale is a reliable instrument for balance assessment of adults with intellectual disabilities. The participants who completed all 14 items of the Berg Balance Scale were the functionally more able part of the study sample, with less severe intellectual disabilities, less spasticity, less scoliosis, less visual and hearing impairments, and less mobility problems. Even this functionally more able part had poor balance capacities, with a mean score on the Berg Balance Scale of 47.2, 95% CI [46.3, 48.0], similar to adults in the general population aged around 20 years older. Balance capacities decreased with increasing age and females had poorer balance capacities than males. Balance scores presented in this study can be used as norm-referenced values for older adults with intellectual disabilities, on the condition that the characteristics of the study sample will be taken into account (functionally more able part of a fairly sedentary population).

The completion rates on the Berg Balance Scale were low for the subgroups with severe to profound intellectual disabilities and wheelchair users, with difficulties understanding the task and physical limitations as the main reasons for drop-out. Yet, feasible subtests, composed with only the feasible items of the Berg Balance Scale, were proposed for these subgroups, enabling some balance assessment in these subgroups.

Low balance capacities of older adults with intellectual disabilities suggest the need for regular screening and the urge for fall prevention programs for older adults with intellectual disabilities.

PREDICTIVE VALIDITY OF THE PHYSICAL FITNESS TESTS

Chapter 6 Physical fitness and falls

Poor balance, strength, muscular endurance, and slow gait speed are well-established risk factors for falls in the general population. Falling is an important issue in the population with intellectual disabilities, with high incidences of falls and related injuries. To assess if low balance capacities and physical fitness levels indeed lead to an increased fall risk, the predictive value of physical fitness (balance, strength, muscular endurance, and gait speed) for falls, over a 3-year period, was assessed.

We found that 25.5% of the participants had fallen in the three months prior to the follow-up measurement. Gait speed was lowest in participants who fell three times or more at follow-up. Gait speed was the only physical fitness component that significantly predicted falls, but did not remain significant after correcting for age, gender, falls at baseline, polypharmacy, Down syndrome, and epilepsy. Falls at baseline and not having Down syndrome were significant predictors for falls.

We found a limited predictive value of physical fitness for falls. Possible explanations may be the extremely low physical fitness levels across the entire group of older adults with intellectual disabilities, possible strategies to compensate for these low levels, and the finding that falls did not increase with age.

Chapter 7 Physical fitness predicts daily functioning

Last, the predictive value of the physical fitness tests for daily functioning, over a 3-year period, was assessed. Daily functioning was operationalized in basic activities of daily living (e.g. feeding, dressing, bathing, transfers) and mobility. Over the 3-year period, more than half of the participants (54.8%) declined in their ability to perform basic activities of daily living, and 37.5% declined in their mobility. At follow-up, 12.6% of the participants were completely independent in performing activities of daily living and 48.5% had no mobility limitations.

Coordination (Box and Block test), visual reaction time (visual reaction time task), balance (Berg Balance Scale), comfortable and fast gait speed, muscular endurance (30s Chair stand), and cardiorespiratory fitness (10-meter incremental shuttle walking test) were significant predictors for a decline in the ability to perform activities of daily living. Coordination, balance, comfortable and fast walking speed, grip strength, muscular endurance, and cardiorespiratory fitness were significant predictors for a decline in mobility.

These results prove the predictive validity of these physical fitness tests for daily functioning (both basic activities of daily living and mobility), and stress the importance of using physical fitness tests in the care of older adults with intellectual disabilities and implementing physical fitness enhancing programs.

Chapter 8 General Discussion

In this chapter the principal findings of this thesis, methodological issues, and implications and directions for practice and future research are discussed.

This thesis showed that physical fitness tests are predictive for a decline in daily functioning. Therefore, improving or maintaining physical fitness, necessary for daily functioning, should become an important part of the care of older adults with intellectual disabilities. For this goal, promoting a physically active lifestyle and providing opportunities to become active should become a high and continuing priority.

Standardized physical fitness testing should be incorporated in the routine (diagnostic) care of older adults with intellectual disabilities, to monitor and evaluate physical fitness levels, and set care goals regarding these fitness levels. To address the need of physiotherapist for physical fitness tests suitable for people with intellectual disabilities, we developed the VB-fitscan (VB is the Dutch abbreviation for intellectual disability). The VB-fitscan consists of the physical fitness tests for the fitness components body composition, static and dynamic balance, strength and muscular endurance, which proved to be suitable for (older) adults with mild to moderate intellectual disabilities and with some mobility. More research is needed to make the VB-fitscan suitable for subgroups with more severe intellectual and physical disabilities, to add physical fitness tests for the remaining physical fitness components (cardiorespiratory fitness, flexibility, and reaction time), and thereby to continue to develop standardized physical fitness testing for the entire population of people with intellectual disabilities.

Nederlandse samenvatting

Hoofdstuk 1 Algemene inleiding

Dit proefschrift gaat over het meten van lichamelijke fitheid bij ouderen met een verstandelijke beperking. Lichamelijke fitheid is een set van eigenschappen die mensen hebben of kunnen verwerven en die hen in staat stelt tot lichamelijke activiteit. Lichamelijke fitheid is sterk gerelateerd aan de gezondheid en beperkingen in het dagelijks leven. Fit zijn is dan ook een essentiële factor voor gezond ouder worden. Mensen met een verstandelijke beperking lopen in het bijzonder risico op een slechte lichamelijke fitheid, vanwege het frequent voorkomen van lichamelijke inactiviteit, sensorische en motorische beperkingen, obesitas en chronische aandoeningen. Net als in de algemene bevolking neemt de levensverwachting van mensen met een verstandelijke beperking toe en fitheidstesten kunnen een belangrijk middel zijn in het optimaliseren van de zorg voor deze verouderende bevolkingsgroep. Echter zijn er op dit moment nog geen geschikte fitheidstesten beschikbaar voor mensen met een verstandelijke beperking, dus hier was meer onderzoek naar nodig. In het onderzoek 'Gezond ouder met een verstandelijke beperking' (GOUD), is een eerste stap gemaakt in het onderzoek naar geschikte fitheidstesten voor ouderen met een verstandelijke beperking.

In de algemene inleiding van dit proefschrift hebben we criteria opgesteld waaraan een ideale fitheidstest moet voldoen als men deze in de dagelijkse praktijk wil gebruiken. Vervolgens hebben we het gebrek aan kennis op deze criteria in kaart gebracht. De criteria zijn ingedeeld in uitvoerbaarheid (deelnamepercentages en duidelijkheid van de instructies), betrouwbaarheid (consistentie van de testscores), validiteit (de mate waarin een test meet wat het beoogt te meten), responsiviteit voor verandering (mate waarin een test in staat is de werkelijke verandering te meten), en interpretatiemogelijkheden met referentiewaarden. Het gebrek aan kennis omtrent uitvoerbaarheid, validiteit, en interpretatiemogelijkheden wordt behandeld in dit proefschrift.

UITVOERBAARHEID

Hoofdstuk 2 Literatuuronderzoek cardiorespiratoire fitheid van mensen met een verstandelijke beperking

De uitvoerbaarheid van de cardiorespiratoire fitheidstest (de 10-meter incremental shuttle walking test) gebruikt in het GOUD onderzoek was beperkt, omdat het grootste deel van de deelnemers niet in staat was de vereiste piekhartslag te behalen die nodig was voor het berekenen van maximale zuurstofopname. Om deze opvallende resultaten in de juiste context te kunnen plaatsen, hebben we de nieuwste kennis over (het testen van) cardiorespiratoire fitheid bij mensen met een verstandelijke beperking door middel van een literatuuronderzoek in kaart gebracht. Uit dit literatuuronderzoek bleek dat mensen met een verstandelijke beperking al op jonge leeftijd een slechte cardiorespiratoire fitheid hebben, met een verdere afname bij het ouder worden. De meest waarschijnlijke determinanten voor deze slechte cardiorespiratoire fitheid zijn lichamelijke inactiviteit en chronotrope incompetentie (het onvermogen van het hart om de hartslag proportioneel aan de toegenomen vraag te verhogen).

Voor het meten van cardiorespiratoire fitheid bleken veldtesten valide en betrouwbare indicatoren. Echter het schatten van maximale zuurstofopname op basis van de resultaten op de veldtesten bleek problematisch, vanwege het gebrek aan geschikte formules voor mensen met een verstandelijke beperking door de vaak kleine en geselecteerde groepen in het onderzoek. Voor een preciezere meting van cardiorespiratoire fitheid zijn er valide en betrouwbare maximale loopbandprotocollen voor in het laboratorium beschikbaar voor mensen met een lichte tot matige verstandelijke beperking. Hiervoor zijn eerst oefensessies nodig.

Hoofdstuk 3 Hartslagherstel na de 10-m incremental shuttle walking test

Om de problemen met het schatten van maximale zuurstofopname van een veldtest te omzeilen, hebben we de bruikbaarheid van hartslagherstel als uitkomstmaat van de 10-meter incremental shuttle walking test onderzocht. Hartslagherstel is de snelheid waarmee de hartslag na inspanning weer terug is op het rustniveau, vaak uitgedrukt in de afname in slagen per minuut in de eerste minuut of minuten na inspanning. Hartslagherstel is een objectieve, niet-invasieve uitkomstmaat, waarvoor geen ingewikkelde formules nodig zijn. Daarnaast zijn de eisen aan de benodigde piekhartslag mogelijk minder belangrijk voor hartslagherstel dan voor het berekenen van maximale zuurstofopname. Tevens is hartslagherstel een indicatie voor de activiteit van het autonome zenuwstelsel. Dit is met name interessant voor de doelgroep mensen met een verstandelijke beperking, aangezien een afwijkende autonome controle (sympatische en parasympatische aansturing) van het hart één van de mogelijke determinanten is voor de slechte cardiorespiratoire fitheid van mensen met een verstandelijke beperking.

We hebben hartslagherstel gedefinieerd als het verschil tussen de piekhartslag behaald gedurende de test en de hartslag gemeten na 1, 2, 3, 4 en 5 minuten van passieve rust. De grootste afname in hartslag werd gevonden gedurende de eerste minuut van herstel, en de afname werd geleidelijk minder richting de vijfde minuut van herstel. Na de vijfde minuut van herstel was de hartslag van 69.4% van de deelnemers met Down syndroom en van 61.4% van de overige deelnemers met een verstandelijke beperking terug op rustniveau. Piekhartslag en de afstand gelopen op de 10-meter shuttle wandeltest waren positief gerelateerd aan hartslagherstel. Dit laat zien dat hartslagherstel mogelijk onderschat wordt als deelnemers zich niet volledig inspannen tijdens de test, en dat dus de behaalde piekhartslag wel degelijk van belang is voor hartslagherstel. Tot slot waren de mate van de verstandelijke beperking en het hebben van Down syndroom gerelateerd aan hartslagherstel, en leeftijd en geslacht niet. Dit is wel het geval in de algemene bevolking. Deze bevinding bevestigt het idee dat de autonome controle van het hart afwijkend is bij mensen met een verstandelijke beperking.

Het gebruik van hartslagherstel als uitkomstmaat lost niet het uitvoerbaarheidsprobleem met betrekking tot het niet kunnen behalen van de benodigde piekhartslag op. Hartslagherstel is echter wel een potentieel relevante uitkomstmaat voor het meten van de cardiorespiratoire fitheid van ouderen met een verstandelijke beperking omdat het een objectieve, niet-invasieve maat is, waar geen ingewikkelde formules voor nodig zijn.

Hoofdstuk 4 Het effect van handvoorkeur op knijpkracht

Om de duidelijkheid van instructies voor het meten van knijpkracht te verbeteren, hebben we het effect van handvoorkeur op de knijpkracht van ouderen met een verstandelijke beperking onderzocht. Zesentwintig procent van de onderzoeksgroep was linkshandig. Dit is ongeveer twee keer zoveel als in de algemene bevolking. Bij de rechtshandige deelnemers was de dominante (rechter-) hand gemiddeld 8.7% sterker dan de niet-dominante hand. Bij linkshandige deelnemers was er geen significant verschil in kracht tussen de dominante en niet-dominante hand. Meer gedetailleerde analyses lieten echter zien dat de dominante hand niet altijd de sterkste hand was. In 34.5% van de deelnemers was de niet-dominante hand sterker. De niet-dominante hand was gemiddeld 16.6% sterker in rechtshandige deelnemers en 16.3% sterker in linkshandige deelnemers.

Vanwege deze grote krachtverschillen, zowel in het voordeel van de dominante als de niet-dominante hand, is het belangrijk dat de knijpkracht van beide handen gemeten wordt om een valide resultaat van de knijpkracht van ouderen met een verstandelijke beperking te krijgen.

UITVOERBAARHEID EN INTERPRETATIEMOGELIJKHEDEN

Hoofdstuk 5 Uitvoerbaarheid en resultaten van de Berg Balans Schaal

In het GOUD onderzoek is de balans van ouderen met een verstandelijke beperking onderzocht met de Berg Balans Schaal. De Berg Balans Schaal bestaat uit 14 balanstaken en is een betrouwbaar instrument om de balans van volwassenen en ouderen met een verstandelijke beperking te meten. De deelnemers die alle 14 items van de Berg Balans Schaal hebben uitgevoerd waren de functioneel betere deelnemers van de studiegroep. Dit betekent dat ze een minder ernstige verstandelijke beperking hadden en minder last hadden van spasticiteit, scoliose, visuele en gehoorbeperkingen en mobiliteitsproblemen. Zelfs deze functioneel betere groep had een slechte balans, met een gemiddelde score op de Berg Balans Schaal van 47.2, 95% betrouwbaarheidsinterval [46.3, 48.0]. Deze score is vergelijkbaar met die van ouderen in de algemene bevolking van ongeveer 20 jaar ouder. De balans nam af met toenemende leeftijd, en vrouwen hadden een slechtere balans dan mannen. De scores op de Berg Balans Schaal gepresenteerd in dit onderzoek kunnen gebruikt worden als referentiewaarden voor ouderen met een verstandelijke beperking, op de voorwaarde dat er rekening gehouden wordt met de kenmerken van de studiegroep (de functioneel betere groep van een behoorlijk sedentaire bevolkingsgroep).

De deelnamepercentages van de Berg Balans Schaal waren laag voor de subgroepen met een ernstige tot zeer ernstige verstandelijke beperking en voor rolstoelgebruikers. De belangrijkste redenen voor uitval waren dan ook problemen met het begrijpen van de taak en lichamelijke beperkingen. Subtesten met alleen de uitvoerbare items (≥ 50% deelnamepercentage) van de Berg Balans Schaal worden voorgesteld voor deze subgroepen, wat het mogelijk maakt om toch een aantal balansmetingen te doen in deze subgroepen.

De slechte balans van ouderen met een verstandelijke beperking geeft aanleiding voor regelmatige screening en het ontwikkelen en invoeren van valpreventieprogramma's voor ouderen met een verstandelijke beperking.

PREDICTIEVE VALIDITEIT VAN DE FITHEIDSTESTEN

Hoofdstuk 6 De voorspellende waarde van lichamelijke fitheid voor vallen

Een slechte balans, weinig kracht en beenkrachtuithoudingsvermogen, en een lage wandelsnelheid zijn risico factoren voor vallen in de algemene bevolking. Vallen is een belangrijk probleem bij mensen met een verstandelijke beperking. Er is een hoge incidentie van vallen met daaraan gerelateerde verwondingen. Om te bepalen of een slechte balans en een slechte lichamelijke fitheid inderdaad leiden tot een verhoogd valrisico, hebben we de voorspellende waarde van lichamelijke fitheid (balans, kracht, beenkrachtuithoudingsvermogen, en wandelsnelheid) voor vallen, over een periode van drie jaar, onderzocht.

Wij vonden dat drie jaar na de start van het GOUD onderzoek, 25.5% van de deelnemers in de drie maanden voor de follow-up meting gevallen was. De wandelsnelheid was het laagste in de deelnemers die drie keer of vaker waren gevallen. Wandelsnelheid was de enige lichamelijke fitheidscomponent die een significante voorspeller was voor vallen, maar bleef geen significante voorspeller na correctie voor leeftijd, geslacht, eerder vallen, het gebruiken van meerdere medicatie en het hebben van Down syndroom en epilepsie. Eerder vallen (in de drie maanden voor de beginmeting van het GOUD onderzoek) en het niet hebben van Down syndroom waren significante voorspellers voor vallen.

In dit onderzoek is een beperkte voorspellende waarde van lichamelijke fitheid voor vallen gevonden. Mogelijke verklaringen hiervoor zijn de extreem lage lichamelijke fitheidsniveaus van ouderen met een verstandelijke beperking, hun mogelijke strategieën om te compenseren voor deze lage fitheidsniveaus, en de bevinding dat vallen niet toeneemt met de leeftijd zoals in de algemene bevolking wel het geval is.

Hoofdstuk 7 Lichamelijke fitheid voorspelt een afname in het dagelijks functioneren

Tot slot hebben we de voorspellende waarde van lichamelijke fitheid voor het dagelijks functioneren, over een periode van drie jaar onderzocht. Dagelijks functioneren werd gedefinieerd als activiteiten van het dagelijks leven (bijvoorbeeld eten, aankleden, baden/douchen, uiterlijke verzorging) en mobiliteit. In de 3-jarige follow-up periode verslechterde meer dan de helft van de deelnemers (54.8%) in hun vermogen om activiteiten van het dagelijks leven uit te voeren, en ook de mobiliteit van 37.5% van de deelnemers verslechterde. Bij de follow-up meting was 12.6% van de deelnemers volledig onafhankelijk in het uitvoeren van dagelijkse activiteiten en 48.5% had geen mobiliteitsbeperkingen.

Coördinatie (Box en Block test), visuele reactietijd (visuele reactietijd taak), balans (Berg Balans Schaal), comfortabele en snelle wandelsnelheid, beenkrachtuithoudingsvermogen (de 30s Chair stand), en cardiorespiratoire fitheid (de 10-meter incremental shuttle walking test) waren significante voorspellers voor een achteruitgang in het vermogen om activiteiten van het dagelijks leven uit te voeren. Coördinatie, balans, comfortabele en snelle wandelsnelheid, knijpkracht, beenkrachtuithoudingsvermogen, en cardiorespiratoire fitheid waren significante voorspellers voor een achteruitgang in mobiliteit.

Deze resultaten tonen de predictieve (voorspellende) validiteit van deze fitheidstesten aan voor het dagelijks functioneren (zowel voor activiteiten van het dagelijks leven als voor mobiliteit). Tevens tonen deze resultaten het belang aan van het gebruik van fitheidstesten in de zorg voor ouderen met een verstandelijke beperking en het implementeren van programma's om de lichamelijke fitheid te verbeteren.

Hoofdstuk 8 Algemene discussie

In dit hoofdstuk zijn de belangrijkste bevindingen van dit proefschrift samengevat. Daarnaast worden de methodologische kwesties en aanbevelingen voor de praktijk en verder onderzoek besproken. Dit proefschrift toont aan dat fitheidstesten voorspellend zijn voor de achteruitgang in het dagelijks functioneren. Het is daarom van belang dat het verbeteren of behouden van lichamelijke fitheid, noodzakelijk voor het dagelijks functioneren, een belangrijk onderdeel wordt in de zorg voor ouderen met een verstandelijke beperking. Het promoten van een actieve leefstijl en het bieden van mogelijkheden om actief te zijn moeten een hoge en blijvende prioriteit worden.

Gestandaardiseerde fitheidsmetingen moeten worden opgenomen in de dagelijkse (diagnostische) zorg voor ouderen met een verstandelijke beperking zodat men de fitheidniveaus kan monitoren en evalueren, en aan de hand hiervan zorgdoelen kan op stellen. Om gehoor te geven aan de vraag van fysiotherapeuten naar geschikte fitheidstesten voor mensen met een verstandelijke beperking, hebben we de VB-fitscan (VB staat voor Verstandelijke Beperking) ontwikkeld. De VB-fitscan bestaat uit de fitheidstesten voor de fitheidscomponenten lichaamssamenstelling, statische en dynamische balans, kracht, en krachtuithoudingsvermogen, waarvan bewezen is dat ze geschikt zijn voor volwassenen met een lichte tot matige verstandelijke beperking en enige mobiliteit. Meer onderzoek is nodig om de VB-fitscan geschikt te maken voor subgroepen met ernstigere verstandelijke en lichamelijke beperkingen en uit te breiden met fitheidstesten voor de overige fitheidscomponenten (cardiorespiratoire fitheid, flexibiliteit, en reactietijd), en daarmee het gestandaardiseerd testen van lichamelijk fitheid te blijven ontwikkelen voor de gehele groep van mensen met een verstandelijke beperking.

Dankwoord

DANKWOORD

Op deze plek wil ik graag iedereen bedanken die heeft bijgedragen aan dit proefschrift.

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Curriculum Vitae

CURRICULUM VITAE

Alyt Oppewal is op 17 april 1988 geboren in Sneek. In 2006 heeft zij haar VWO diploma gehaald aan de RSG Magister Alvinus te Sneek. Aansluitend begon zij aan de opleiding Bewegingswetenschappen aan de Rijksuniversiteit Groningen. In haar bachelor afstudeeronderzoek onderzocht ze de relatie tussen balans en aandacht bij ouderen met dementie. Dit heeft haar interesse gewekt voor het verouderingsproces en de relatie tussen beweging en cognitie. De keus voor de master Bewegingswetenschappen met de afstudeerrichting 'Veroudering, bewegen en gezondheid' was daarom snel gemaakt. Haar afstudeeronderzoek ging over het effect van een beweegprogramma op de fitheid, cognitie en het dagelijks functioneren bij ouderen met dementie. Na haar afstuderen in augustus 2011, gaf zij kort statistiek bijles aan pre-master HBO studenten.

In februari 2012 verhuisde ze naar Rotterdam om daar in maart te beginnen aan haar promotieonderzoek aan de leerstoel Geneeskunde voor Verstandelijk Gehandicapten bij het Erasmus MC. Dit promotieonderzoek was onderdeel van het onderzoek Gezond ouder met een verstandelijke beperking (GOUD) dat werd opgezet vanuit een consortium bestaande uit de Leerstoel Geneeskunde voor Verstandelijk Gehandicapten en drie zorgorganisaties (Ipse de Bruggen, Abrona, Amarant), en in samenwerking met Bewegingswetenschappen Groningen. Haar promotieonderzoek richtte zich op het meten van lichamelijke fitheid bij ouderen met een verstandelijke beperking en de resultaten van dit onderzoek staan beschreven in dit proefschrift.

Per 1 maart 2014 is zij werkzaam bij de leerstoel Geneeskunde voor Verstandelijk Gehandicapten als postdoc, waar ze werkt aan een onderzoek naar het looppatroon van volwassenen met een verstandelijke beperking. Tevens geeft ze methodologische begeleiding bij leeronderzoeken van de specialistenopleiding tot arts voor verstandelijk gehandicapten van het Erasmus MC.

PhD Portfolio

PHD PORTFOLIO

Summary of PhD training and teaching

Name PhD student:	Alyt Oppewal
Erasmus MC department:	Intellectual Disability Medicine, Department of General Practice
PhD period:	March 2012 – March 2014
Promotor:	Prof. dr. H.M. Evenhuis
Supervisor:	Dr. T.I.M. Hilgenkamp

1. PhD training	Year	Workload (ECTS)
General courses		
- Biomedical English Writing and Communication	2013	4.0
- BROK ('Basiscursus Regelgeving en Organisatie van Klinisch onderzoek')	2012	1.0
Specific courses		
- Gait analysis course ESMAC	2013	1.0
- Biostatistical Methods I: Basic Principles	2012	5.7
Seminars and workshops		
- Workshop Physiotherapy congres	2013	1.0
- Workshop GOUD symposium	2014	1.0
Presentations		
- Departmental presentations (oral presentations)	2012 – 2014	2.0
- International meeting research group Mental health & Wellbeing Glasgow (oral presentation)	2014	0.8
- Department of Primary and Community Health Care Nijmegen (oral presentation)	2013	0.8
- International meeting research group Institute for Biomedicine of Aging (oral presentation)	2013	0.8
- Physiotherapists meeting (oral presentation)	2013	0.8
(Inter) national conferences		
- 19th annual Congress European College of Sport Science (mini-oral)	2014	1.0
- 9th International Congress EUGMS (poster presentation)	2013	1.0
- 22nd annual meeting ESMAC (attendance)	2013	1.0
- Symposium VvBN (attendance)	2013	0.3
- VvBN intellectual disability meeting (attendance)	2013	0.1
- Annual congress SMALLL (attendance)	2012	0.3
- NVFVG study day (attendance)	2012	0.3
- Symposium VvBN (attendance)	2012	0.3

2. Teaching	Year	Workload (ECTS)
Supervising		
- 2 bachelor Physiotherapy student research projects	2013 – 2014	2.0
- Human Movement Engineering student internship	2013 – 2014	3.0
- International master Physical Activity and Health research project	2013	2.0
Other		
- Supervising student sessions 'How to judge a paper'	2013	0.3

List of publications

LIST OF PUBLICATIONS

Oppewal, A., Hilgenkamp, T.I.M., van Wijck, R., Schoufour, J.D., Evenhuis, H.M. Physical fitness is predictive for a decline in daily functioning in older adults with intellectual disabilities: Results of the HA-ID study. (2014). *Research in Developmental Disabilities, 35*(10), 2299-2315 (5-year IF 2.869, rank 2/69 Rehabilitation, 1/37 Special Education).

Oppewal, A., Hilgenkamp, T.I.M., van Wijck, R., Schoufour, J.D., Evenhuis, H.M. The predictive value of physical fitness for falls in older adults with intellectual disabilities. (2014). *Research in Developmental Disabilities, 35*(6), 1317-1325 (5-year IF 2.869, rank 2/69 Rehabilitation, 1/37 Special Education).

Oppewal, A., Hilgenkamp, T.I.M., van Wijck, R., Evenhuis, H.M. Heart rate recovery after the 10-m incremental shuttle walking test in older adults with intellectual disabilities. (2014). *Research in Developmental Disabilities, 35*(3), 696-704 (5-year IF 2.869, rank 2/69 Rehabilitation, 1/37 Special Education).

Oppewal, A., Hilgenkamp, T.I.M., van Wijck, R., Evenhuis, H.M. Cardiorespiratory fitness in individuals with intellectual disabilities – A review. (2013). *Research in Developmental Disabilities, 34*(10), 3301-3316 (5-year IF 2.869, rank 2/69 Rehabilitation, 1/37 Special Education).

Oppewal, A., Hilgenkamp, T.I.M., van Wijck, R., Evenhuis, H.M. Feasibility and outcomes of the Berg Balance Scale in older adults with intellectual disabilities. (2013). *Research in Developmental Disabilities, 34*(9), 2743-2752 (5-year IF 2.869, rank 2/69 Rehabilitation, 1/37 Special Education).

Oppewal, A., Hilgenkamp, T.I.M., van Wijck, R., Evenhuis, H.M. The effect of handedness on grip strength on older adults with intellectual disabilities. (2013). *Research in Developmental Disabilities, 34*(5), 1623-1629 (5-year IF 2.869, rank 2/69 Rehabilitation, 1/37 Special Education).

CONFERENCE PROCEEDINGS

Oppewal, A., Hilgenkamp, T.I.M., van Wijck, R., Evenhuis, H.M. Feasibility and outcomes of the Berg Balance Scale in older adults with intellectual disabilities. (2013). *European Geriatric Medicine, 4* (suppl. 1), S1-S234 (Meeting abstract 9th EUGMS Congress; 5-year IF 0.613, rank 47/49 Geriatrics and Gerontology).