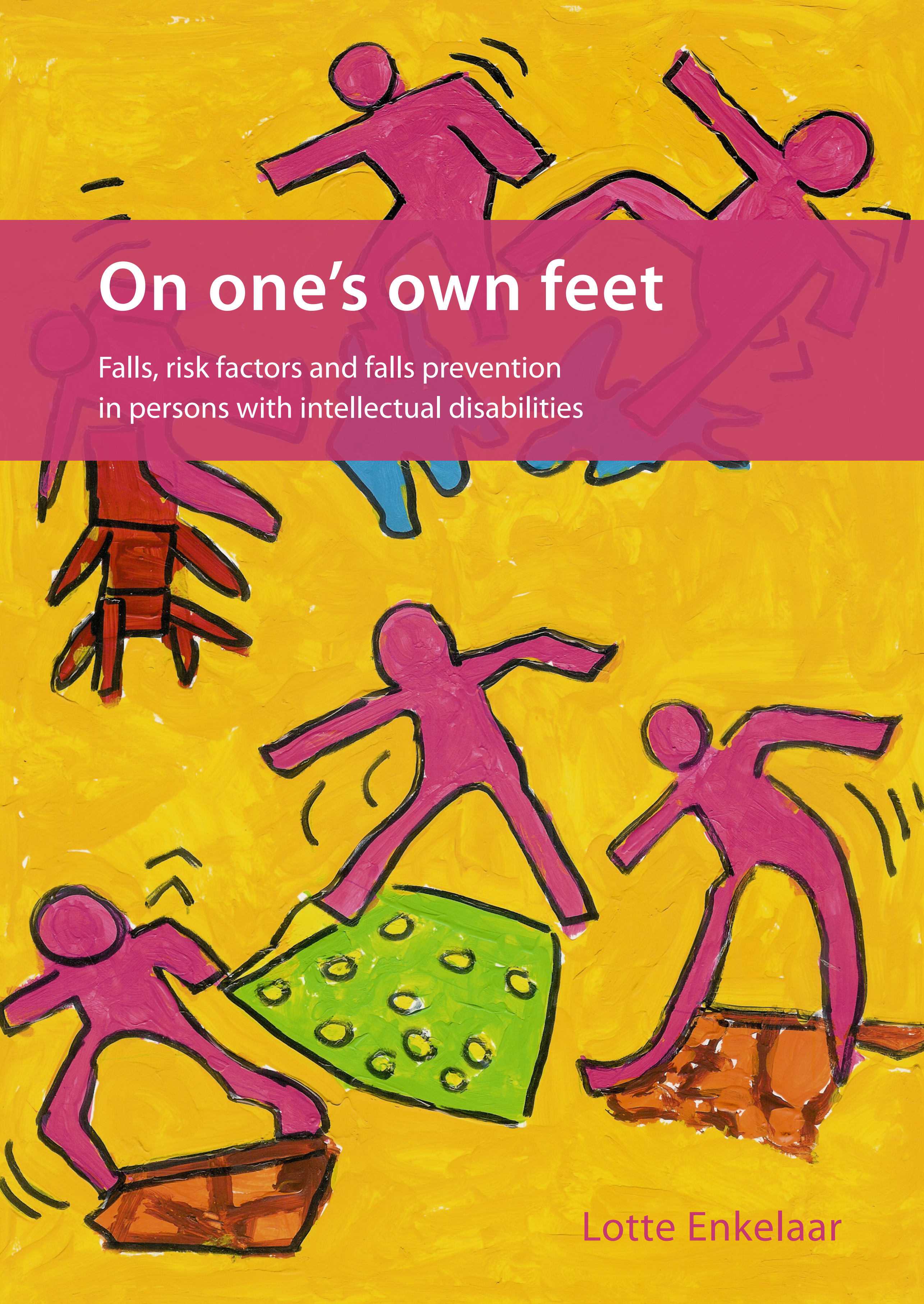
# On one's own feet

## Falls, risk factors and falls prevention in persons with intellectual disabilities



Lotte Enkelaar

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**Lotte Enkelaar**

The studies represented in this thesis were carried out at the Radboud University Medical Centre (Department of Rehabilitation), Nijmegen, the Netherlands and supported by grants from the consortium 'Stronger on your own feet' and the Organization for Health-care Research and Development in the Netherlands (ZonMw).

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## Falls, risk factors and falls prevention in persons with intellectual disabilities

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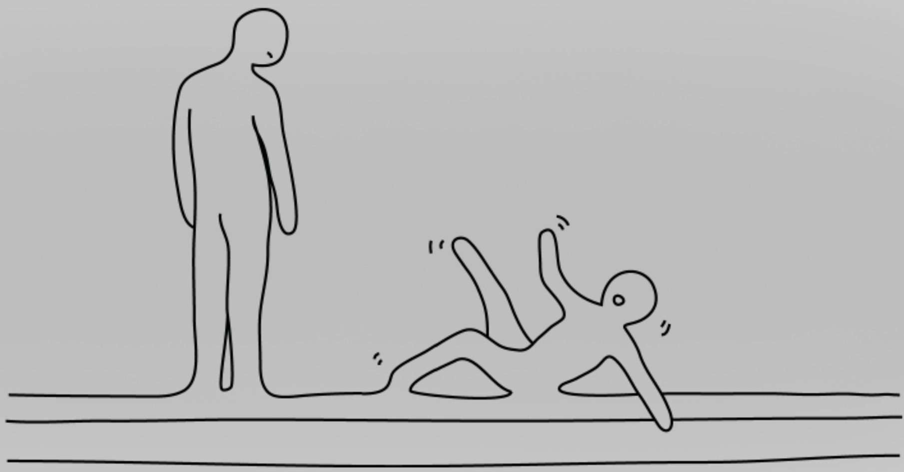
*Voor Thijs*

# Contents



# Chapter 1

# General introduction

## Falls in elderly persons with intellectual disabilities

Elderly persons with Intellectual Disabilities (ID) are at an increased risk of falls[1,2] and fall related injuries compared to elderly in the general population. Furthermore, they are at a greater risk of fractures, which is probably related to a relatively low bone density.[3-5] Although there has been extensive research on risk factors for falls in the general elderly population, similar studies in persons with ID are sparse. Therefore, the causes underlying their increased fall risk remain largely unknown.

A fall is an unexpected event in which a person comes to rest on the ground, floor, or lower level.[6] Because of the high morbidity and mortality rates associated with falls, a lot of research has been conducted on falls among elderly in the general population. This research has shown that one third of the community-dwelling elderly falls at least once a year.[7,8] Of these falls, approximately 10% result in injuries, hospitalization and/or death.[9] In the Netherlands, the direct total health costs related to falls in persons older than 65 years have been estimated at 820 million euro per year.[10]

Because of the major impact falls can have on the lives of individuals and their surrounding and because of the high costs that are associated with falls, fall prevention is very important. To develop effective fall prevention strategies it is essential to first identify the most important risk factors for falls. These risk factors have been extensively studied and documented for the general elderly population and can be divided into *extrinsic* (i.e. environmental factors such as obstacles and support surface) and *intrinsic* factors (i.e. factors related to the physical and cognitive status of an individual).[7] The most important intrinsic risk factors for falls in the general population are mobility problems (reduced balance and gait capacity), advanced age, inability to perform activities of daily living, impaired sensory and neuromuscular functions, medical conditions (e.g. stroke and Parkinson's disease), use of psychotropic drugs, poly-pharmacy, and cognitive and behavioural impairments.[7,8]

Although little scientific data are available on the risk factors for falls in (elderly) persons with ID, many of the above-mentioned intrinsic risk factors for the general population seem to be applicable to the ID population as well. For instance, gait problems are more prevalent in persons with ID[11], while they also have more balance problems[12,13] and less muscle strength compared to age matched control subjects.[14] Furthermore, sensory impairments are highly prevalent[15] in persons with ID, of which visual impairments are particularly important for balance and gait capacities.[16,17] The ID population is also characterized by frequent co-morbidities and poly-pharmacy that render these persons prone to falling.[18] Lastly, persons with ID (per definition) suffer from cognitive impairments, which further adds to their increased fall risk.[7,8]

Even though many of the possible intrinsic risk factors for falls may be comparable for the general elderly population and (elderly) persons with ID, their relative importance may differ substantially between these populations. Moreover, while falling becomes a health problem in the general population usually above the age of 65 years, it seems a health problem in the ID population already at a relatively young age.[3] This may be due either to the early onset of co-morbidities or to the early manifestation of generalized age-related decline of physical and cognitive functioning in the ID population.[19,20] This empirical knowledge is the reason that in this thesis persons with ID are considered 'elderly' from the age of 50 years.

Although there have been some explorative studies that addressed falling, prospective studies on risk factors for falls are not available for the ID population. Yet, prospective monitoring of falls is recommended by the Prevention of Falls Network Europe (ProFaNe), because it is much less sensitive to recall bias and, thus, underestimation of fall rate than retrospective studies.[6] Knowledge on risk factors for falls in persons with ID based on prospective cohort studies is a prerequisite for the development of targeted intervention strategies and a first step towards the prevention of falls in this population.

In 2007, based on the intention to improve their health care based on scientific evidence, three service providers for persons with ID in the eastern part of the Netherlands (Dichterbij, Siza and Pluryn) in collaboration with the Radboud University Medical Centre (RUMC) started the Dutch research consortium 'Stronger on your own feet'. They organized a consultation amongst clinicians and managers of the three service providers to identify a top-ten of most urgent health problems in the ID population and invited scientist of the RUMC to propose a research project on one of these topics. One of the elected research projects, initiated by the department of Rehabilitation, was a prospective study on the risk factors for falls in elderly with ID. This research project has eventually led to the studies that constitute this thesis. Before the overall objective and outline of this thesis are addressed, this introduction will elaborate on some of the important definitions, underlying causes and health problems associated with intellectual disabilities.

## Intellectual disabilities

Intellectual Disability (ID) is a disability characterized by significant limitations both in intellectual functioning and in adaptive behaviour as expressed in conceptual, social, and practical adaptive skills. ID originates before the age of 18 years.[21] According to the World Health Organisation (WHO) the severity of ID can be classified into mild (Intelligence

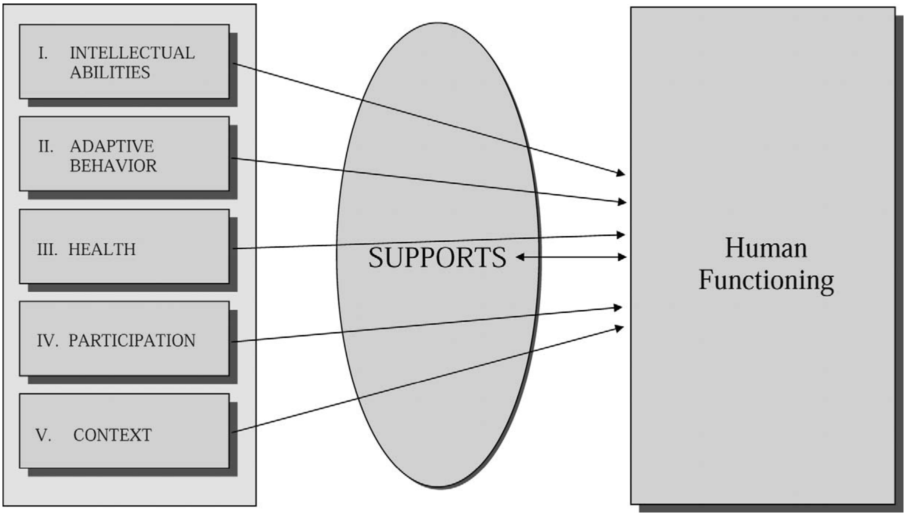



**Figure 1.1** Conceptual framework of human functioning.[21]

Quotient (IQ) 50-69, adult developmental age 9-12 years), moderate (IQ 49-35, adult developmental age 6-9 years), severe (IQ 34-20, adult developmental age 3-6 years) and profound (IQ <20, adult developmental age < 3 years).[22] A widely used multidimensional framework for understanding ID is shown in Figure 1.1.[21]

This model shows that human functioning, and thus the manifestation of ID, is not only influenced by intellectual abilities, but also by (adaptive) behaviour, health, (social) participation, (social) context and individual support. This model emphasises the critical role that support can play in individual human functioning, which opens possibilities for improving human functioning.[21]

There are multiple causes of ID, however, the exact cause remains unknown in many individuals. The causes of ID can be divided into a genetic and environmental origin. Some well known genetic causes of ID are expressed in the following syndromes: Down syndrome; Williams syndrome; Fragile X syndrome; Prader-Willi syndrome; Velocardiofacial syndrome; Rubinstein-Taybi syndrome; Smith-Magenis syndrome; and Angelman syndrome.[21,23] An example of an environmental origin of ID is acquired brain damage, for instance as a result of a maternal infection during pregnancy or perinatal complications.[23]

## Recent developments in health care for persons with intellectual disabilities

In the Netherlands, the number of persons with ID who are receiving care is increasing. Some important underlying reasons for this development are better diagnostics in early childhood and increased life expectancy due to improved health care in persons with ID.[24] In 2009 the estimated number of persons with ID in the Netherlands was 160,000.[25] The latest available figures have shown that in 2007 the total costs involved in the care for persons with ID took up roughly a quarter of the total budget funded through the Exceptional Medical Expenses Act (4.7 billion euro).[24]

Until the nineties of the previous century, half of the people with ID in the Netherlands lived in residential facilities, whereas the other half lived with their families or in small scale supported living accommodations in the community. In the last decades an increasing number of persons with ID moved from residential care facilities to such smaller housing in the society.[24,26,27] This development was facilitated by the Dutch government's policy targeted at 'full citizenship' for everyone, including persons with ID.[26]

## Health and aging in persons with intellectual disabilities

As already mentioned, persons with ID often have more health problems than their peers of similar age in the general population.[28,29] Indeed, persons with ID pay 1.7 times more visits to their general practitioner and receive four times as many repeat prescriptions for drugs than their counterparts.[18] Nevertheless, their life expectancy is increasing.[30] As a result, the number of elderly persons with ID is growing.[31] Because health problems generally increase with age, this development results in more age related problems also in the ID population.[11,15] Frequent age related problems in persons with ID are visual impairments, hearing loss, mobility problems, osteoporosis, gastrointestinal problems, in addition to cardiovascular, musculoskeletal, neurological, infectious and respiratory disorders.[11,15,20,28] Moreover, a study on the health status of adults with ID in 14 European countries showed that 52% of these people hardly participated in physical activities.[11] In the same vein, a recent study in elderly persons with ID showed that only 17% complied with the recommended 10,000 steps/day.[32]

One of the major age related problems in persons with ID is a decline in mobility.[19] Mobility is the activity of moving from one place to another and is depending upon a person's body functions, structures and capacities, with balance and gait being two key aspects.[33] In the general elderly population impaired mobility is known to be the most important risk factor for falls.[34] It is therefore likely that elderly persons with ID are at an even higher risk of falls and it is essential that falls and fall risk are better understood with regard to this specific and vulnerable population.

## Aim and outline of this thesis

The overall objective of this thesis is to determine the most important risk factors for falls in elderly persons (>50 years) with mild to moderate ID and to explore possible interventions to prevent falls. More specifically, it was aimed to investigate the role of mobility (gait and balance) problems in the causation of falls in persons with ID. Deliberately, people with severe and profound ID were not included in the majority of studies in this research because it was expected that their verbal capacities were too limited to comply with the balance and gait test which was a vital part of our assessment.

The **first part** of this thesis focuses on balance and gait impairments in persons with ID, because these problems have been shown to be the most important risk factors for falls in the general population.[34] It starts with a literature review on balance and gait problems in persons with ID, in which also their relation to falls and their trainability in persons with ID are addressed (**Chapter 2**). The next chapter (**Chapter 3**) describes a study that aimed to determine whether it was feasible to apply a comprehensive set of frequently used clinical balance and gait tests to older persons with ID. An additional goal of this study was to compare the balance and gait capacities of the persons with ID to those of their age matched peers in the general population. Thirdly, it was aimed to identify possible determinants that might contribute to balance and gait performance, such as age, sex, Body Mass Index (BMI), etiology and severity of ID, fear of falling, number of co-morbidities, number of medications, and use of psychotropic drugs.

In the **second part** of this thesis fall rate and risk factors for falls in elderly persons with ID are prospectively investigated. **Chapter 4** describes a prospective study on fall rate, fall circumstances and consequences of falling in older (>50 years) persons with mild to moderate ID. Fall incidents were monitored for one year by means of monthly fall registration calendars. Information about the circumstances and consequences of the falls was collected with a fall incidence questionnaire. In **Chapter 5** the most important risk factors for falls in elderly persons (>50 years) with mild to moderate ID were identified based on the results of Chapter 4. This longitudinal cohort study involved a one-year follow-up on fall incidents. All participants completed a fall risk assessment at baseline which enabled the prospective comparison of risk factors between fallers and non-fallers. The baseline assessments consisted of clinical tests of mobility and cognition, questionnaires regarding sensorimotor abilities, activity level and behaviour, and a medical chart review regarding demographic characteristics, medication use and co-morbidities. The results were compared between fallers and non-fallers to gain more insight in risk factors for falls in persons with ID. In addition, the differences in risk factors between indoor and outdoor fallers were explored.

The **third part** of this thesis focuses on possible interventions to prevent future falls in persons with ID. **Chapter 6** illustrates the development, implementation and evaluation of a multifactorial fall risk assessment and intervention strategy for persons with ID. This "Falls clinic for persons with ID" was developed based on existing guidelines, literature, and expert meetings. A process evaluation was conducted using evaluation forms and focus groups. **Chapter 7** describes a study that evaluated whether an obstacle course training would improve balance and gait capacity and prevent falls in persons with ID. The obstacle course training applied in this study was derived from the "Nijmegen Falls Prevention Program" originally developed for healthy elderly with a fall history.[35]

In the final chapter (**Chapter 8**) all research findings are summarized and discussed. Moreover, recommendations for future research and clinical practice are given.

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# PART I

## Balance and gait problems in persons with ID

# Chapter 2

# A review of balance and gait capacities in relation to falls in persons with intellectual disability

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## Abstract

Limitations in mobility are common in persons with intellectual disabilities (ID). As balance and gait capacities are key aspects of mobility, the prevalence of balance and gait problems is also expected to be high in this population. The objective of this study was to critically review the available literature on balance and gait characteristics in persons with ID. Furthermore, the consequences of balance and gait problems in relation to falls were studied, as well as the trainability of balance and gait in persons with ID. The systematic literature search identified 48 articles to be included in this review. The literature consistently reports that balance and gait capacities are affected in persons with ID compared to their age-matched peers. These problems start at a young age and remain present during the entire lifespan of persons with ID, with a relatively early occurrence of age-related decline. From these results a conceptual model was suggested in which the development of balance and gait capacities in the ID population across the life span are compared to the general population. Regarding the second objective, our review showed that, although the relationship of balance and gait problems with falls has not yet been thoroughly investigated in persons with ID, there is some preliminary evidence that these aspects are also important in the ID population. Finally, this review demonstrates that balance and gait are potentially trainable in persons with ID. These results suggest that falls might be prevented with ID-specific exercise interventions.

## Introduction

Independent and safe mobility is important for participation in the community and activities of daily life. Mobility is the activity of moving from one place to another and is depending upon a person's body functions, structures and capacities, with balance and gait as two key aspects.[1] Limitations in mobility have been reported to be common in persons with Intellectual Disabilities (ID), which suggests that the prevalence of balance and gait problems is also high.[2]

There are several mechanisms that might contribute to limitations in balance and gait capacities in persons with ID. First, ID is a condition of arrest or incomplete development of the mind, which does not only affect cognitive functions, but motor functions as well.[3] A second mechanism that might contribute to balance and gait problems in persons with ID is premature aging. Balance and gait deteriorate with age due to a decline of, for instance, muscle strength and sensory functions (vision, proprioception, vestibular function). Compared to the general population, age related problems in persons with ID are, to a great extent, similar, but seem to occur more frequently and at a younger age.[4,5] Furthermore, as a result of an improved life expectancy, the number of elderly persons with ID and consequently the number of persons with balance and gait problems, is growing rapidly.[6,7] A third mechanism potentially contributing to balance and gait problems is related to the lifestyle of persons with ID. Persons with ID are generally rather inactive,[8] as a result of which their physical capacities like endurance, balance and strength will be trained less compared to their peers in the general population. This in turn may lead to lower levels of physical functioning.

Balance and gait problems are well-established risk factors for falling.[9] Some studies have indicated that persons with ID have a relatively high fall rate and an increased risk of fall-related injuries.[10-13] For example, persons with ID are more at risk of fall-related fractures because of low bone mineral density.[7,14,15] The rate of hospitalization because of an injury is twice as high in persons with ID compared to the general population, with most of these injuries being caused by falls.[13] A good understanding of the nature of balance and gait problems and their role in the causation of falling in persons with ID may help to develop intervention strategies to prevent falls and injuries.

In the general population, there is convincing evidence for exercise programs to be effective, not only to improve balance and gait capacities, but also to reduce the number of falls.[16] Such evidence is currently lacking for persons with ID. In view of this, it would be essential to establish the trainability of balance and gait capacities in this group. The objective of this study was to critically review the available literature on balance and gait characteristics in persons with ID. Furthermore, the consequences of balance and gait problems in relation to falls were studied, as well as the trainability of balance and gait in persons with ID. This information is expected to give directions to the development of interventions to improve daily life mobility and to prevent falls in persons with ID.

## Systematic literature search

A systematic literature search in the Pubmed database was conducted. The search aimed to include all studies that investigated balance and gait in persons with ID. All records covering the time span from January 1985 until January 2010 were collected. The search strategy included the following MeSH terms: Mental Retardation, Postural Balance and Gait. Records were limited to studies on humans and articles written in English. In total, the search yielded 104 references. From these 104 references the titles and abstracts were screened by one reviewer (LE). In case of doubt a second reviewer (VW) also screened the abstract. Studies were included if: (1) the abstract described assessments of gait and/or balance; (2) the participants were persons in whom ID was the primary disability that was present since childhood; and (3) the study was published in a peer-reviewed journal. Forty-nine articles were selected by reading the titles and abstracts. Subsequently, the full-text articles were checked and 13 studies were excluded, because they did not meet the inclusion criteria. Furthermore, reference lists of the remaining articles were checked for additional relevant studies and abstracts and full-text articles of these studies were screened. Another 12 relevant articles were found, which fulfilled the inclusion criteria. In total, 48 articles were included in this review. The search is outlined in Figure 2.1.

## Results

### Balance and gait characteristics in persons with ID

In Table 2.1 the design, patient characteristics, outcome measures and main results of the studies on balance and gait in persons with ID are presented. In this review, a distinction is made between quantitative studies which make use of posturographic assessment and/or gait analysis (e.g. video registration) and studies using clinical balance and gait tests.

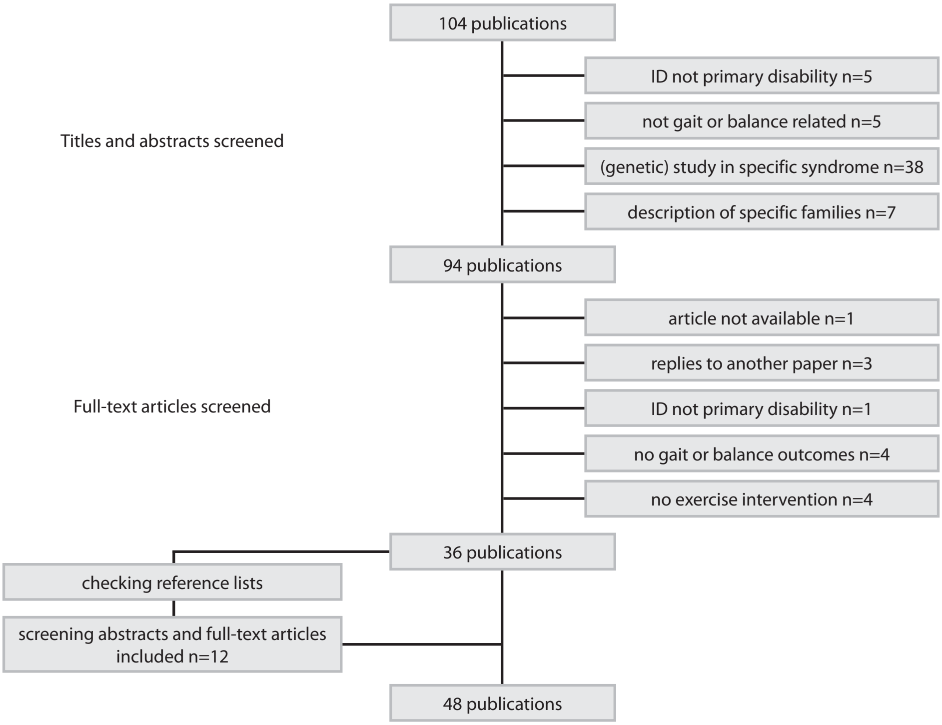


**Figure 2.1** Flow chart of the systematic literature search.

### Posturography

Static posturography is the quantification of movements of the human body (body sway) during quiet upright stance. These movements can be quantified by the displacement of the Centre Of Pressure (COP), as measured with force platforms.[17] Multiple studies indicated that during quiet standing the sway amplitude was larger and more variable in persons with ID than in controls.[18-22] Persons with ID also demonstrated a more laterally orientated sway pattern,[21-23] i.e. the increase in sway was more pronounced in the frontal than in the sagittal plane. There was no significant correlation between the sagittal/lateral sway ratio and IQ within the ID group.[21]

In the specific group of persons with Down Syndrome (DS), sway amplitudes were not always larger than in controls, but they did show higher sway velocities.[17] These results can be explained by persons with DS using an alternative balance strategy to control the amount of sway, namely by increasing the frequency of sway in all directions.[23,24] This notion is consistent with the fact that electromyographic assessments have demonstrated that persons with DS use co-activation of the agonist and antagonist leg muscles to stabilize their posture, whereas healthy controls used an alternating muscle activation pattern.[25]

**Table 2.1** Balance and gait in persons with ID

| Study | Design | Population | N | Age | Sex M/F | Outcome measures | Results | |
|---|---|---|---|---|---|---|---|---|
| ***Balance in persons with ID (compared to controls)*** | | | | | | | | ***Balance***[a] |
| Dellavia et al., 2009[18] | Case-control study | ID inclusive DS | 60<br>(30 ID,<br>30 DS) | 20-39 | 30/30<br>(15/15 ID,<br>15/15 DS) | Sway amplitude | ↑ in ID vs C and ↑in ID vs DS<br>↓ in eyes open vs eyes closed for all groups | - |
| Hale et al., 2009[27] | Case-control study | ID who experienced a fall | 7 ID,<br>13 C | 58 (42-71)<br>49 (42-61) | 4/3<br>5/8 | Response latency | ↑ in ID vs C | - |
| Carvalho & Almeida, 2009[25] | Case-control study | DS | 6 DS,<br>6 C | 28.1<br>27.5 | 3/3,<br>3/3 | Time on seesaw | = in DS vs C<br>DS other strategy and continuous muscle activation vs C alternated muscle activation. | = |
| Smith & Ulrich, 2008[36] | Case-control study | DS | 12 DS,<br>12 C | 35-62 | 6/6,<br>1/11 | Berg Balance Scale | ↓ in DS vs C | - |
| Lahtinen et al., 2007[46] | Prospective Cohort study | <br>ID IQ 46 (30-70)<br>DS IQ 36.6 (30-70) | 77<br>(58 ID,<br>19 DS)<br>195 C | 13.5 (11-16)<br><br><br>(11-16) | 44/33<br><br><br>N/A | Stork stance test | ↓ in ID vs C<br>Male ↑ than female and ID ↑ than DS on static balance tests | - |
| Gomes & Barela, 2007[19] | Case-control study | DS | 9 DS,<br>9 C | 21 (19-29),<br>21.2 (19-27) | 4/5,<br>4/5 | Sway amplitude | ↑ in DS vs C<br>↓ in eyes open vs eyes closed for all groups | - |
| Hale et al., 2007[11] | Retrospective Cohort study | Profound ID, who experienced a fall | 20 ID | 52 (21-81) | 14/6 | Berg Balance Scale<br>Timed Up and Go Test<br>Functional Reach<br>Single Leg Stance<br>Beamwalking<br>Motor Responses (latency) | ↓ in ID vs norm (N=7)<br>↑ in ID vs norm (N=8)<br>↓ in ID vs norm (N=3)<br>↓ in ID vs norm (N=3)<br>was not possible to assess<br>↑ in ID vs C | - |

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| Galli et al., 2008[23] | Case-control study | DS | 60 DS,<br>10 C | 18.7 (16-22)<br>22.3 (19-25) | N/A,<br>N/A | Sway time<br>Sway frequency | ↑ in DS vs C only for medial/lateral direction<br>↑ in DS vs C for all directions (anterior/posterior and medial/lateral)<br>No influence of vision in both groups | - |
| Webber et al., 2004[17] | Case-control study | DS | 9 DS,<br>9 C | 30.8 (19-38)<br>25.1 (21-40) | 3/6,<br>3/6 | Sway amplitude<br>Sway velocity<br>Postural stiffness | ↑ in DS vs C<br>↑ in DS vs C<br>↑ in DS vs C<br>↓ stiffness in eyes open vs eyes closed in DS<br>↑ Eyes open/eyes closed effect in DS vs C | - |
| Kokubun et al., 1997[24] | Case-control study | ID Dev age 7.4 yr<br>DS Dev age 5.1 yr | 28<br>(17 ID,<br>11 DS) | 17.0 (13.7-18.6)<br>15.1 (10.9-19.4) | N/A,<br>N/A | Sway amplitude<br>Sway frequency<br>Single Leg Stance | = in DS vs ID<br>↑ in DS vs ID<br>↓ in DS vs ID | - |
| Okuzumi et al., 1997[73] | Case-control study | ID Dev age 5.6 (3-8) yr | 10 ID,<br>39 C Children,<br>13 C Adults | 19.5 (17-22),<br>3-6,<br>19-22 | N/A,<br>N/A,<br>N/A | Head movement | ↑ in ID vs C (adults)<br>Significant relation between head movement and mental age not with chronological age | - |
| Suomi & Koceja, 1994[21] | Case-control study | ID IQ 57.9 (9.7) | 22 ID,<br>22 C | 30.3,<br>28.1 | All male | Sway amplitude | ↑ in ID vs C in lateral direction<br>↓ sagital/lateral sway ratio in ID vs C<br>No significant correlation between IQ and sagital/lateral sway ratio<br>↑ Eyes open/eyes closed effect in ID vs. C | - |

*Table 2.1 continues on next page*

**Table 2.1** *Continued*

| Study | Design | Population | N | Age | Sex M/F | Outcome measures | Results | |
|---|---|---|---|---|---|---|---|---|
| DePaepe & Ciccaglione, 1993[50] | Cohort study | 31 IQ<20<br>60 IQ 20-29 | 91 ID | 35 (9) (24-61) | 67/24 | Papcsy-DePaepe Test<br><br>1 item of Bruininks-Oseretski Test (both Beamwalking tests) | ↑ in severe ID vs profound ID performance<br>↑ in severe ID vs profound ID performance<br>Score test associated with ID not with Age and Gender | - |
| Van Emmerik et al., 1993[22] | Case-control study | Severe and profound ID | 40 ID,<br>26 C | 35 (21-60)<br>33 (24-59) | N/A,<br>N/A | Sway | ↑ in ID vs C<br>More lateral orientated sway in ID | - |
| Ko et al., 1992[20] | Case-control study | ID, 8 severe, 19 profound, 4 moderate, 1 mild | 32 ID,<br>26 C | 36 (21-62)<br>33 (24-59) | N/A,<br>N/A | Sway amplitude<br>Sway variability | ↑ in ID vs C<br>↑ in ID vs C | - |
| Haley, 1986[69] | Case-control study | DS | 20 DS,<br>40 C | 11.88 (2-24) mo<br>5.97 (2-10) mo | 7/13,<br>23/17 | Postural reactions<br>Motor milestones | ↓ in DS vs C<br>↓ in DS vs C<br>Association postural reactions and motor milestones in DS = C | - |
| Shumway-Cook & Woollacott, 1985[28] | Case-control study | DS<br>Dev. age 2.3-3.6 yr | 6DS, 11C<br>4DS, 6C<br><br>2DS, 5C | 1–6<br>4–6<br><br>1.5-2.5 | N/A,<br>N/A,<br><br>N/A | Response latency | ↑ in DS vs C<br>Both groups use knee and hip motions next to the ankle strategy | - |

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| Butterworth & Cicchetti, 1978[26] | Case-control study | DS | Exp.1: Stand 43 DS, 60 C | 0.5-3.5 | N/A | Falls | ↑ in ID vs C in standing | - |
| | | | Exp.2: Sit 24 DS, 26 C | | | Influence of discrepant visual feedback | ↓ in ID vs C in sitting<br>↑ in ID vs C in standing<br><br>In ID correlated with experience in standing, not with age | |
| ***Gait characteristics in persons with ID (compared to controls)*** | | | | | | | | ***Gait***[a] |
| Martin et al., 2009[60] | Cohort | DS | 60 DS | N/A | N/A | Observational Gait Analysis for DS | Good reliability, but less validity.<br>Validity study was based on 60 video observations. | - |
| Agiovlasitis et al., 2009[39] | Case-control study | DS | 15DS, | 27.1 (19-44), | 8/7, | General pattern of Centre Of Mass (COM) | = in DS vs C | - |
| | | | 15C | 28.2 (18-42) | 8/7 | M/L COM displacement | ↑ in DS vs C | |
| | | | | | | Variability in M/L COM | ↑ in DS vs C | |
| | | | | | | A/P COM displacement | = in DS vs C | |
| | | | | | | Variability in A/P COM | ↑ in DS vs C | |
| | | | | | | Vertical COM displacement | = in DS vs C | |
| | | | | | | Variability in vertical COM | ↑ in DS vs C | |
| | | | | | | Step length variability | ↑ in DS vs C | |
| | | | | | | Step width variability | ↑ in DS vs C | |
| | | | | | | | DS shorter height and leg length and greater Body Mass Index | |

*Table 2.1 continues on next page*

**Table 2.1** *Continued*

| Study | Design | Population | N | Age | Sex M/F | Outcome measures | Results | |
|---|---|---|---|---|---|---|---|---|
| Gontijo et al., 2008[42] | Case-control study | DS | 12 DS, | 2, | 5/7, | Co-Contraction Indices stance | = in DS vs C | - |
| | | | 12 C | 1 | 6/6 | Co-Contraction Indices swing | ↑ in DS vs C | |
| Smith & Ulrich, 200836 | Case-control study | DS | 12 DS,<br>12 C | 35-62 | 6/6,<br>1/11 | Velocity of gait | ↓ in DS vs C | - |
| | | | | | | Step length | ↓ in DS vs C | |
| | | | | | | Step width | ↑ in DS vs C | |
| | | | | | | Support (stance and double) | ↑ in DS vs C | |
| | | | | | | Berg Balance Scale | ↓ in DS vs C | |
| | | | | | | Crossing step in response to obstacle in Forward direction | ↑ in DS vs C | |
| | | | | | | Dorso flexion ankle at crossing | ↓ in DS vs C | |
| Galli et al., 2008[30] | Case-control study | DS | 98 DS,<br>30 C | 11.7 (6-15),<br>11 (5-13) | N/A,<br>N/A | Velocity of gait | ↓ in DS vs C | - |
| | | | | | | Step Length | ↓ in DS vs C | |
| | | | | | | Flexion in hip and knee | ↑ in DS vs C | |
| | | | | | | Range Of Motion | ↓ in DS vs C | |
| | | | | | | Strength at push-off | ↓ in DS vs C | |
| | | | | | | Stiffness hip | ↑ in DS vs C | |
| | | | | | | Stiffness ankle | ↓ in DS vs C | |
| Black et al., 2007[40] | Case-control study | DS | 8 DS, | 8-10 | 5/3, | Variability in Centre Of Mass (COM) | ↑ in DS vs C | - |
| | | | 8 C | | 5/3 | Variability in head position | ↑ in DS vs C | |
| | | | | | | Stability at heel contact | COM>head in DS | |

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| Smith et al., 2007[35] | Case-control study | DS | 8 DS,<br>8 C | 8-10 | 5/3,<br>5/3 | Velocity of gait<br>Step Length<br>Step Width (corrected for leg length)<br>Bruininks-Oseretski Test (Beamwalking)<br>After practice on treadmill, stiffness | ↓ in DS vs C<br>↓ in DS vs C<br>↑ in DS vs C<br>↓ in DS vs C<br>↓ in DS than before but still ↑vs C | - |
| Kubo & Ulrich, 2006[32] | Case-control study | DS | 12 DS,<br>10 C | 8.75 (8-10),<br>8.90 (8-10) | N/A,<br>N/A | Velocity of gait<br>Step length<br>Step width<br>Sway amplitude | = in DS vs C<br>↓ in DS vs C<br>↑ in DS vs C<br>↑ in DS vs C especially in Medial/Lateral direction | - |
| Kubo & Ulrich, 2006[31] | Case-control study | DS | 8 DS,<br>8 C | 10 mo | N/A,<br>N/A | Cadence<br>Step width<br>Variability<br>Walking onset | ↑ in DS vs C as part of alternative strategy for balance during gait<br>↑ in DS vs C as part of alternative strategy for balance during gait<br>↑ in DS vs C<br>↓ in DS vs C | - |
| Looper et al., 2006[71] | Case-control study | DS | 26 DS,<br>9 C | 10 mo | N/A,<br>N/A | Variability of step length<br>Variability of step width<br>Maturing of the gait<br>Maturing of gait | ↑ in toddlers vs norms for adults<br>↓ in toddlers vs norms for adults<br>When control mechanism change from variability mainly in Anterior/Posterior direction (toddlers) too more variability in Medial/Lateral direction (adults)<br>↓ in DS vs C | - |

*Table 2.1 continues on next page*

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**Table 2.1** *Continued*

| Study | Design | Population | N | Age | Sex M/F | Outcome measures | Results | |
|---|---|---|---|---|---|---|---|---|
| Buzzi & Ulrich, 2004[41] | Case-control study | DS | 8 DS,<br>8 C | 8-10,<br>8.75 | N/A,<br>N/A | Dynamic stability<br>Variability | ↓ in DS vs C<br>↑ in DS vs C | - |
| Ulrich et al., 2004[37] | Case-control study | DS | 12 DS,<br>12 C | 8-10 | 8/4,<br>5/7 | Cadence on treadmill<br>Step length on treadmill<br>Stiffness | ↑ in DS vs C<br>↓ in DS vs C<br>↑ in DS vs C | - |
| Carmeli et al., 2004[48] | Case-control study | DS and other forms of ID | 61 ID<br>(23 DS,<br>38 ID)<br>31 C | (52,<br>53)<br>75 | (7/16,<br>14/24)<br>5/26 | Timed Up and Go Test<br>3 Minute Walking Distance | ↑ in DS vs ID and C<br>↓ in DS vs ID and C<br>DS more obese, shorter and more medical problems than ID and C | - |
| Virji-Babul & Brown, 2004[38] | Case-control study | DS Dev. age 46 mo | 5 DS,<br>6 C | 5.5 (5-6),<br>5 (4-7) | N/A,<br>N/A | Step length<br>Stops before obstacle<br>Variability in response to obstacle | ↓ in DS vs C<br>↑ in DS vs C<br>↓ in DS vs C | - |
| Cioni et al., 2001[29] | Case-control study | DS IQ 50-70 (and 2<50) | 17 DS,<br>10 C | 14.5 (8-36),<br>17.2 (8-30) | 13/4,<br>7/3 | Velocity of gait<br>Plantar flexion in ankle<br>Strength at push-off | ↓ in DS vs C<br>↓ in DS vs C<br>↓ in DS vs C | - |
| Brzezniak, 1998[75] | Retrospective Cohort study | ID who were ambulant 10 years ago | 103 ID | 28-80 (M),<br>36-81 (F) | 71/32 | Independent ambulation with Developmental Disability Profile | ↓ in ID with more developmental disabilities decline faster in women vs men | - |

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| Sparrow et al., 1998[43] | Case-control study | ID IQ 50-73 | 16 ID,<br>16 C | 60.3 | 7/9,<br>7/9 | Cadence<br>Step length<br>Crossing step in response to obstacle<br>Obstacle clearance<br>Climbing stairs | ↑ in ID vs C<br>↓ in ID women vs C<br>ID earlier than C<br>↑ in ID vs C<br>↓ beginning in ID and ↑ late phase in ID vs C | - |
| Accardo & Whitman, 1989[72] | Prospective Cohort study | ID,<br>Toe Walker IQ 76,<br>C IQ 85 | 799 ID,<br>224 Toe Walker,<br>575 C | 6,<br>8 | 156/68,<br>397/178 | Toe walking | ↑ in persons with more severe language disorders and it is associated with lower IQ | - |
| Parker et al., 1986[34] | Case-control study | DS | 10 DS,<br>9 C | 5 | N/A,<br>N/A | Step length<br>Total support phase<br>Double support<br>Single/stance support<br>Flexion in hip and knee<br>Fluctuation of ankle movement | ↓ in DS vs C<br>↑ in DS vs C<br>↑ in DS vs C<br>↓ in DS vs C<br>↑ in DS vs C<br>↑ in DS vs C | - |
| Parker & Bronks, 1980[33] | Cohort study | DS Dev. age 2.6 | 6 DS | 7.1 | 3/3 | Total support phase<br>Flexion in hip and knee<br>Abduction of hip<br>Variability<br>Asymmetry | ↑ in DS vs C<br>↑ in DS vs C<br>↑ in DS vs C<br>↑ in DS vs C<br>↑ in DS vs C | - |

ID, Intellectual Disabilities; DS, Down Syndrome; C, Control; E, experimental; IQ, Intelligence Quotient; Dev age, Developmental age; yr, year; mo, months; M, Male; F, Female; N/A, Not Available; m, meter; vs, versus; COM, Centre Of Mass; M/L, Medial/Lateral; A/P, Anterior Posterior; NS, Not Significant; Exp., Experiment.

[a]Column indicates if balance or gait was worse (-), the same (=) or better (+) in persons with ID.

In maintaining upright balance visual, somatosensory and vestibular information is used. The literature reported inconsistent results regarding the dependency on visual information in persons with ID. Two studies found that in persons with ID, the difference in sway amplitude between standing with eyes open and closed was larger compared to controls.[17,21] Discrepant visual feedback was more destabilizing to upright stance in persons with ID than in controls.[26] In contrast, two other studies did not observe differences in visual dependency between persons with ID and controls.[18,19]

Another form of posturography is the study of human postural responses to balance perturbations, i.e. dynamic posturography. Two studies of which the results have been reported in three papers, investigated balance corrections in response to sudden unexpected movements of the support surface.[11,27,28] The data showed that persons with ID had delayed responses to the perturbations compared to controls. However, completion of these balance perturbation tests was difficult for persons with profound ID, resulting in small sample sizes (N=6 and N=9).[17,27,28]

### Gait analysis

The vast majority of gait analysis studies in persons with ID (14 out of 15) were confined to persons with DS, specifically children (12 studies). These studies all reported differences in the spatiotemporal characteristics of gait in persons with DS compared to controls. In general, persons with DS showed a lower walking speed, higher cadence, shorter step length, larger step width and longer double support time.[29-38] Furthermore, variability in step length, step width and head movement was larger in persons with DS and their walking pattern was more asymmetric.[33] Kinetic data showed that less force was generated during push off,[29,30,32,35,36] which is in agreement with the lower walking speed.

Centre Of Mass (COM) displacements were also more variable in persons with DS,[31-33,39-41] demonstrating greater lateral excursions.[31,32,39,41] Furthermore, electromyographic measurements indicated that persons with DS use more co-activation of the leg muscles, especially during the swing phase of gait.[42] The resulting increase in joint stiffness levels is reflected in reduced Range Of Motion (ROM) in the lower extremity joints, with the hip and knee remaining more flexed during the whole gait cycle.[30,33,34,37]

The only study that assessed gait in a general group of persons with ID found a higher cadence compared to a control group.[43] Furthermore, women with ID had a shorter step length compared to controls.[43] These findings are consistent with the studies on gait in persons with DS.[30-32,34-36,38]

Most studies investigated unperturbed gait, but the ability to step over obstacles (e.g. doorsteps) during walking is very important during activities of daily life. Therefore, some studies also investigated obstacle negotiation in persons with ID. The most pronounced differences between persons with ID and controls were found in the anticipatory adjustments of gait prior to obstacle crossing. In children with DS, more frequent stops were observed before crossing. They also demonstrated less variability in the strategies to avoid the obstacle compared to controls.[38] Furthermore, persons with ID anticipated earlier in response to an obstacle to gain more time to plan and implement the crossing manoeuvre.[36,43,44] In the last three pre-obstacle steps they reduced their gait velocity, lowered the cadence, reduced step length and enlarged step width.[44] With respect to the actual crossing manoeuvre, two studies reported conflicting results. One study found a lower toe clearance of the crossing foot,[36] whereas another study found that persons with ID had a higher obstacle clearance compared to controls.[43]

### Clinical balance and gait tests

The clinical balance and gait tests that have been used in persons with ID are the Berg Balance Scale (BBS),[11,36] the Performance Oriented Mobility Assessment (POMA also known as the Tinetti scale),[45] the Single Leg Stance (SLS),[11,24,46] the Functional Reach Test (FR),[11,47] the Timed Up & Go Test (TUGT),[47,48] the Beamwalking tests[11,35,49-51] and a three-Minute Distance Walk test (3MDW).[48] In Table 2. 2 the scores on these clinical tests as reported in the different studies are presented. Normative values of the general elderly population are also included in Table 2.2. In general, persons with ID performed poorer compared to controls and their scores largely fell outside the range of normative values for the respective age groups.[11,35,36,45,47,48,52-59]

Only a few studies investigated the feasibility, reliability and validity of the clinical balance and gait tests in persons with ID.[11,45,46,52,60] The feasibility of the BBS, TUGT, FR and SLS appeared to be a problem in persons with profound ID who had experienced a fall.[11] The reliability of the TUGT was good, but the validity in elderly persons with ID was poor.[52] The POMA was found to have good validity to detect increased risk of falls in persons with ID.[45] Another study showed good reliability of a specially designed gait assessment tool for persons with DS; the Observational Gait Analysis for Down Syndrome (OGA DS).[60]

## Balance and gait problems as risk factors for falls

In Table 2.3 two studies on balance and gait problems as risk factors for falls in persons with ID are described. These studies compared the scores on the POMA[45] and TUGT[52] in persons with ID who had experienced a fall or multiple falls with the scores obtained in non-fallers. In both studies falls were assessed retrospectively,[45,52] but the definition of a faller was more stringent (2 or more falls in the prior 3 months vs. at least one fall in the person’s record)

**Table 2.2** Results on performance-based balance and gait tests in persons with Intellectual Disabilities (ID) and controls

| | Age in years | In ID | In DS | In controls | Normative values |
|---|---|---|---|---|---|
| ***Berg Balance Scale*** | | | | | |
| Smith & Ulrich, 2008[36] | 44 (35-62) | | 47 (38-54) | 56 (55-56) | |
| Hale et al., 2007[11] | 52 (21-81) | 42 (34-45) | | | |
| Steffen et al., 2002[55] | (61-89) | | | | |
| | 60-69 | | | | 55 (male)/55 (female) |
| | 70-79 | | | | 54 (male)/53 (female) |
| | 80-89 | | | | 53 (male)/50 (female) |
| ***Performance Orientated Mobility Assessment/Tinetti*** | | | n/a | n/a | |
| Chiba et al., 2009[45] | 48±9 | 20 (16.5-23) fallers | | | |
| | 52±10 | 28 (27-28) non fallers | | | |
| Tinetti et al., 1986[57] | 81±7 | | | | 14±6 recurrent fallers |
| | 78±7 | | | | 21±4 one time or no fallers |
| ***Single Leg Stance in s*** | | | | n/a | |
| Kokubun et al., 1997[24] | 15 (11-19) | | 20.2±20.7 | | |
| | 17 (14-19) | 47.8±18.8 | | | |
| Lahtinen et al., 2007[46] | | | | | |
| | 11-16 | 24.2±23.6 | 5.0±5.8 | | |
| | 17-22 | 32.9±22.6 | 11.6±16.0 | | |
| | 34-39 | 14.4±19.4 | 5.3±13.9 | | |
| | 41-46 | 16.6±21.7 | 2.9±6.3 | | |
| Hale et al., 2007[11] | 52 (21-81) | 11.3 (1-30) | | | |
| Vereeck et al., 2008[58] | 49 (21-83) | | | | |
| | 20-30 | | | | 30.0±0 |
| | 30-40 | | | | 30.0±0 |
| | 40-50 | | | | 29.6±2.1 |
| | 50-60 | | | | 30.0±0 |
| | 60-70 | | | | 27.7±5.3 |
| | 70-80 | | | | 21.4±10.1 |

| | | | | | |
|---|---|---|---|---|---|
| ***Functional Reach in cm*** | | | n/a | n/a | |
| Hale et al., 2007[11] | 52 (21-81) | 17.5 (10-25) | | | |
| | | | | | |
| Carmeli et al., 2005[47] | (54-66) | 23 | | | |
| Duncan et al., 1990[53] | | | | | |
| | 20-40 | | | | 42.49±4.93 (male)/37.19±5.54 (female) |
| | 41-69 | | | | 38.05±5.61 (male)/35.08±5.59 (female) |
| | 70-87 | | | | 33.43±3.94 (male)/26.59±8.97 (female) |
| Isles et al., 2004[54] | | | | | |
| | 20-29 | | | | 42.71±0.78 (female) |
| | 30-39 | | | | 41.01±0.73 (female) |
| | 40-49 | | | | 40.37±0.53 (female) |
| | 50-59 | | | | 38.08±0.53 (female) |
| | 60-69 | | | | 36.85±0.53 (female) |
| | 70-79 | | | | 34.13±0.54 (female) |
| ***Timed Up and Go Test (3m) in s*** | | | | | |
| Carmeli et al., 2004[48] | | | | | |
| | 44±3 | | 7.0 | | |
| | 59±4 | | 13.2 | | |
| | 75±7 | | | 7.3 | |
| Hale et al., 2007[11] | 52 (21-81) | 14.4 (7.4-23.7) | | | |
| Bruckner & Herge, 2003[52] | 65 (55-79) | 14.18 (6.9-29.1) | | | |
| Vereeck et al., 2008[58] | 49 (21-83) | | | | |
| | 20-30 | | | | 4.4±0.8 |
| | 30-40 | | | | 4.6±1.0 |
| | 40-50 | | | | 4.9±1.2 |
| | 50-60 | | | | 5.6±1.0 |
| | 60-70 | | | | 6.7±0.7 |
| | 70-80 | | | | 7.8±1.1 |
| Isles et al., 2004[54] | | | | | |
| | 20-29 | | | | 5.31±0.25 (female) |

*Table 2.2 continues on next page*

**Table 2.2** *Continued*

| | Age in years | In ID | In DS | In controls | Normative values |
|---|---|---|---|---|---|
| | 30-39 | | | | 5.39±0.23 (female) |
| | 40-49 | | | | 6.24±0.67 (female) |
| | 50-59 | | | | 6.44±0.17 (female) |
| | 60-69 | | | | 7.24±0.17 (female) |
| | 70-79 | | | | 8.54±0.17 (female) |
| Steffen et al., 2002[55] | (61-89) | | | | |
| | 60-69 | | | | 8 (male)/8 (female) |
| | 70-79 | | | | 9 (male)/9 (female) |
| | 80-89 | | | | 10 (male)/11 (female) |
| ***Timed Up and Go Test (9m) in s*** | | | | n/a | n/a |
| Carmeli et al., 2005[47] | (54-66) | 26 | | | |
| Carmeli et al., 2002[64] | (56-75) | | 29 | | |
| ***Beamwalking in number of steps*** | | | | | n/a |
| Wang & Ju, 2002[51] | 4.6 (3-6) | | 0.85±0.77 | | |
| | 4.3 (3-6) | | | 3.45±1.86 | |
| DePaepe & Ciccaglione, 1993[50] | 35 (24-61) | | | | |
| | Severe ID | 2.1±1.7 | | | |
| | Profound ID | 0.7±1.0 | | | |
| ***Beamwalking in cm (3 trails)*** | | | n/a | n/a | n/a |
| Boswell, 1991[49] | (8-13) | 860±324.21 | | | |
| ***Total score Bruininks-Oseretsky Test of Motor Proficiency*** | | n/a | | | n/a |
| Smith et al., 2007[35] | (8-10) | | 6.50 | 24.25 | |
| ***Three-minute distance walk test in m*** | | n/a | | | n/a |
| Carmeli et al., 2004[48] | | | | | |
| | 44±3 | | 162 | | |
| | 59±4 | | 129 | | |
| | 75±7 | | | 150 | |

ID, Intellectual Disabilities; DS, Down Syndrome; s, seconds; cm, centimetres; m, meters and n/a = not available. Results are reported as mean ± SD and/or (range).

**Table 2.3** Balance and gait problems as a risk factor for falls in persons with ID

| Study | Design | Population | N | Age | Sex M/F | Falls | Outcome measures | Results |
|---|---|---|---|---|---|---|---|---|
| Chiba et al., 2009[45] | Retrospective Cohort study | Mild – profound ID | 144 ID | 44.8 (28-68) | 71/73 | 28.5%[a] | Performance Oriented Mobility Assessment (POMA)/Tinetti | ↓ in ID vs norm, POMA distinguishes fallers from non-fallers. Cut-off ID=25 |
| | | | | | | | Base width | ↑ in fallers |
| | | | | | | | Step length | ↓ in fallers |
| | | | | | | | Walking speed | ↓ in fallers |
| Bruckner & Herge, 2003[52] | Retrospective Cohort study | ID | 18 ID | 65 (55-79) | 8/10 | 39%[b] | Modified Timed Up and Go Test (TUGT) | ↑ in ID vs norm, TUGT did not distinguished fallers from non-fallers |

ID, Intellectual Disabilities; M, Male; F, Female; vs, versus.
[a]Faller = 2 or more falls in preceding 3 months.
[b]Faller = 1 fall reported in record.

in the study using the POMA (see Table 2.3). In this study, the POMA was able to identify persons at risk of falling, with a sensitivity and specificity of 88.9% and 91.9%, respectively, when the cut-off score was set at 25 (N=73).[45] Furthermore, this study showed that fallers with ID had a greater stance width, shorter step length, and lower walking speed compared to non-fallers.[45] The modified Timed Up & Go Test could not distinguish fallers from non-fallers in persons with ID (N=18).[52]

### Trainability of balance and gait

In Table 2.4 studies on the trainability of balance and gait in persons with ID are described. These studies comprise five (non-randomized) clinical trials and five randomized clinical trials (RCTs). The methodological quality of the RCTs was determined with the PEDro scale.[61,62] The methodological quality was poor (PEDro scores of 3-4 out of 10; N=2) to moderate (PEDro scores of 5-6 out of 10; N=3). All the RCTs studied the effect of treadmill training on balance and gait in persons with DS. Based on these studies of limited methodological quality treadmill training was found to improve balance, gait and strength in persons with DS.[44,63-66]

Furthermore, in a group of infants of 10 months a high-intensity individualized bodyweight supported treadmill walking program resulted in a significantly faster onset of walking and improvement of the walking pattern by reducing the double support time and increasing the step length, compared to a low-intensity fixed treadmill walking program and compared to controls receiving regular care.[44,63,65,66]

The other studies on trainability were uncontrolled and therefore represent a lower level of evidence. These studies demonstrated that balance performance, as assessed with different clinical balance tests (see Table 2.4), could be significantly improved by various interventions.[47,49,51,67,68] Positive effects were found after 6 weeks of jump training,[51] 8 weeks of creative dance training,[49,67] a 3-6 month balance and strength training program.[47,68] Besides improving balance, several of these programs also improved muscle strength in the participants.[47,68]

## Lifespan trends of balance and gait capacities in persons with ID

In persons with ID, the acquisition of balance and gait capacities in the various developmental stages during childhood is delayed, but it follows the same pattern as in persons without ID. This is, for instance, indicated by the fact that motor milestones (e.g. independent walking) are reached in the same sequence, but at a higher age in persons with ID.[39,69]

The characteristics of gait and balance in the adult ID population, as identified with instrumented assessments (posturography and gait analysis), are comparable to observations in children in the general population[70] and may, therefore, be interpreted as an indicator for incomplete development. Maturation of balance and gait capacities does occur in persons with ID, but it may not reach the same level of maturation as persons without ID.[17,18,39,71] Which level of maturation will be achieved by persons with ID seems to be more dependent on their developmental age, Intelligence Quotient (IQ) or experience with the required skill than on their chronological age.[25,46,50,72,73]

In the general population, aging is related to deterioration in balance and gait capacities.[70,74] This is also true for the ID population. Elderly persons with ID perform worse on balance and gait tasks than their peers in the general population.[20,22,36,43,48] This may partly be explained by their lower performance levels during adulthood, but it also appears that the decline of motor skills in persons with ID occurs at an earlier age.[36,75] For example, persons with ID show a deterioration in SLS performance at a much younger age compared to the general population (see Table 2.2).[46,59] This earlier decline in motor skills in persons with ID could further magnify the contrast with the performance of their healthy peers. Given the central role of balance and gait in mobility, it is therefore not surprising that mobility limitations are highly prevalent in older persons with ID.[2]

From these results obtained from the systematic literature search on lifespan trends in balance and gait capacities in persons with ID, a conceptual model was suggested (Figure 2.2) in which the development of balance and gait capacities in the ID population is compared to the general population.

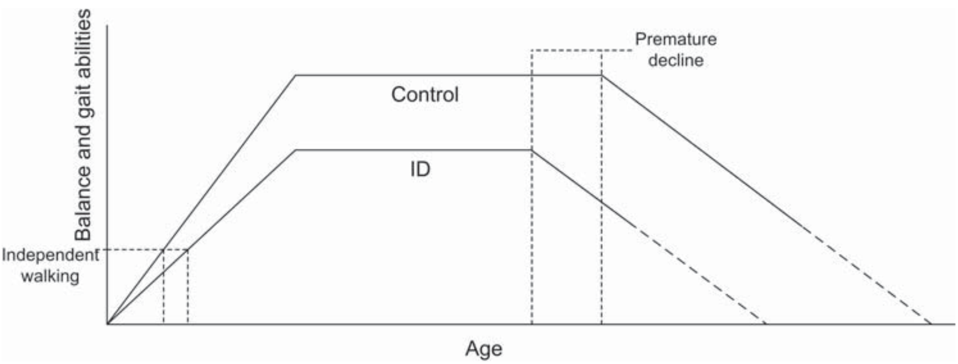


**Figure 2.2** Conceptual model of balance and gait capacities during the lifespan of persons with ID and controls. Independent walking is an example of a motor milestone which is reached at higher age in ID than in controls.

**Table 2.4** *Continued*

| Study | Design | PEDro score[a] | Population | N | Age | Sex M/F | Outcome measures | Results | Intervention[b] |
|---|---|---|---|---|---|---|---|---|---|
| Wu et al., 2008[44] | Randomized Clinical trial | 5 | DS | 30 DS: | | 18/12 | Walking onset | ↓ in DS vs norm | + |
| | | | | 14 LG, | 10.4 mo | 5/9 | Walking onset after treadmill training | earlier in High-intensity individualized (HI=5 days/ week ↑ duration, speed and weight at ankles) than Lower-Intensity Generalized (LG=5 days/week, 6 min/day 0.18 m/s), NS difference | |
| | | | | 16 HI | 9.7 mo | 13/3 | | | |
| | | | | | | | Strategy of obstacle negotiation | ↑ Walk strategy, ↓crawl strategy for HI vs LG earlier in time | |
| | | | | | | | Pre-obstacle Velocity of gait | ↓ In last 3 steps, in both groups, NS group difference | |
| | | | | | | | Pre-obstacle Cadence | ↓ In last 3 steps, in both groups, NS group difference | |
| | | | | | | | Pre-obstacle Step Length | ↓ In last 3 steps, in both groups, NS group difference | |
| | | | | | | | Pre-obstacle Step Width | ↑ In last 3 steps, in both groups, NS group difference | |
| Angulo-Barroso et al., 2008[63] | Randomized Clinical trial | 3 | DS | 30 DS: | 10.0 mo | 18/12 | Cadence | ↑ in both groups, ↑ in HI group vs LG | + |
| | | | | 14 LG | | 5/9 | Velocity of gait | ↑ in both groups, group difference approach significance | |
| | | | | 16 HI | | 13/3 | Double Support | ↓ in both groups, ↓ in HI group vs LG | |
| | | | | | | | Step Length | ↑ in both groups, NS group difference | |

| | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| | | | | | | | Step Width and asymmetry | ↓ in both groups, NS group difference<br>On long term in High-intensity individualized (HI=5 days/ week ↑ duration, speed and weight at ankles) than in Lower-Intensity Generalized (LG=5 days/ week, 6 min/day 0.18 m/s) | |
| Wu et al., 2007[66] | Randomized Clinical trial | 4 | DS | 45 DS:<br>30 E<br>(14LG, 16HI), | 10 mo<br>10 mo | 26/19<br>18/12 | Walking onset<br>Walking onset after treadmill training | ↓ in DS vs norm<br>earlier in High-intensity individualized (HI=5 days/ week ↑ duration, speed and weight at ankles) than Lower-Intensity Generalized (LG=5 days/week, 6 min/day 0.18 m/s), Significant difference | + |
| | | | | 15 C | 10.4 mo | 8/7 | Step Length | ↑ in HI group vs LG | |
| Carmeli et al., 2005[47] | Clinical trial | N/A | Mild ID | 22 ID:<br>10E, 12C | 54-66 | 15/7 | Timed Up & Go (9m)<br>Functional Reach<br>Strength<br>Self-concept of well-being | ↑ in Specific balance & strength training (E) vs general program (C)<br>↑ in Specific balance & strength training (E) vs general program (C)<br>↑ in Specific balance & strength training (E) vs general program (C)<br>↑ Effect in Specific balance & strength training (E) vs general program (C) | + |
| Tsimaras & Fotiadou, 2004[68] | Clinical trial | N/A | DS IQ 45-60 | 25 DS:<br>15E, 10C | 24.6 | All male | Time on balance deck<br>Strength | ↑ with 12 week training programme in E vs C<br>↑ with 12 week training programme in E vs C | + |

*Table 2.4 continues on next page*

**Table 2.4** Trainability of balance and gait capacities in persons with ID

| Study | Design | PEDro score[a] | Population | N | Age | Sex M/F | Outcome measures | Results | Intervention[b] |
|---|---|---|---|---|---|---|---|---|---|
| Carmeli et al., 2002[64] | Randomized Clinical trial | 6 | DS IQ 56-75 | 26 ID: 16E, 10C | 63 (57-65) | 10/16 | Timed Up & Go (9m)<br>Strength | ↑ with 6 month of treadmill training in E vs C<br>↑ with 6 month of treadmill training in E vs C | + |
| Wang & Ju, 2002[51] | Case-control study | N/A | DS | 20 DS,<br>30 C | 4.6 (3-6),<br>4.3 (3-6) | 11/9,<br>18/12 | Bruininks-Oseretski Test (Beamwalking)<br>Horizontal and vertical jumping distance<br>Motor Skill Inventory | ↑ Effect in 6 weeks jumptraining (DS) vs C group<br>↑ Effect in 6 weeks jumptraining (DS) vs C group<br>↑ Effect in 6 weeks jumptraining (DS) vs C group | + |
| Ulrich et al., 2001[65] | Randomized Clinical trial | 5 | DS | 30 DS: 15 E, 15C | 10 mo | N/A | Time passed between onset of independent sitting for 30 sec and onset of walking | ↓ in Treadmill Training (5 days/ week, 8 min/day 0.2 m/s) group (E) vs control group (C) | + |
| Boswell, 1991[49] | Clinical trial | N/A | ID mild to moderate | 26 ID: 13 E, 13 C | 8-13, 10.5, 11,1 | 6/7, 8/5 | Beamwalking<br>Stabilometer | = group with a 8 week creative dance program (E) vs a 8 week exercise program (C) | = |
| Boswell, 1993[67] | Clinical trial | N/A | Mild ID | 25 ID: 12 E, 13 C | 7-10 | N/A | Stabilometer | ↑ with a 12 week creative dance program (E) vs a traditional gross motor program (C) | + |

ID, Intellectual Disabilities; DS, Down Syndrome; C, Control; E, experimental; IQ, Intelligence Quotient; yr, year; mo, months; M, Male; F, Female; N/A, Not Available; min, minutes; m/s, meter per second; vs, versus; HI, High-intensity individualized; LG, Lower-Intensity Generalized; NS, Not Significant.

[a]PEDro scores 0-10 only applicable for randomized clinical trails.

[b]Column indicates if balance and/or gait was worse (-), the same (=) or better (+) in persons with ID after intervention.

2

## Implications and recommendations for future research

The objective of this study was to review balance and gait capacities in persons with ID, since these capacities are important for many activities of daily living and have shown to be one of the most important risk factors for falls. The results obtained from the systematic search illustrate that the literature consistently reports that balance and gait capacities are affected in persons with ID. Compared to their non-disabled counterparts, persons with ID demonstrate greater instability during both quiet standing and walking as indicated by a larger and more variable body sway.[18-23,25,32,39,41,42,65] Furthermore, they exhibit co-contraction of agonist and antagonist muscles, which results in higher levels of stiffness when executing balance and gait tasks.[25,30,37,42] Gait in persons with ID is slower and more asymmetric, with shorter and wider steps.[29-38] The findings from studies using clinical, performance-based balance and gait tests were consistent with those using instrumented assessments, despite the wide variety of tests used. Overall, they showed that persons with ID performed worse than controls and that their performance was outside the range of normative values for the specific tests.[11,35,36,45,47,48,52,53,55-59]

One of the goals of this review was to identify the implications of balance and gait problems for the risk of falling in persons with ID. In the general elderly population, balance and gait problems have been identified as the most important risk factor for falls.[9,59,76,77] Our review provides preliminary evidence that in the ID population these mobility problems also contribute to a higher fall risk. Gait problems have been identified as risk factors for falls.[45,52] Indeed recent studies show that specifically ambulatory persons with ID are more at risk of falling.[12,78] This is consistent with the observation that, in the general population, falls occur most frequently during walking.[79,80] Furthermore, persons with ID who had lower scores on the Performance Oriented Mobility Assessment (POMA), a wider step base, shorter steps and altered walking velocity, were more prone to falling.[45,52] A recent review underlined the importance of mobility problems with respect to falling in persons with ID.[81] However, no previous study has directly investigated the relationship between balance and gait capacities and falls in persons with ID. Furthermore, studies investigating falls in persons with ID mostly used retrospective reports or medical records to identify fall incidents.[10-12,45,52,82] These methods are likely to underestimate the number of falls.[83] Therefore, there is a need for studies with detailed baseline screening of risk factors for falls followed by prospective monitoring of falls for at least one year.[84] In this way, the baseline characteristics of the fallers can be compared to those of the non-fallers to identify the unique contributing risk factors in a multivariate design.

Assuming a central role for balance and gait problems in the fall risk of persons with ID, it would be necessary to establish whether balance and gait capacities in persons with ID can be improved by training to prevent falls. In the general elderly population it has been shown that exercise programs are the most effective single intervention to prevent falls.[85,86] This specifically concerns multi-modal interventions, including at least two of the following training modalities: balance, strength, flexibility and endurance.[16,87] In persons with ID, no studies have directly investigated the effect of exercise interventions on the reduction of falls, but this review showed that, despite methodological limitation, several interventions were successful in improving balance, strength in persons with ID and to promote gait in children with ID.[44,47,49,51,63-68] The findings demonstrate that balance and gait capacities can potentially be trained in persons with ID, which implies that exercise interventions may also be effective in reducing falls in the ID population.

Several comments are warranted with regard to the methodological quality of the studies included in this review. Many studies had very low sample sizes and lacked information on the study population and clear definitions of concepts used, like ID and/or mobility. Because the population of persons with ID is very diverse, this paucity of information makes it difficult to compare the different studies and make valid statements about the results. Another limitation in the literature is that the majority of the studies have been performed in children. Particularly the studies on gait and the trainability of gait were limited to children with DS. Thus, information on this topic in adult and elderly persons, and persons with ID in general is lacking.

This review also revealed that responses to perturbations of balance and gait, as an important aspect of safe and independent mobility in daily life, have barely been investigated in persons with ID. The feasibility of such perturbation tests seems to be a problem in the ID population, particularly in those persons with profound ID. Some studies, with low numbers of participants, reported that the reactions to external perturbations were different in persons with ID compared to controls. Reactions to unexpected perturbations were delayed[11,27,28] and persons with ID needed more time to anticipate to obstacles.[36,38,43,44] In addition to the poor feasibility of the perturbation tests, the clinical performance tests often showed a lack of feasibility in persons with ID as well.[11] Furthermore, the validity and reliability of the clinical tests to measure balance and gait capacities in the population of persons with ID needs to be investigated more thoroughly.[46,50,60]

## Conclusions

In conclusion, balance and gait capacities are affected in persons with ID compared to their age-matched peers in the general population. These problems start at a young age and remain present during the entire lifespan of persons with ID, showing a relatively early occurrence of age-related decline. The relationship of these problems with falls has not yet been thoroughly investigated in persons with ID but, since they are important risk factors for falls in the general elderly population, it can be expected that they are also important in persons with ID. This needs to be confirmed in a large study with detailed screening of possible fall risk factors at baseline and prospective monitoring of falls. Furthermore, the finding that balance and gait are potentially trainable in persons with ID suggests that falls might be prevented with ID-specific adjusted exercise interventions.

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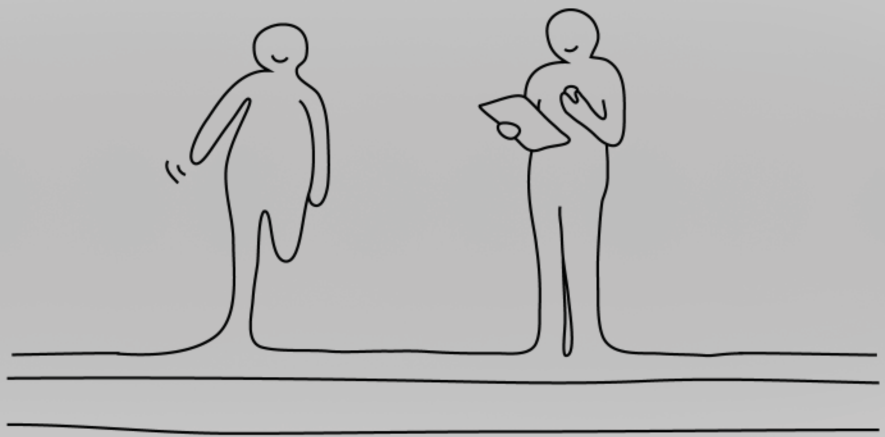

# Chapter 3

# Clinical measures are feasible and sensitive to assess balance and gait capacities in older persons with mild to moderate Intellectual Disabilities

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## Abstract

Mobility limitations are common in persons with Intellectual Disabilities (ID). Differences in balance and gait capacities between persons with ID and controls have mainly been demonstrated by instrumented assessments (e.g. posturography and gait analysis), which require sophisticated and expensive equipment such as force plates or a 3D motion analysis system. Most physicians and allied healthcare professionals working with persons with ID do not have such equipment at their disposal, so they must rely on clinical tests to determine whether balance and gait are affected. The aim of this study was to investigate whether existing clinical balance and gait tests are feasible in older persons with mild to moderate ID and to examine whether these tests are able to show limitations in balance and gait capacities in the ID population compared to age-matched peers in the general population. Furthermore, it was aimed to identify the most important determinants of balance and gait disability in persons with the ID. A total of 76 older persons with mild to moderate ID (43 male, mean age 63.1±7.6y) and 20 healthy controls (14 male, mean age 62.2±5.6y) participated. Balance and gait abilities were assessed with the Berg Balance Scale (BBS), the Functional Reach test (FR), the Timed Up and Go Test (TUGT), the timed Single Leg Stance (SLS) and the Ten Meter Walking Test (TMWT). Our study showed that it is feasible to conduct standard clinical balance and gait tests in older persons with mild to moderate ID. Balance and gait performance of persons with ID is substantially worse compared to older persons of the general population. Age, number of co-morbidities, Body Mass Index (BMI), body sway and fear of falling are associated with balance and gait performance in persons with ID. These factors might help in the selection of subjects to be monitored on their balance and gait capacities.

## Introduction

Mobility limitations are common in persons with Intellectual Disabilities (ID), with a reported prevalence of up to 63%.[1] Mobility is the activity of moving from one place to another and is depending upon a person's body functions, structures and capacities, with balance and gait being two key aspects.[2] Hence, limitations in balance and gait capacities can be expected to be common in this population as well. Indeed, a recent review[3] has shown that in persons with ID balance and gait capacities are affected compared to their age-matched peers. For instance in laboratory assessments, persons with ID demonstrate greater postural instability than their age-matched peers during both quiet standing and walking as indicated by increased and more variable body sway. These balance problems start at a young age and remain present during the entire lifespan of persons with ID, with a relatively early occurrence of age-related decline.[3] Because mobility problems have been identified as the most important risk factors for falls, specifically elderly persons with ID might have an increased fall risk.[4]

Differences in balance and gait capacities between persons with ID and controls have mainly been demonstrated by instrumented assessments (e.g. posturography and gait analysis), which require sophisticated and expensive equipment such as force plates or a 3D-motion analysis system. Most physicians and allied healthcare professionals working with persons with ID do not have such equipment at their disposal, so they must rely on clinical tests to determine whether balance and gait are affected. In clinical practice, frequently used clinical balance and gait tests are the Berg Balance Scale (BBS), the Functional Reach test (FR), the Timed Up and Go Test (TUGT), the Single Leg Stance (SLS), and the Ten Meter Walking Test (TMWT).[5-9]

These clinical tests have been used in previous studies on balance and gait capacities in persons with ID.[10-12] A limitation, however, was that it can be rather cumbersome to conduct such tests in this population. For instance, in the study by Hale et al. (2007)[10] only a small number of participants were able to complete an assessment involving several clinical balance and gait tests, which was mainly due to the fact that the participants did not understand the instructions. This poor feasibility may be related to the study population which consisted of persons with profound ID.[10] It remains unknown, however, whether these common clinical balance and gait tests are feasible in persons with mild to moderate ID.

Another limitation of the previous studies on balance and gait in persons with ID is that they did not investigate the influence of different etiological diagnoses on balance and gait functioning. Studies either targeted a specific ID subgroup (Down syndrome, DS) or did not differentiate in etiological diagnosis. As two studies have demonstrated that persons with DS had poorer balance and gait capacities compared to a general group of persons with ID,[11,13] etiological diagnosis may be one of the determinants contributing to balance and gait limitations. Hence, it has yet to be investigated which determinants contribute to balance and gait limitations in the general ID population. Furthermore, it has to be determined whether clinical tests can also demonstrate balance and gait deficits in the general ID population compared to controls, similar to the results obtained with instrumented assessments.[11,14,15]

The aim of the present study was threefold. First, we aimed to identify whether it is feasible to conduct a comprehensive set of frequently used clinical balance and gait tests in older persons with Intellectual Disabilities (ID). The second purpose of the study was to compare balance and gait capacities between persons with ID and their age-matched peers in the general population. The general hypothesis was that persons with ID will perform worse on the clinical balance and gait tests compared to their peers. Third, we aimed to identify possible determinants that might contribute to balance and gait performance. The results of this study may help professionals to select appropriate tests for assessing balance and gait capacities in this population, which in turn will serve as the basis for determining treatment goals.

## Methods

### Participants

Persons with ID were recruited from three service providers for persons with ID in the Netherlands. The involved service providers had different types of living facilities available for persons with ID: community based group homes, campus facilities and independent living situations with ambulatory support. The participants had to be at least 50 years with mild (IQ 70-50) to moderate (IQ 50-35) ID.[16] They had to be able to walk independently for at least 10 meters and to understand simple instructions. Since this study was part of a prospective study on fall risk, persons with epilepsy were excluded. The rationale for this exclusion was that a fall as a result of an epileptic seizure, has a different cause than falling related to ID and ageing.

Persons with ID older than 50 years were selected from the service providers database and were screened by physicians, allied health professionals, and caregivers on all in- and exclusion criteria. In the case of eligibility, an information letter with text and pictures adjusted to the individual intellectual level, was sent to the participants and their caregivers. The legal representative also received an information letter. These letters contained information about the study as well as a reply form of interest. After obtaining this information, the primary researcher (LE) made a home visit to each person who had indicated interest in the study. During this visit a final check of the in- and exclusion criteria was done, additional information about the study was given on request, and the informed consent form was signed. If participants had a legal representative, written informed consent was obtained from this person as well.



Twenty healthy age-matched control subjects were recruited from a database of healthy volunteers for research into human movement available at the department of Rehabilitation in the Radboud University Medical Centre. The controls gave their written informed consent as well. The study was conducted in agreement with the declaration of Helsinki and approved by the regional medical ethical committee.[17]

## Procedure

During the home visit, the primary researcher conducted an interview on the activities of daily life, use of care and aids, health status,[18] medication, fall history, and fear of falling (see appendix A).

In a second session, balance and gait capacities in persons with ID were assessed. These assessments were conducted in an environment that was familiar to the participant, e.g. at home or at day activity centres. All participants were assessed by a physical therapist experienced in performing the test battery. Furthermore, the majority of the assessments took place in the presence of a therapist or caregiver familiar to the participant. Test instructions were given verbally. If participants did not understand the instructions, the desired test item was demonstrated. Practice trials were allowed prior to testing. During the assessments the participants wore their usual footwear. They were not allowed to use walking aids, such as a cane or walker.

## Clinical tests

Balance and gait capacities were assessed with a battery of clinical tests including the Berg Balance Scale (BBS), the Functional Reach test (FR), the Timed Up and Go Test (TUGT), the timed Single Leg Stance (SLS) and the Ten Meter Walking Test (TMWT). The FR, TUGT, SLS and TMWT were performed three times for each participant.

The BBS is a performance based measure of balance, consisting of 14 observational tasks. Examples of tasks are quiet standing, picking up an object from the ground, and turning 360° around one's body axis. The items are scored on an ordinal scale (0-4 points), with a score of 0 indicating inability and a score of 4 full ability to complete the task. The test is a quasi-hierarchical scale with a maximum score of 56. The reliability in healthy elderly persons is excellent (test-retest and inter-rater reliability ICC of 0.98) and balance scores predicted the occurrence of multiple falls among elderly residents indicating its validity.[5,19,20]

The FR measures the maximal forward arm reach (cm), while maintaining a feet-in-place position with the legs slightly apart. The FR has shown to be a reliable (test-retest and inter-rater reliability ICC of 0.92 and 0.98, respectively) and valid (Pearson correlation with center-of-pressure excursion on force plates 0.71) tool to measure balance in healthy persons.[8]

The TUGT measures the time (s) it takes to rise from a chair, walk 3 meters, turn around, walk back and sit down again. The TUGT is a reliable (test-retest and inter-rater reliability ICC of 0.99) and valid test (Pearson correlation with Barthel Index 0.78) for quantifying functional mobility.[9]

The SLS measures the time (s) a person can stand on one leg on a firm surface with the eyes open. For this study, the maximal score was set at 10 seconds. The SLS has been correlated with amplitude and speed of body sway in healthy persons.[6]

During the TMWT, the time (s) needed to walk 10 meters is assessed to determine the comfortable gait speed (m/s). Assessment took place on an even surface and participants walked in a straight line. Gait speed measures obtained during a single session have been found to be reliable in healthy elderly persons.[7]

### Determinants

Etiological diagnosis (genetic cause, brain damage, unknown cause), severity of ID (mild/moderate), age (years), sex (male/female), fear of falling (present/absent), number of co-morbidities, number of medications, use of psychotropic drugs (yes/no) were all considered as possible determinants of fall risk.[21] Length and weight were measured to calculate the Body Mass Index (BMI = weight/length$^2$).[22]

Because we also wanted to introduce a physiological measure of equilibrium, body sway during quiet standing was assessed with the SwayStar™ system. This system was attached to a belt strapped around the waist at the level of the lumbar spine. It consists of body-worn gyroscopes that measure the angular velocity of trunk sway in the forward/backward and sideways directions (deg/s).

## Data analysis

In accordance with the test protocol, for the FR and SLS the maximal score and for the TUGT and TMWT the mean score of three attempts was used for statistical analysis.

To determine if the tests were feasible for persons with ID, percentages of successfully completed tests were calculated. A test was defined unsuccessful when it could not be executed because the participant did not understand the instruction (even after demonstration), or if the participant refused or was too afraid to perform the test. Feasibility was considered sufficient if the percentage of succeeded assessments was above 85%. To examine whether the clinical tests consistently measured the same concept, Spearman correlation coefficients were calculated. Correlations lower than (-)0.50 were considered 'poor', from (-)0.50 to (-)0.75 'moderate', and above (-)0.75 'good'.[23]

To compare the performance on the clinical balance and gait tests between persons with ID and their age-matched peers in the general population, independent samples t-tests were used. Because five clinical balance and gait tests were used to compare between the groups, a Bonferroni correction was applied and alpha was set at 0.01.

To analyze which determinants contributed to the clinical balance and gait performance of the ID group, Spearman correlations were calculated between the scores on the different balance and gait tests and the following variables: age, BMI, number of co-morbidities, number of medications and body sway. Point biserial correlations were used to test the role of the dichotomous variables: sex (male/female), severity of ID (mild/moderate), fear of falling (yes/no) and psychotropic drug use (yes/no). To identify the possible influence of etiological diagnosis, a one-way ANOVA was performed for each balance and gait test. Determinants that were correlated with clinical scores or showed significant group effects were entered as independent variables in a backward linear regression model for each clinical test, separately. Because of the explorative character of the study and to avoid too much restriction on factors that might be of influence on the results of the clinical test outcomes, a p-value of <0.1 was taken to decide which determinants should be included in the backward linear regression model. The score on the clinical test was used as the dependent variable in the backward linear regression. All data were analysed with SPSS 16.0 for Windows.

# Results

### Participants

A total of 78 older persons with mild to moderate ID (44 male, mean age 63.2±7.6 years) and 20 control subjects (14 male, mean age 62.2±5.6 years) were included. Two persons with ID could not participate in the clinical assessments. One person refused to perform the tests. In another case, caregivers advised not to start the clinical assessment since they feared adverse effects of the assessment on the person's (increased) behavioural problems. Both subjects were suspected to be in an early stage of dementia. Thus, clinical data were available for 76 persons with ID. The characteristics of persons with ID are presented in Table 3.1. Of two persons no SwayStar™ data was available.

### Clinical balance and gait test

The assessments of persons with ID took place at their homes (88.2%) or at the physical therapy accommodations of the day activity centres (11.8%). In 71% of the cases, the investigator was assisted by a therapist, staff member or caregiver. In 64.5% of the cases, it was too burdensome for the participants to do all the measurements in one session, because of which a second assessment had to be planned. The total time (without breaks) to complete the assessment protocol was approximately 2 hours.

### Feasibility of the clinical tests in persons with ID

Almost all participants understood how to perform the various items of the clinical tests, either after verbal instructions or after demonstration of the tasks. The tests that were most difficult to understand were the FR, the tandem stance item of the BBS, and the SLS. It was not always possible to perform these three tests in the standardized manner as described in the test protocol. To facilitate maximal reach of the FR the investigator allowed the participant to reach to the hands of the helper. To assess tandem stance participants were helped by placing their feet in the desired position, after which it was tested whether they were able to maintain balance. If participants were initially not able to perform the SLS, a gradual decrease in external support was applied. Two hands were given as a support at the start, after which the participant took weight on one leg. Then, if possible, one hand was removed and finally also the other hand in order to assess the SLS performance without support. With these adjustments the percentage of succeeded assessments for the TUGT, SLS and TMWT was 100%. For the BBS and the FR the feasibility was 96%. Three persons were not able to perform these latter tests, because they did not understand the instructions.

**Table 3.1** Characteristics of persons with ID (N=76)

| Measure | |
|---|---|
| Sex, N (%) | |
| Male | 43 (57%) |
| Female | 33 (43%) |
| Age, Mean ± SD | 63.1±7.6 |
| BMI, Mean ± SD | 27.4±5.6 |
| Type of living facility, N (%) | |
| Community based group homes | 66 (87%) |
| Campus facilities | 4 (5%) |
| Independent living situation, with ambulatory support | 6 (8%) |
| Diagnosis, N (%) | |
| Genetic cause | 9 (12%) |
| Brain damage | 16 (21%) |
| Unknown cause | 49 (64%) |
| Missing | 2 (3%) |
| Severity ID, N (%) | |
| Mild | 33 (43%) |
| Moderate | 41 (54%) |
| Missing | 2 (3%) |
| Co-morbidity based on Rigler et al.[18], N (%) | |
| Visual | 42 (55%) |
| Musculoskeletal | 34 (45%) |
| Cardiac | 25 (33%) |
| Psychosocial/Behavioural | 24 (32%) |
| Hearing | 21 (28%) |
| General | 11 (14%) |
| Digestive | 11 (14%) |
| Respiratory | 11 (14%) |
| Neurologic | 9 (12%) |
| Dermatologic | 9 (12%) |
| Incontinence | 8 (11%) |
| Diabetes | 5 (7%) |
| Cancer | 3 (4%) |
| Medication according to ATC Index, N (%) | |
| Nervous system | 40 (53%) |
| Alimentary tract and metabolism | 25 (33%) |
| Psychotropic medicine | 20 (26%) |
| Cardiovascular system | 20 (26%) |
| Dermatologicals | 11 (14%) |
| Respiratory system | 10 (13%) |
| Musculoskeletal system | 9 (12%) |
| Blood and blood forming organs | 9 (12%) |
| Systemic hormonal preparations | 7 (9%) |
| Genito-urinary system en sex hormones | 5 (7%) |
| Sensory organs | 4 (5%) |
| Anti-infectives for systemic use | 1 (1%) |
| Body sway (angular velocity, deg/s), Mean ± SD | 0.99±0.57 |
| Fear of falling, N (%) | |
| Yes | 33 (43%) |
| No | 43 (57%) |

### Relationship between the clinical balance and gait test in persons with ID

The scores on the different balance and gait tests were significantly correlated with each other (all p<0.001). The BBS, TUGT, SLS and TMWT always showed moderate to good correlation. The correlation of the FR with the other tests was poor to moderate (see Table 3.2).

### Comparison of persons with ID and the control group

Table 3.3 shows the results of the balance and gait tests for persons with ID and the control group as well as the percentage of persons with ID who scored within the range of the control group. On all the tests, persons with ID performed significantly worse than their healthy age-matched controls (all p<0.001). All test scores of the control participants were representative of the general population, as they were within the normal reference values of persons between 50 and 90 years old.[24-26] In contrast, only a small proportion of persons with ID performed the tests within the range of scores of the control group (varying from 3.9% to 32.9%).

**Table 3.2** Associations between balance and gait tests in persons with ID (Spearman correlation, N=76)

| Clinical test | BBS | FR | TUGT | SLS | TMWT |
|---|---|---|---|---|---|
| BBS | - | 0.594 | -0.718 | 0.861 | -0.712 |
| FR | | - | -0.458 | 0.445 | -0.412 |
| TUGT | | | - | -0.646 | 0.714 |
| SLS | | | | - | -0.646 |
| TMWT | | | | | - |

**Table 3.3** Means and SDs of the balance and gait tests of persons with ID and the control group

| Clinical test | ID (N=76) | Control (N=20) | Persons with ID who scored within range of controls |
|---|---|---|---|
| | Mean±SD | Mean±SD | % |
| BBS | 46.8±6.9* | 55.8±0.4 | 3.9 |
| FR (cm) | 14.3±8.5* | 30.3±6.7 | 32.9 |
| TUGT (s) | 17.3±8.0* | 9.3±1.0 | 15.8 |
| SLS (s) | 3.33±3.42* | 10±0.0 | 10.5 |
| TMWT (s) | 12.2±4.8* | 7.9±0.8 | 27.6 |

*p<0.001

## Determinants of balance and gait in persons with ID

The factors that were significantly associated with the clinical test scores ($p<0.1$) are shown in Table 3.4. Etiological diagnosis, severity of ID, number of medications and the use of psychotropic medication were not associated with any of the balance and gait tests.

The factors described in Table 3.4 were included in a backward linear regression analysis for each clinical test, separately. The results of the regression analyses are shown in Table 3.5.

Age and number of co-morbidities significantly contributed to all clinical balance and gait tests. Older persons and persons with more co-morbidities had lower scores on the



**Table 3.4** Factors that were significantly associated with the balance and gait tests in persons with ID

| Clinical test | Factor | N | Spearman | Pearson | p |
|---|---|---|---|---|---|
| BBS | Age | 76 | -0.314 | | 0.006 |
| | BMI | 76 | -0.221 | | 0.055 |
| | Body sway | 74 | -0.427 | | <0.001 |
| | Number of co-morbidities | 76 | -0.379 | | 0.001 |
| | Sex (male/female) | 76 | | 0.264 | 0.021 |
| | Fear of falling (yes/no) | 76 | | -0.303 | 0.008 |
| FR | Age | 76 | -0.324 | | 0.004 |
| | Body sway | 74 | -0.304 | | 0.009 |
| | Number of co-morbidities | 76 | -0.333 | | 0.003 |
| TUGT | Age | 76 | 0.356 | | 0.002 |
| | BMI | 76 | 0.216 | | 0.061 |
| | Body sway | 74 | 0.294 | | 0.011 |
| | Number of co-morbidities | 76 | 0.365 | | 0.001 |
| | Fear of falling (yes/no) | 76 | | 0.199 | 0.085 |
| SLS | Age | 76 | -0.293 | | 0.010 |
| | BMI | 76 | -0.313 | | 0.006 |
| | Body sway | 74 | -0.238 | | 0.041 |
| | Number of co-morbidities | 76 | -0.255 | | 0.026 |
| | Sex (male/female) | 76 | | 0.211 | 0.068 |
| | Fear of falling (yes/no) | 76 | | -0.273 | 0.017 |
| TMWT | Age | 76 | 0.359 | | 0.001 |
| | BMI | 76 | 0.205 | | 0.075 |
| | Body sway | 74 | 0.380 | | 0.001 |
| | Number of co-morbidities | 76 | 0.309 | | 0.007 |
| | Sex (male/female) | 76 | | -0.300 | 0.008 |
| | Fear of falling (yes/no) | 76 | | 0.311 | 0.006 |

**Table 3.5** Regression analyses for all balance and gait tests in persons with ID

| Clinical test | Factor | N | b-coefficient | SE | β | p | $r^2$ |
|---|---|---|---|---|---|---|---|
| BBS | | 74 | | | | | 0.413 |
| | Age | | -0.347 | 0.088 | **-0.383** | <0.001 | |
| | BMI | | -0.343 | 0.114 | 0.277 | 0.004 | |
| | Body sway | | -2.579 | 1.189 | -0.211 | 0.034 | |
| | Fear of falling | | -2.463 | 1.289 | -0.177 | 0.060 | |
| | Number of co-morbidities | | -0.887 | 0.369 | -0.222 | 0.019 | |
| FR | | 74 | | | | | 0.258 |
| | Age | | -0.430 | 0.112 | **-0.387** | <0.001 | |
| | Number of co-morbidities | | -1.698 | 0.494 | -0.374 | 0.001 | |
| TUGT | | 74 | | | | | 0.347 |
| | Age | | 0.456 | 0.097 | **0.446** | <0.001 | |
| | BMI | | 0.305 | 0.134 | 0.218 | 0.026 | |
| | Number of co-morbidities | | 1.580 | 0.429 | 0.350 | <0.001 | |
| SLS | | 74 | | | | | 0.253 |
| | Age | | -0.156 | 0.045 | **-0.356** | 0.001 | |
| | BMI | | -0.195 | 0.061 | -0.326 | 0.002 | |
| | Number of co-morbidities | | -0.453 | 0.197 | -0.234 | 0.025 | |
| TMWT | | 74 | | | | | 0.418 |
| | Sex | | -1.788 | 0.893 | -0.184 | 0.049 | |
| | Age | | 0.200 | 0.061 | **0.315** | 0.002 | |
| | Body sway | | 2.386 | 0.829 | 0.278 | 0.005 | |
| | Fear of falling | | 1.891 | 0.897 | 0.194 | 0.039 | |
| | Number of co-morbidities | | 0.660 | 0.258 | 0.235 | 0.023 | |

BBS, FR and SLS and needed more time to complete the TUGT and TMWT. The presence of fear of falling and increased body sway were additional factors associated with poorer BBS and TMWT performance. BMI significantly contributed to the performance of the BBS, TUGT and SLS. A higher BMI was associated with lower scores on the clinical tests. Sex significantly contributed to the TMWT, with women needing more time than man.

The overall explained variances ($r^2$) of the clinical tests were 25%, 26%, 35%, 41% and 42% for the SLS, FR, TUGT, BBS and TMWT, respectively. The most important determinant of all clinical tests was age as indicated by the highest β value (presented in bold).

## Discussion

The aim of this study was to investigate whether a comprehensive set of frequently used clinical balance and gait tests are feasible in older persons with mild to moderate ID and to examine whether these tests are able to show limitations in balance and gait capacities in the ID population compared to age-matched peers in the general population. Furthermore, it was aimed to identify determinants of balance and gait performance in persons with ID.

Our results show that is was well feasible to conduct standard clinical balance and gait tests in ambulant elderly persons with mild to moderate ID. The TUGT, SLS and TMWT could be performed by all participants, and the BBS and FR by 96% of them. However, in a study targeted at persons with profound ID who had experienced a fall, the percentages of successfully performed tests were much lower: 15, 30, 35 and 40% for the SLS, FR, BBS and TUGT, respectively.[10] Apparently, the above-mentioned clinical balance and gait tests are feasible in persons with mild to moderate ID, but less so in persons with severe ID. This indicates that the feasibility of the balance and gait tests depends on the intellectual level of the target group.

Of all the clinical balance and gait tests, The FR and BBS had the lowest feasibility. The FR is one of the items of the BBS and all unsuccessful assessments of the BBS were in the participants who could not perform the FR. Although the FR was found to be feasible in persons with mild to moderate ID in other studies,[27,28] questions can be raised with respect to its validity in the ID population. The FR scores in the present study were lower than reported in other studies.[10,28] As indicated, the protocol of the FR could not always be followed, because the participants had difficulty with understanding the test. In most of the cases, they were asked to reach for the hands of the helper, which might have led to a suboptimal forward reach. This may also explain the low correlation of the FR with other clinical balance and gait tests and the large standard deviation of the FR scores. Therefore, it is concluded that the FR might not be the most suitable test to assess balance in elderly persons with mild to moderate ID.

The BBS scores observed in the present study were comparable with previous studies conducted in persons with DS.[28,29] Lower BBS scores were found by another study in persons with profound ID.[10] Interestingly, this latter study reported better scores on the FR, SLS and TUGT. For the TUGT, several other studies found that persons with ID needed on average 13-14 seconds to perform the test, which is slightly faster than in our study.[10,30,31] An explanation for the observed discrepancies would be that our participants were all above 50 years of age, whereas other studies also included persons younger than 50 years. The persons with

ID in the present study performed significantly worse than their age-matched controls on all balance and gait tests, which confirms our hypothesis. Because the scores of the control group were all within the reference values of the general population, the observed group effects are considered to reflect true differences in balance and gait performance between persons with ID and age-matched controls.[24-26]

The BBS gives an overall impression of static and dynamic balance performance during sitting and standing, whereas the FR and SLS reflect aspects of static standing balance. The TUGT reflects the ability to rise from a chair, walk, turn around and sit down, which are all aspects of dynamic standing and walking balance. The TMWT primarily reflects gait speed. Together, these tests represent most basic aspects of sitting, standing and walking capacity. The finding that persons with ID perform worse than age-matched control subjects on all of these tests is in agreement with the conclusion of a recent review. This review showed that instrumented assessments of balance and gait (i.e. posturography and gait analysis) demonstrated limitation in balance and gait capacities in persons with ID.[3] Apparently, less expensive and more accessible clinical tests can also be used to identify balance and gait disabilities in persons with ID.

The observed differences in balance and gait capacity between the ID and control group in the present study are not only significant but also seem to be clinically relevant. For the BBS, for instance, the mean group difference was 9 points, where a difference of 7.7 points on the BBS is usually considered clinically relevant.[32] Furthermore, it has been determined that a score of 45 on the BBS is the cut-off point for a higher fall risk in the general elderly population.[20] For the FR, a reaching distance of less than 25 cm is associated with a higher risk of recurrent falling in elderly over the age of 70.[33] For the TUGT, a duration of 14 seconds or more to complete the test is associated with a higher risk of falls in community-dwelling older adults.[34] Although these critical values have not been validated in the ID population, the fact that in the present study the mean scores on all tests were below or just above these critical values suggests that our ID population indeed had an increased fall risk.

To our knowledge, this is the first study that identified determinants of balance and gait performance in persons with ID. Of all possible factors that were included, age and number of co-morbidities most consistently and independently contributed to the explained variance of the balance and gait tests. Of these, age was the strongest predictor. Previous studies also investigated the relationship between age and balance and gait performance in persons with ID and found that older age negatively influenced the scores on the BBS[29] and the SLS[12]. However, no other study has investigated the influence of co-morbidities on balance and gait capacity in persons with ID. The influence of number of co-morbidities on balance and gait seems to be supported by the fact that one study showed that a combination of disabling diseases rather than a single condition affects functional recovery of balance and gait in the general elderly population.[35] In contrast to what might be expected based on earlier studies,[11,13] etiological diagnosis and severity of ID did not influence balance and gait performance. Besides age and number of co-morbidities, body sway and fear of falling seem to contribute to explaining balance and gait performance, which is coherent with the fact that postural imbalance and fear of falling are known risk factors for falls in the general elderly population.[13,36] Another determinant which was associated with balance and gait performance was the BMI. It is known that body weight is negatively correlated with balance, because overweight results in a more anterior position of the centre of mass which needs to be compensated.[22] All the factors together explained less that 50% of the overall variance, which justifies the conclusion that there must be other, unknown factors that determine balance and gait disabilities in persons with ID.

A strength of this cross-sectional cohort study is the inclusion of a relatively large and homogeneous sample of ambulant persons with mild and moderate ID as well as the fact that all assessments were performed in an environment familiar to the patient and in the presence of a known therapist or caregiver. In addition, before the actual assessment took place, a home visit was paid so that the participant and the investigator could get to know each other. These preparations greatly contributed to the feasibility and validity of the assessments. We purposely included all causes of ID to determine the feasibility and level of performance in the general population with mild to moderate ID. As a consequence, the results cannot be generalized to persons with more severe ID. Another limitation is that we did not investigate the reliability or validity of the balance and gait tests. Previous studies in persons with ID showed that the reliability of the TUGT, BBS, SLS and FR was good.[13,27,30,37] One study focused on the validity of the TUGT, but no relationship was found between TUGT performance and fall history in persons with ID.[13,30] In the present study, the BBS, TUGT, SLS and TMWT showed moderate to good correlations, which suggests that these tests measure the same construct "balance and gait". Still, more research is needed on the validity of these tests in the ID population, particularly to identify persons at risk of falling.

In conclusion, our study showed that it is feasible to conduct standard clinical balance and gait tests in older persons with mild to moderate ID. The results demonstrated that overall balance and gait performance of persons with ID is substantially worse compared to older persons of the general population and that a large proportion of the persons with ID has clinically relevant balance and gait disabilities. The most important determinants for balance and gait performance in persons with ID were age, BMI, number of co-morbidities, body sway and fear of falling.

Because the number of elderly persons with ID is increasing, it seems important to monitor their balance and gait capacity on a regular basis using standardized measures. The BBS, TUGT, SLS, and TMWT can be used for this purpose. The FR is in our opinion not the most suitable test for balance assessment in persons with ID. As balance and gait problems are important risk factors for falls, it can be expected that older persons with ID are particularly prone to falling. This notion brought us to conduct a prospective study on the risk factors for falling in the same population.

**Acknowledgements**

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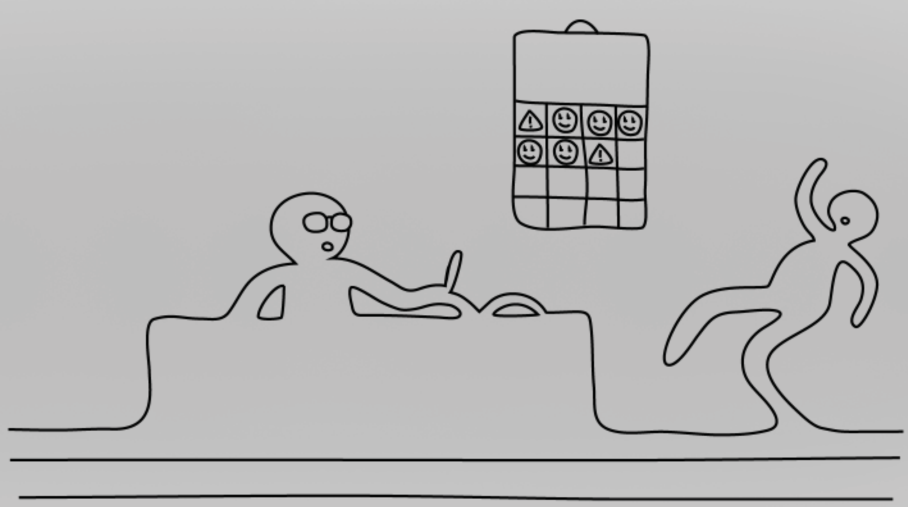
# Appendix A

Structure of interview

| Domain | Topic | Question |
|---|---|---|
| Demographic | | |
| | Gender | |
| | Age | |
| Psychosocial | | |
| | Occupation | What kind of work do you do, how many hours? |
| | Hobbies/sports/activities | What kind of hobbies/sport/activities in your spare time do you have, how many hours? |
| | Help in activities of daily life | Do you need help during activities of daily life and from whom? |
| | Use of care | Do you go to a health professional and how often? |
| | Use of (walking) aids | Do you use (walking) aids and what kind? |
| Medical condition (Co-morbidities classification based on Rigler et al.[18]) | | |
| | Health status | How is your overall health, do you have any co-morbidities, what kind? |
| Medication (according to ATC index of WHO Collaborating Centre for Drug Statistics Methodology[38]) | | |
| | Medicine | What kind of medication do you use on a daily basis? |
| History of falling | | |
| | Fall history | Have you experienced a fall during the past year, how, many, cause and consequences? |
| | Fear of falling | Are you afraid to fall? (yes/no) |

# PART II

## Falls and risk factors for falls in persons with ID



# Chapter 4

# Falls in older persons with intellectual disabilities: Fall rates, circumstances, and consequences

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## Abstract

**Background:** Falling is a common cause of injuries and reduced quality of life. Persons with Intellectual Disabilities (ID) are at increased risk for falls and related injuries. As the number of elderly persons with ID is growing rapidly, it is imperative to gain insight into the quantity of the problem of falling, the circumstances that precipitate falls and to better understand their etiology in persons with ID. This is the first study to prospectively investigate fall rate, circumstances, and fall consequences in older adults with mild to moderate ID.

**Method:** Eighty-two individuals with mild to moderate ID, 50 years and over (mean age 62.3 (SD=7.6), 34 male), participated in this study, which was conducted at the three service providers for persons with ID in The Netherlands. Falls were registered for one year with monthly fall registration calendars to determine the fall rate (mean number of falls per person per year). Information on fall circumstances and consequences was obtained from questionnaires completed by caregivers and study participants after each fall.

**Results:** We determined that the fall rate in this sample was 1.00 falls per person per year. Thirty-seven participants reported at least one fall (range 1-6). Sex and age were not related to falls. Most falls occurred while walking (63.3%), outside (61.7%), and in familiar environments (88.9%). Importantly, 11.5% of falls resulted in severe injuries, approximately half of which were fractures.

**Conclusion:** The circumstances and consequences of falls in persons with ID are comparable to those of the general elderly population, but the rate is substantially higher. As such, appropriate fall prevention strategies must be developed for individuals with ID.

## Introduction

Falling is a common cause of injuries and reduced quality of life. In the general elderly population, one out of three persons falls each year,[1-4] and the estimated fall rate is 0.45 to 0.65 falls per person per year.[3-5] Approximately 10% of these falls result in serious injuries, half of which are fractures.[4,6] In addition, falls may have psychological consequences that further affect well-being, such as increased fear of falling and reduced independence.[6-8]

Persons with intellectual disabilities (ID) are reported to be at increased risk for falls and fall-related injuries.[9-13] It is estimated that 50 to 60% of injuries in persons with ID are caused by falls.[10,11,14] Injury-related visits to emergency departments and hospital admittances in persons with ID are primarily due to falls.[15] These falls and associated injuries may impact on the individuals who fall, but also on their environment, health services, and the entire community.

Risk factors for falling in persons with ID may be specifically related to their condition (e.g., epilepsy),[10,11,13,16] but overall they are largely similar to those identified for the general elderly population, including older age, visual deficits, medication use, and co-morbidity.[10,11,13,14,16-19] However, several of these fall risk factors are more prevalent in persons with ID. Cognitive impairments have been associated with an increased risk for falls and fall-related injuries.[4,6,20] Furthermore, persons with ID have more co-morbidities and higher rates of medication use,[21-23] which are both related to falls and injuries.[6,24-26] Balance and gait problems (impaired mobility) are also well-established risk factors for falling,[4] and a recent review reported that these problems occur more often and start at younger age in persons with ID.[27] In addition to being at greater risk for falls, the risk of fall-related fractures is augmented in persons with ID because of lower bone mineral density.[28-30]

Previous studies have found that 34-70% of persons with ID in their study population have experienced falls.[9,10,13,18] However, these studies varied with regard to age groups and study duration. Furthermore, the studies investigating falls and fall risk factors in persons with ID mostly obtained data on fall incidents from retrospective reports, medical records, or client records.[9-11,13] It is likely that the number of falls is underestimated in retrospectively collected data.[31] For this reason, the Prevention of Falls Network Europe (ProFaNe) recommends that monthly fall calendars should be used to prospectively monitor falls for at least one year.[32]

Longer average life expectancy means that the number of elderly persons with ID is growing rapidly.[29,33] Therefore, it is imperative to gain insight into the quantity of the problem of falling, and to understand the circumstances and consequences of falls in this population so that effective fall prevention strategies can be designed and implemented. The aim of this study was to prospectively investigate fall rate, circumstances, and consequences in older adults (aged 50 years and over) with mild to moderate ID.

## Methods

### Participants

This work was part of a prospective study on fall risk factors in persons with ID. Participants were recruited from three service providers for persons with ID in The Netherlands. The participants had to be at least 50 years old with mild to moderate ID (IQ 35-70). To be eligible for inclusion, participants had to be able to walk independently for at least 10 meters and understand simple instructions. Epilepsy was an exclusion criterion in the original study because epileptic seizures, which might be seen as a fall, have a different cause than falling related to ID and aging.

First, individuals with ID older than 50 years were selected from the service providers' database and were screened for inclusion and exclusion criteria by physicians, allied health professionals, and caregivers. Their selection resulted into 260 eligible candidates who were invited to participate, and 90 of the individuals with ID and their legal representatives expressed interest. The next step was a home visit. One person passed away before the home visit took place, and for one person it was impossible to schedule a home visit during the study period. These visits were used as an introductory meeting, a final verification of meeting the study criteria, and to provide more information about the study. We also conducted an interview to collect information on the type of living facility (community-based group home, campus facility, or supported independent living situation), activities of daily life (work and sports related, hours per week), fear of falling (yes or no), and the number of falls in the past 12 months. Two individuals were not able to continue the study after the home visit; one moved to a home with less supervision, and the other was not willing to continue participation. Ultimately, 86 persons were enrolled.

This study was conducted in agreement with the Declaration of Helsinki and was approved by the regional Medical Ethics Committee. All participants and their legal representatives provided written informed consent prior to participation.

### Fall registration

Falls were registered for one year using monthly fall registration calendars (Figure 4.1). Participants put a sticker on their calendars every day; a smiley face sticker if no fall occurred,

| March 2011 | | | | | | | |
|---|---|---|---|---|---|---|---|
| Week | *Monday* | *Tuesday* | *Wednesday* | *Thursday* | *Friday* | *Saterday* | *Sunday* |
| 44 | | 1 | 2 | 3 | 4 | 5 | 6 |
| | | | | | | | |
| 45 | 7 | 8 | 9 | 10 | 11 | 12 | 13 |
| | | | | | | | |
| 46 | 14 | 15 | 16 | 17 | 18 | 19 | 20 |
| | | | | | | | |
| 47 | 21 | 22 | 23 | 24 | 25 | 26 | 27 |
| | | | | | | | |
| 48 | 28 | 29 | 30 | 31 | | | |
| | | | | Please send calendar | | | |

**Put a sticker on every day!**

-  **when you did not fall**
-  **when you did fall. Fill out the questionnaire 'Fall Incident' with your caregiver.**
- **If you put a sticker on every day, your caregiver will put a Week sticker**  **at the end of the week.**

**Figure 4.1** Example of Fall registration calendar.

and a red sticker if they experienced a fall. At the end of each week, their caregivers checked the calendar and marked the week with a sticker. When a fall occurred, the caregiver and participant completed a fall questionnaire to describe the fall circumstances and consequences (see appendix). This information was used to verify whether the reported fall met the common definition of a fall, which is 'an unexpected event in which the participant comes to rest on the ground, floor, or lower level'.[32] At the end of the month, the calendars were sent to the researcher. If no calendar was received, the researcher contacted the caregiver to remind them to send it in.

## Analysis

The number of fallers (persons with one or more falls) and fall rates were determined from the fall registration calendars. The fall rate is the overall number of falls per person per year. The effect of age, sex, fear of falling at baseline, reported falls in the past year, activities, and type of living facility on the fall rate was determined by means of independent sample t-tests and $\chi^2$ tests. These variables were also compared between single and recurrent fallers (>1 fall).

With respect to fall circumstances and consequences, frequency distributions were calculated, and the prevalence was determined. The influences of age, sex, and the relationship between fall circumstances and possible injuries were analyzed ($\chi^2$ tests for nominal data and independent-sample t-tests or analysis of variance (ANOVAs) for interval/ratio data). For these analyses, injuries were divided into three categories: 'no injuries,' 'mild injuries' (bruises, scratches, or pain), or 'severe injuries' (fractures, cerebral concussions, or severe sprains that required consultation with a general practitioner). The alpha level was set at 0.05.

# Results

## Participants

In total, 86 persons with ID received a fall registration calendar. Four of them never started the fall registration because they found it too burdensome or stressful. Therefore, a total of 82 participants started the fall registration period of one year. Nine persons were lost to follow-up; one person died (2 months follow-up), one person was too ill to continue (7 months follow-up), three persons moved out of their living facilities (1, 5, and 6 months follow-up), and four persons stopped sending the calendars despite multiple telephone reminders (at 5, 7, 7, and 8 months follow-up). The available monthly fall registration calendars for those who did not return all 12 months were included in the analysis. The baseline characteristics of the participants who started the fall registration period are presented in Table 4.1.

## Fall rate

Of the 82 participants for whom fall data were available, 37 (45%) reported a fall incident (range 1-6 falls, see Figure 4.2 for the distribution of the number of falls per person) during the one year follow-up period. In total, 77 falls were reported, with a fall rate of 1.00 falls per person year.

Women fell more often than men (56% of women versus 38% of men), but this difference was not significant ($\chi^2$ (1, n=82)=2.716, p=0.099). The mean age of fallers was 62.2 (SD=7.3) years versus 64.3 (SD=8.0) years for non-fallers (p=0.223).

Fifteen participants experienced a single fall, and 22 participants experienced more than one fall (recurrent fallers). Among female fallers, 74% reported recurrent falls versus 44% of male fallers ($\chi^2$ (1, n=37)=3.278, p=0.070). Single and recurrent fallers did not differ in age (63.1 (7.6) and 61.5 (7.2) years, respectively, p=0.507).

**Table 4.1** Participants' characteristics (n=82)

| Characteristics | |
|---|---|
| Sex: female:male (n) | 34:48 |
| Age: years, mean (SD), range | 62.9 (7.6), 51.6-84.6 |
| Weight: kg, mean (SD) | 74.5 (16.1) |
| Height: m, mean (SD) | 1.65 (0.12) |
| Type of living facility (n) | |
| Group home | 73 |
| Campus facility | 4 |
| Independent, with ambulatory support | 5 |
| Day activity: n: hours per week, mean (SD) | |
| (Paid) Work | 52: 27.5 (7.6) |
| Arts and crafts at day activity centre | 26: 20.8 (8.1) |
| Retired | 3 |
| No day activity | 1 |
| Sport activity: minutes per week, mean (SD) | 45.6 (44.7) |
| Fall history: yes:no (n) | 40:42 |
| Number of falls previous year: range, mean (SD)) | 0-10, 1.10 (1.9) |
| Fear of falling: yes:no (n) | 46:36 |

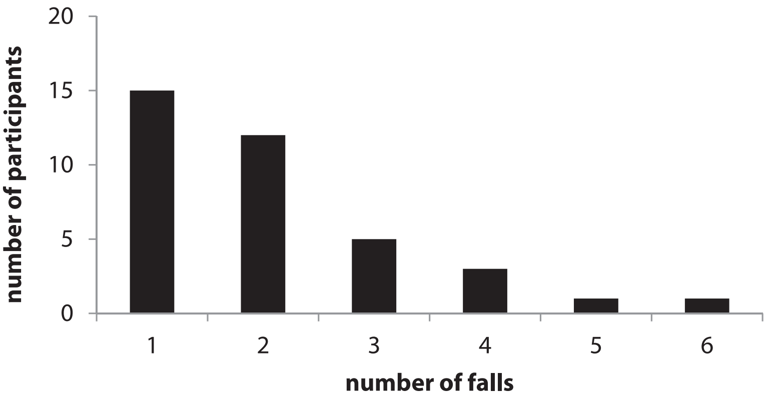


**Figure 4.2** Number of falls (total n=77) per faller (n=37) during one year follow-up.

Fear of falling at baseline, fall history (based on retrospective recollection of the previous year), type of living situation, hours of activity per week (work or arts and crafts at a day activity center), or participation in sports activities did not differ between fallers and non-fallers (p=0.218, p=0.983, p=0.167, p=0.511, and p=0.996, respectively). Fear of falling at baseline, fall history, type of living situation, and daily activity also did not differ between single and recurrent fallers (p=0.254, p=0.522, p=0.174, and p=0.371, respectively). However, recurrent fallers were more active in sports activities (58.6 (SD=39.3) minutes per week) compared to single fallers (26.3 (SD=42.5) minutes per week) (p=0.041).

## Circumstances of falls

The causes and circumstances of most falls could be determined from the questionnaires. For 17 falls, no questionnaire was received; these falls were unknown to the caregivers, and the participants were unable to remember the requested information regarding fall cause and circumstances.

Most falls occurred during walking (63.3%). Other common activities were cycling (11.7%), which is a customary Dutch mode of transportation, or while using stairs (6.7%). The cause of the fall was often unknown (31.7%). Among the known causes, tripping was mentioned most frequently (25.0%), followed by slipping (15.0%), loss of balance (13.3%), missing a stair (5.0%), other reasons (5.0%), loss of support surface (3.3%), and being knocked over (1.7%) (Figures 4.3 and 4.4).

Most falls occurred outside the house (61.7%), in a familiar environment (88.9%), and in well-lit areas (84.7%). Forty-five percent of the falls occurred in the afternoon, 26.7% in the morning, 21.7% in the evening, and 5.2% took place at unknown times. None of the reported falls occurred at night.

With regard to the seasons, most falls occurred in winter (34.2%), followed by spring (25.0%), summer (23.7%), and autumn (17.1%). There was a significant relationship between season and fall cause ($\chi^2$ (21, n=60)=35.353, p=0.026), with most falls caused by slipping in winter (n=7) and unknown causes of falls in summer (n=8).

The majority of the falls were in the forward direction (44.3%), and the direction was unknown in 21.3%. Sideways and backward falls accounted for 19.7% and 13.1% of falls, respectively. Obstacles in the nearby environment were reported in 35% of falls, and the faller was distracted during 8.3% of falls.

Of the 60 falls for which information was available, 66.7%, 13.3%, and 13.3% of participants were wearing conventional shoes, orthopedic shoes, and sandals at the time of the fall, respectively. Only one person (1.7%) fell while barefooted.

The causes and circumstances of the falls did not differ between women and men (p-values varying from 0.195 to 0.890). Age was not related to the causes or circumstances of the falls (p-values varying from 0.194 to 0.970).

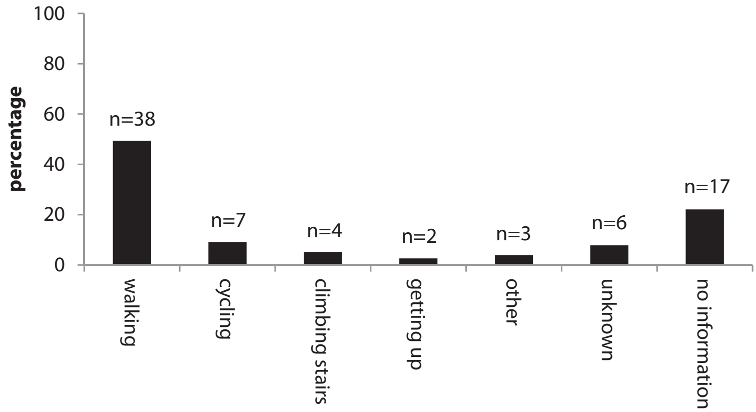


**Figure 4.3** Activity during falls (n=77) in the study participants with ID (percentage and number).

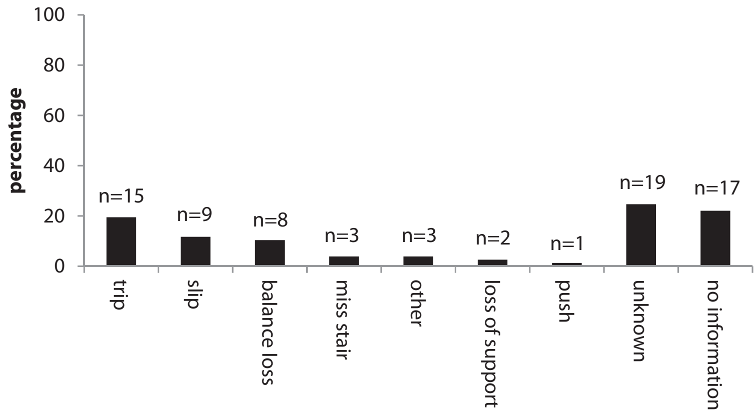


**Figure 4.4** Cause of falls (n=77) in the study participants with ID (percentage and number).

## Consequences of fall

For one individual there was no information on the causes or circumstances of the fall, but we did receive information about the consequences. Thus, the consequences were known for 61 falls. Mild injuries occurred in the majority of the falls (n=37, 60.7%). Seven (11.5%) resulted in severe injuries, including three lower extremity fractures, three sprains that required consultation by a general practitioner, and one cerebral concussion. Seventeen falls (27.9%) did not result in injuries. Fall circumstances and causes were not related to injuries (p-values varying from 0.210 to 0.871).

Seventeen persons (28.3%) needed help getting up after they had fallen. All seven individuals with severe injuries and two with mild injuries subsequently visited their general practitioner. Fallers visited the hospital five times, all for severe injuries.

Of five participants with severe injuries, the activity during the fall was known: two were walking, two were cycling, and one was descending the stairs. Four of the seven severe injuries were experienced by recurrent fallers. One person had two falls that resulted in severe injuries.

Sex and age were not related to injury severity. Among women, 24.3% had no injury, 64.9% had mild injuries, and 10.8% experienced severe injuries. For men, these percentages were 33.3%, 54.2%, and 12.5%, respectively ($\chi^2$ (2, n=61) = 0.735, p=0.693). The mean age of the participants without injuries was 61.2 (7.3) years, with mild injuries 61.6 (6.3) years, and with severe injuries 57.8 (4.4) years (p=0.364).

After experiencing a fall, 45% of participants reported fear of falling and 45% did not. This parameter was unknown in 10% of fallers. The participants who reported fear of falling after a fall (n=27) were slightly but significantly younger (59.3 (SD=3.7) years) than those who reported no fear of falling (n=27) (62.7 (SD=8.1) years) (p=0.048).

## Discussion

The aim of this study was to prospectively investigate fall rate, circumstances, and consequences in persons with ID. Our study showed that fall registration with monthly fall calendars was feasible in older adults with mild to moderate ID. The results showed that the ID study population fell more often than the general elderly population. This was reflected by a larger number of persons who fell (45% of individuals with ID versus 33% in the general population) and a higher fall rate (1.00 vs. 0.45-0.65 falls per person per year).[1,3-5] It is important to emphasize that the participants with ID in our study were on average younger (aged 50 years and over) than the general elderly population (aged 65 years and over) for whom fall rates have been reported in the literature.

This is the first study that prospectively measured fall incidents in persons with ID by using monthly fall calendars. This method is less prone to recall bias (and thus under-registration) than retrospective reports (e.g., questionnaires or medical charts) used in previous studies. Therefore, the presently reported fall rates are likely higher, but it is difficult to compare the values because of differences in age groups, level of ID, and study periods. Two retrospective studies in adults with ID (mean ages of 35 and 44 years, compared to 62 years in our study) showed that 34% and 40% of their study populations had fallen in the previous year.[9,10] Because older age is an important risk factor for falls,[9,11,13,14,17-19] age differences among the study populations might be a possible explanation for discrepancies in the proportion of fallers. Furthermore, differences in the level of ID of the studied populations might also influence the results. The higher proportions of fallers reported by Wagemans (57%) and Grant (70%) are likely due to the fact that they looked at fall incident reports over a period of more than 2.5 years and included persons with more severe disabilities.[13,18]

Mobility problems, i.e., balance and gait problems, have been identified as an important risk factor for falls, especially in persons with ID who experience these problems more often and at a younger age.[27] Our study confirms the importance of mobility; most falls for which the cause was known occurred during walking. This is consistent with reports for the general elderly population.[34,35] It is also corroborated by other studies in persons with ID that reported that ambulatory persons with ID are at a higher risk of falls.[11,13,19] The most important reason for falling during walking in the general elderly population is tripping,[34,35] which was also seen in our study. Generally, tripping is due to failure to recover balance while negotiating an obstacle. Indeed, the participants reported that there were obstacles in the environment for 80% of falls due to tripping. The training of obstacle avoidance skills may therefore be a logical intervention to prevent falls in older adults with mild to moderate ID.



The results regarding the circumstances of the falls are also consistent with earlier studies in the general elderly population. Most falls occurred during the daytime,[34-36] probably because most activities that put a person at risk of falls occur during the day. The finding that most falls occurred outside the house is similar to what has been reported for the general elderly population.[34,37] Another congruency is that most falls occurred in winter,[34] which has previously been reported for persons with ID.[10] Snowy and icy conditions increase the risk of slipping; indeed, we found that the majority of falls during the winter occurred outdoors on slippery surfaces.

The prevalence of severe injuries in our study population was comparable with those in the general elderly population; 11.5% of falls resulted in severe injuries, of which approximately half were fractures.[4,6,20] The injuries occurred mostly in recurrent fallers. Interestingly, fall rates were not different between those with and without fall histories, which is a well-established and strong risk factor for future falls in the general elderly population. This can probably be explained by the fact that data on fall history was obtained by asking the participants and their caregivers whether a fall had occurred in the past year. Recollection of such events is a problem in this particular group, which further stresses the importance of prospectively collecting fall data in persons with ID.

We did not observe differences in fall rate, circumstances, or consequences between men and women. Although some previous studies in the general elderly population reported that women fall more often than men,[38,39] our findings are in agreement with other reports that did not find sex-related differences in fall rate.[4,34,40] The few studies on the risk of falls and fall-related injuries in persons with ID also provided conflicting results on the influence of sex. Two studies reported that sex was not related to fall risk in persons with ID[9,16], whereas another[18] found that men were more at risk of fall-related injuries.

Older age is a well-known risk factor for falls, both in the general elderly population4 and in persons with ID.[9,11,13,14,17-19] However, we did not find an effect of age on the fall rate, circumstances, or consequences. This might be due to the fact that we only included participants over the age of 50, whereas other studies on persons with ID enrolled a wider age range (varying from 20 to 88 years). We did observe age-related differences related to fear of falling, which is related to a higher fall risk[4,7,41] and was reported by 44% of the participants at baseline. One other study in persons with ID reported fear of falling in 33% of participants; however, their cohort was much younger than ours.[10] A review on fear of falling in community-dwelling elderly persons reported prevalence rates varying between 21 and 85%.[42] In this review, the fear of falling was reportedly higher in women compared to men and appeared to increase with age. This is in contrast with our study, in which no difference between sexes was found and an increased number of younger participants who had experienced a fall reported a fear of falling.

This study has several limitations, some of which are related to the study population. Several participants were lost to follow-up; caregivers were not always present during a fall; and the participants could not always provide information on fall causes, circumstances, and consequences. This made it difficult and occasionally even impossible for caregivers to complete the fall questionnaire. In addition, although this was a prospective study, we were dependent on self-reported information, which is subject to recall bias.

In conclusion, our study shows that falling is a substantial problem in older persons with mild to moderate ID. Although fall circumstances and consequences have several similarities to those in the general elderly population, the rate of falls is much higher. This indicates that falls prevention in older adults with mild to moderate ID is very important, and appropriate fall prevention strategies must be developed. This necessitates the identification of targetable risk factors, such as training on good walking practices and obstacle avoidance. In addition, there is a need for future studies in which potential risk factors for falls in older adults with ID are related to prospectively collected fall data.

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# Appendix

Items questionnaire on fall circumstances and consequences

| **Circumstances** |
|---|
| Date of the fall (and season)<br>Time of the fall<br>Activity during fall<br>Cause of fall<br>In- or outside the house<br>Familiar environment<br>Lighting conditions<br>Direction of the fall<br>Obstacles in near environment<br>Distraction during fall<br>Shoes |
| **Consequences** |
| Injuries<br>Consultation general practitioner<br>Hospital<br>Fear of falling |

# Chapter 5

# Prospective study on risk factors for falling in elderly persons with mild to moderate intellectual disabilities

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## Abstract

Elderly persons with intellectual disabilities (ID) are at increased risk for falls and fall-related injuries. Although there has been extensive research on risk factors for falling in the general elderly population, research on this topic in persons with ID is rather sparse. This is the first study to prospective investigate risk factors for falling among elderly persons with mild to moderate ID. Seventy-eight ambulatory persons with mild to moderate ID (mean age 62.8±7.6 years; 44 (56%) men; 34 (44%) mild ID) participated in this study. This longitudinal cohort study involved extensive baseline assessments, followed by a one-year follow-up on fall incidents. Falls occurred in 46% of the participants and the fall rate was 1.00 falls per person per year. The most important risk factors for falling in elderly persons with mild to moderate ID were (mild) severity of ID, (high) physical activity, (good) visuo-motor capacity, (good) attentional focus and (high) hyperactivity-impulsiveness, which together explained 56% of the fall risk. This pattern of risk factors identified suggests a complex interplay of personal and environmental factors in the aetiology of falls in elderly persons with ID. We recommend further research on the development of multifactorial screening procedures and individually tailored interventions to prevent falling in persons with ID.

## Introduction

Falls cause high morbidity and mortality rates in elderly persons.[1] In the community-dwelling elderly population, one-third of all individuals fall at least once a year.[2,3] Approximately 10% of these falls result in injuries, half of which are fractures. Furthermore, falling can often have psychosocial consequences such as fear of falling.[4,5] Consequently, this may lead to a reduction in physical activity, which in turn may result in (further) functional decline and a loss of independence.[3,6]

Elderly persons with intellectual disabilities (ID) seem to be at an even higher risk of falling and experiencing fall-related injuries than their mentally healthy peers.[6-10] The reported percentage of 'fallers' (i.e. persons who fall at least once during the observation period) range from 34% to as high as 70%.[7-10] In the aforementioned studies, the observation period ranged from one year up to five years. Injuries have been attributed to falls in 50-62% of cases.[10,11] Nevertheless, our understanding of the factors that underlie the increased risk of falling among persons with ID is rather limited.

In the general elderly population, the risk factors associated with falling have been studied extensively.[2,3] These risk factors can be divided into extrinsic (e.g. environmental factors such as obstacles and support surface) and intrinsic (e.g. personal factors related to the physical and/or cognitive status of the individual) factors.[2] In the elderly population, the primary intrinsic risk factors for falling are mobility problems (e.g. impaired balance and/or gait), advanced age, limitations in activities of daily living, sensorimotor impairments, medication use (e.g. polypharmacy and/or psychoactive drugs), and medical conditions such as (pre-) dementia, stroke and Parkinson's disease.[2]

Elderly persons with ID encounter the same extrinsic risk factors for falling. The aforementioned intrinsic risk factors may also apply to persons with ID, but perhaps to a different degree, as several fall risk factors are more prevalent among persons with ID. A recent review has indicated that balance and gait impairments occur more often and start at a younger age in persons with ID.[12] Moreover, visual impairments and polypharmacy are more prevalent among persons with ID.[13,14] Finally, impaired cognition itself is a known risk factor for falling.[2,3]

Several exploratory studies have been performed to investigate intrinsic risk factors for falling among persons with ID.[7-9,15] Although a recent review identified advanced age, impaired mobility, epilepsy, medication use, and behavioural problems as risk factors for falling among persons with ID, the authors concluded that additional research is needed to prospectively investigate these factors in this population.[16] Indeed, most of the data regarding fall incidents in previous studies has been collected from retrospective reports, medical records, or client records,[6-9] and a retrospective assessment of falls often leads to an underestimation of the fall rate.[17] Therefore, the Prevention of Falls Network Europe (ProFaNe) recommends prospectively monitoring falls for a follow-up period of at least one year.[18] However, to the best of our knowledge, no such prospective study has investigated risk factors for falling among the elderly ID population.

The aim of this study was to identify the specific risk factors that underlie falling among elderly persons with mild-to-moderate ID. In addition, we tested whether differences in risk factors exist between persons who fall indoors and persons who fall outdoors, as in community-dwelling older people, their characteristics have been shown to differ distinctly.[19]

## Methods

### Study design

This longitudinal cohort study involved extensive baseline assessments, followed by a one-year follow-up of fall incidents. Risk factors for falling among elderly persons with ID were determined by baseline assessments including clinical assessments of mobility and cognition, questionnaires regarding sensorimotor abilities, activity level and behaviour, and a review of the medical record, including demographics, medication use, and co-morbidities (see Appendix). The study was performed in accordance with the declaration of Helsinki and was approved by the medical ethics committee of the region Arnhem-Nijmegen, the Netherlands.

### Participants

Participants were recruited from three service providers for persons with ID in the Netherlands. To be eligible, each participant had to be at least 50 years of age when recruited, with mild–to-moderate ID (defined as an Intelligence Quotient (IQ) of 35-70). Because age-related problems are more prevalent and occur at a younger age in persons with ID than in the general elderly population,[12,20,21] the relatively low minimum age of 50 years was chosen as an inclusion criterion in this study. Furthermore, each participant had to be able to walk at least ten meters without assistance and understand simple instructions. Epilepsy was an exclusion criterion because dropping to the ground during a seizure – which can be considered a fall – has a different cause than falling associated with ID and ageing.

## Procedure

Persons with ID who were 50 years of age or older were selected from the service provider database and screened by physicians, allied health professionals, and caregivers using a checklist of the inclusion and exclusion criteria. Two hundred and sixty participants met the inclusion and exclusion criteria and received an information letter regarding the study and a reply form in which they could express their interest in participating. This information letter was adjusted to their level of understanding using simple language, pictograms, and pictures. If the eligible person had a legal representative, the representative and caregiver also received an information letter. Ninety eligible participants (or their legal representative, if applicable) provided written permission to be actively contacted. The eligible patients who were interested in participating did not differ from the eligible candidates who declined to participate with respect to age (mean age (SD): 63.1 (7.6) and 62.2 (7.1) years, respectively; p=0.321) or gender (43% and 47% women, respectively; p=0.585). The flow of the participants through the study is depicted in Figure 5.1.

After receiving the participants' forms indicating their interest, the researcher visited the home of 88 of the 90 eligible participants. During this visit, eligibility based on the inclusion and exclusion criteria was confirmed, additional information regarding the study was given to the participants, and an informed consent form was signed. If the participant had a legal representative, written informed consent was obtained from this person as well. Subsequently, the primary researcher interviewed the participant regarding activities of daily living, the use of care and aids, co-morbidities, current medication use, fall history, and fear of falling. Furthermore, the living environment of each participant was examined with respect to safety. During this home visit, two persons declined to participate further. In total, informed consent was given by 86 persons, and these participants received the fall calendars at the end of the home visit.

## Baseline assessments

Mobility and cognition were assessed clinically in an environment that was familiar to the participant (e.g. in their home or at a day activity centre). In addition, the majority of the clinical assessments occurred in the presence of a familiar therapist or caregiver. Instructions for the tests were given verbally. If the participant did not understand the instructions, the test item was demonstrated. If needed, practice trials were performed prior to testing.

Mobility was assessed using a set of clinical balance and gait tests, including the Berg Balance Scale (BBS), the Functional Reach test (FR), the Timed Up and Go Test (TUGT), the

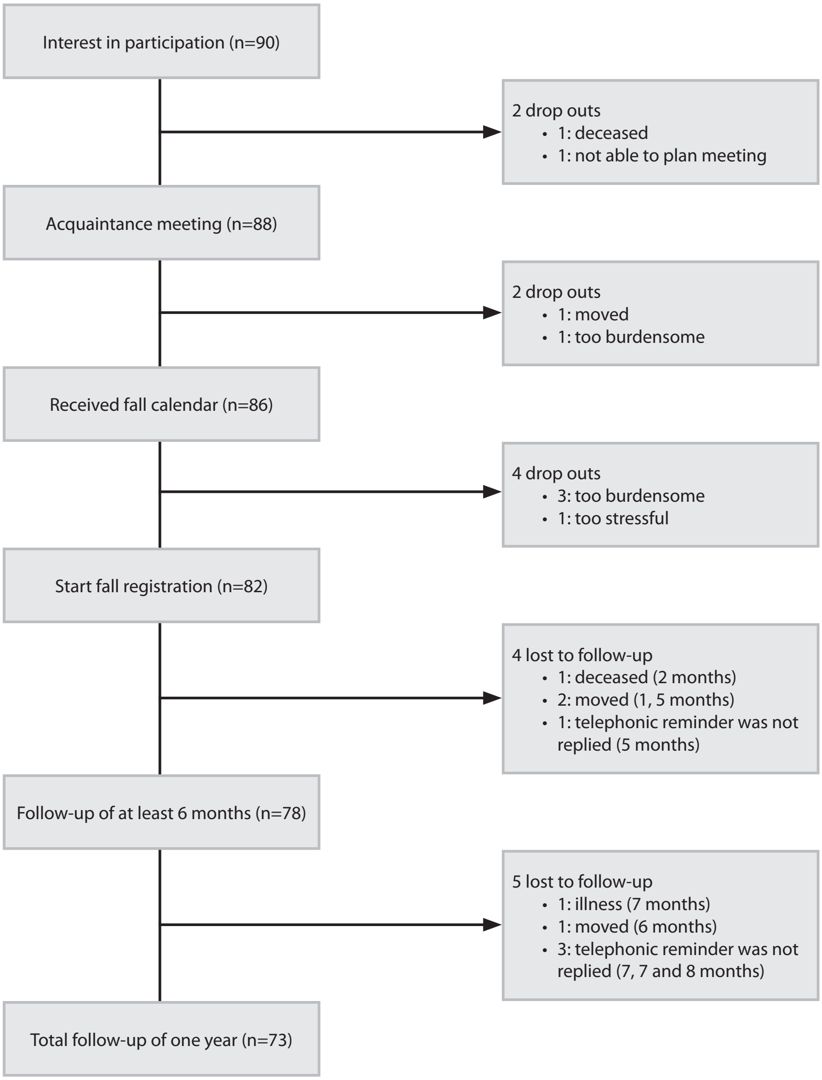


**Figure 5.1** Flow chart of fall registration.

timed Single Leg Stance (SLS), and the Ten Meter Walking Test (TMWT).[22-27] In addition, the level of human assistance required for ambulation was measured using the Functional Ambulation Classification (FAC)[28]. All clinical balance and gait tests have been shown to be both reliable and valid for assessing mobility among elderly persons.[22-27] Moreover, we reported previously that these tests can be administered to persons with ID.[29] The participants wore their usual footwear during the clinical tests and were not permitted to use a walking aid. Each participant was assessed by a physical therapist (author LE) who was experienced in the administration of the tests.

Cognition was assessed using a general IQ test (The Raven's Coloured Progressive Matrices)[30] and two Dutch neuropsychological test series (the 'Amsterdamse Neuropsychologische Taken' (ANT)[31] and 'NEuropsychologische Testserie voor Oudere Licht verstandelijk gehandicapten' (NETOL)[32]). The ANT was used to assess specific cognitive functions such as reaction time, memory, and sustained and divided attention. NETOL was designed specifically for persons with ID, and the following tasks were selected: a visuo-spatial memory task, a visual-search task, a visuo-motor task, and a visuo-constructive task. The cognitive tests have been shown to be both reliable and valid for assessing cognitive functioning.[30-32] All tests were administered by trained psychological assistants.

The caregivers of the participants completed three questionnaires. Physical activity was measured using the Physical Activity Scale for the Elderly (PASE).[33,34] The Adolescent Adult Sensory Profile (AASP) provided information regarding sensory processing with respect to the following four aspects: sensitivity to sensory stimuli, avoidance of sensory stimuli, poor perception of sensory stimuli, and sensation seeking.[35] The Adult Behaviour Checklist (ABCL) was used to assess depression, anxiety, attention problems, and hyperactivity-impulsiveness.[36-38] The reliability and validity of these questionnaires has been demonstrated previously.[33-37]

Finally, the participants' medical charts were reviewed to obtain information regarding diagnosis (genetic cause, brain damage, unknown cause), severity of ID (mild/moderate), co-morbidities (based on Rigler et al., 2002)[39], medication use (according to the Anatomical Therapeutic Chemical (ATC) index)[40], and history of falls.

## Fall registration

Information regarding falls was collected for one year by monthly fall registration calendars and the completion of fall incident questionnaires. This method of data collection is recommended by the Prevention of Falls Network Europe.[18] At the end of each day, the participant affixed a sticker on their calendar – either a 'smiley face' sticker was affixed if no fall had occurred, or a red sticker was affixed if they had experienced a fall. At the end of each week, their caregiver checked the calendar and marked with a green sticker for each week whether the calendar was completed. For each fall incident, descriptive data regarding the circumstances and consequences of the incident were obtained using a fall incident questionnaire. In the event of more than one fall in a single day, a separate fall incident questionnaire was completed for each fall incident. The fall incident questionnaire included questions regarding the date, time, location, direction, cause, and consequence of the fall. The consequences of the fall were categorised as 'no injury', 'mild injury' (bruises, scratches, and/or pain), or 'severe injury' (fracture, cerebral concussion, and/or a severe sprain that required care by a clinician). Detailed information regarding these methods have been published previously.[41]

Each month, the calendar and – if applicable – completed fall incident questionnaire(s) were sent to the researcher. If no calendar was received, the caregiver was reminded by telephone.

Four of the 86 participants did not begin the fall registration process. Of the remaining 82 participants, nine were lost to follow-up, four of whom were lost within the first six months (see Figure 5.1).

### Data analysis

Fall rates were calculated as the number of falls per person per year. We only included fall data of participants with at least six months of follow-up. To identify the potential risk factors for falling, we first identified differences between fallers and non-fallers using univariate binary logistic regression. Each variable that differed between the groups (p-value $<0.2$) were subsequently included in a multiple regression analysis, with fall status (faller vs. non-faller) as the dependent variable ($\alpha=0.05$). For this analysis, participants were required to register their falls for at least six months. Therefore, data from 78 participants (mean age 62.8±7.6 years; 44 men; 34 with mild ID) were included in the analysis, including five participants who were lost to follow-up after six months (see Figure 5.1).

Because previous studies reported different risk profiles for individuals who fall indoors versus individuals who fall outdoors,19 additional analyses (Students t-tests and Chi-square tests) were performed to identify possible differences between participants who fell indoors only and participants who fell outdoors only. All data were analysed using SPSS version 18.0 for Windows.

## Results

### Fall rate

Of the 78 participants with a follow-up of at least 6 months, 36 (46%) reported at least one fall incident within the follow-up period (range: 1-6 falls). In total, 76 falls were reported during the year of follow-up. The fall rate was 1.00 falls per person per year. The falls usually occurred during the day and in familiar surroundings. The majority of the falls occurred during walking (62%) and were primarily due to tripping, slipping, and/or loss of balance. Six persons fell only indoors, 13 fell only outdoors, 10 fell both indoors and outdoors, and 7 persons did not report the location of the falls. Of the 76 falls, 72% resulted in injury. The majority of these injuries were mild (bruises, scratches, and/or pain); 10% of the falls resulted in severe injury, of which one-third were fractures. Detailed information regarding the circumstances and consequences of these reported falls has been published previously.[41]

**Risk factors for falls**

The characteristics of the fallers and non-fallers and the results of the univariate binary logistic regression are shown in Table 5.1. For two participants, their legal representatives did not give permission to access the medical files. Therefore, the aetiological diagnosis and severity of ID were not available for these two persons. In addition, some questionnaires were not returned by some of the participants (four AASP questionnaires, three ABCL questionnaires, and eight PASE questionnaires were not returned). The balance and gait tasks were not performed by three participants – one person refused to perform the tests, one person had moved before the assessment could take place, and one person's caregivers advised against the assessment due to potential adverse effects from the assessment based on the person's behavioural problems. Therefore, data regarding the balance and gait tasks were available for 75 persons, except for the FR that could not be performed by one participant (n=74).

The cognitive assessments turned out to be rather difficult for some of the participants. Some persons did not understand what was requested from them and – according to the psychological assistant – provided arbitrary answers or pushed the buttons randomly. Because of this poor feasibility, we only analysed cognitive tasks that were assessed properly in at least 75% of the participants.

The fallers differed from the non-fallers with respect to the following factors: gender, severity of ID, hearing problems, physical activity, visuo-spatial memory, visuo-motor capacity, perception of sensory stimuli, sensation seeking, attention problems, and hyperactivity-impulsiveness. Women fell more often than men. Persons with mild ID, better visuo-spatial memory and visuo-motor capacity, better perception of sensory stimuli, more sensation-seeking behaviour, higher activity level, and fewer hearing problems fell more often. With respect to behaviour, the fallers reported more hyperactivity-impulsiveness and fewer attention problems.

**Table 5.1** Characteristics of the fallers and non-fallers and the crude odds ratios (OR) of the variables for the risk of falling within one year using univariate logistic regression (full sample n=78)

| Determinant | N | Faller (n=36) | Non-faller (n=42) | OR (95% CI) | p-value |
|---|---|---|---|---|---|
| Gender | 78 | | | | |
| Male | | 17 (47.2%) | 27 (64.3%) | 0.50 (0.20-1.23) | **0.132*** |
| Female | | 19 (52.8%) | 15 (35.7%) | | |
| Age (years) | 78 | 61.6±7.4 (51.6-84.6) | 63.7±7.7 (51.6-80.7) | 0.96 (0.91-1.02) | 0.216 |
| Body Mass Index (BMI) (weight/length$^2$) | 75 | 28.3±4.2 (21.1-38.2) | 26.8±6.5 (14.8-48.9) | 1.05 (0.97-1.15) | 0.243 |
| Aetiological diagnosis | 76 | | | | |
| Genetic cause | | 5 (14.7%) | 6 (14.3%) | 1 | |
| Brain damage | | 5 (14.7%) | 11 (26.2%) | 0.55 (0.11-2.67) | 0.455 |
| Unknown cause | | 24 (70.6%) | 25 (59.5%) | 1.15 (0.31-4.28) | 0.833 |
| Severity of ID | 76 | | | | |
| Mild | | 21 (61.8%) | 13 (31.0%) | 3.60 (1.39-9.34) | **0.008***** |
| Moderate | | 13 (38.2%) | 29 (69.0%) | | |
| Living facility | 78 | | | | |
| Central setting | | 0 (0.0%) | 4 (9.5%) | 1 | |
| Community based | | 34 (94.4%) | 35 (83.3%) | 1.57E9 (0.00-.) | 1.000 |
| Independent | | 2 (5.6%) | 3 (7.1%) | 1.08E9 (0.00-.) | 1.000 |
| Group size | 78 | 5.50±3.37 (1-17) | 6.14±4.23 (1-17) | 0.96 (0.85-1.08) | 0.461 |
| Safety habitat | 78 | | | | |
| Very good | | 34 (94.4%) | 41 (97.6%) | 2.41 (0.21-27.76) | 0.480 |
| Good | | 2 (5.6%) | 1 (2.4%) | | |
| Duration work (hour/week) | 78 | 25.15±9.86 (0-36) | 23.25±9.84 (0-38) | 1.02 (0.97-1.07) | 0.394 |

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| Exposure to falls work | 78 | | | | | | |
| Yes | | | 7 (19.4%) | | 8 (19.0%) | 1.03 (0.33-3.17) | 0.965 |
| No | | | 29 (80.6%) | | 34 (81.0%) | | |
| Duration sports (min/week) | 78 | 47.24±42.87 (0-150) | | 48.03±47.07 (0-180) | | 1.00 (0.99-1.01) | 0.943 |
| Exposure to falls sports | 78 | | | | | | |
| Yes | | | 22 (61.1%) | | 24 (57.1%) | 1.18 (0.48-2.92) | 0.723 |
| No | | | 14 (38.9%) | | 18 (42.9%) | | |
| Help in Activities of Daily Life (ADL) | 78 | | | | | | |
| Yes | | | 18 (50.0%) | | 25 (59.5%) | 0.68 (0.28-1.67) | 0.400 |
| No | | | 18 (50.0%) | | 17 (40.5%) | | |
| Orthopaedic shoes | 78 | | | | | | |
| Yes | | | 7 (19.4%) | | 7 (16.7%) | 1.21 (0.38-3.84) | 0.750 |
| No | | | 29 (80.6%) | | 35 (83.8%) | | |
| Type of walking aid | 78 | | | | | | |
| Yes | | | 9 (25.0%) | | 10 (23.8%) | 1.07 (0.38-3.01) | 0.903 |
| Cain | | | 2 (5.6%) | | 2 (4.8%) | | |
| Walker | | | 7 (19.4%) | | 8 (19.0%) | | |
| No | | | 27 (75.0%) | | 32 (76.2%) | | |
| History of falls in previous year | 78 | | | | | | |
| Yes | | | 17 (47.2%) | | 21 (50.0%) | 0.90 (0.37-2.18) | 0.807 |
| No | | | 19 (52.8%) | | 21 (50.0%) | | |
| Number of retrospective falls in previous year | 78 | 1.17±2.02 (0-10) | | 1.00±1.79 (0-9) | | 1.05 (0.83-1.33) | 0.697 |
| Fear of falling at baseline | 78 | | | | | | |
| Yes | | | 18 (50.0%) | | 17 (40.5%) | 1.47 (0.60-3.61) | 0.400 |
| No | | | 18 (50.0%) | | 25 (59.5%) | | |

*Table 5.1 continues on next page*

**Table 5.1** *Continued*

| Determinant | N | Faller (n=36) | Non-faller (n=42) | OR (95% CI) | p-value |
|---|---|---|---|---|---|
| Number of co-morbidities | 78 | 3.1±1.8 (0-9) | 3.0±1.5 (1-7) | 1.01 (0.77-1.33) | 0.924 |
| Visual problems | 78 | | | | |
| Yes | | 18 (50.0%) | 27 (64.3%) | 0.56 (0.22-1.38) | 0.205 |
| No | | 18 (50.0%) | 15 (35.7%) | | |
| Hearing problems | 78 | | | | |
| Yes | | 6 (16.7%) | 25 (59.5%) | 0.29 (0.10-0.86) | **0.025**** |
| No | | 30 (83.3%) | 17 (40.5%) | | |
| Number of medication | 78 | 3.2±2.5 (0-10) | 2.8±2.6 (0-10) | 1.06 (0.89-1.26) | 0.505 |
| Psychotropic drug use | 78 | | | | |
| Yes | | 12 (33.3%) | 9 (21.4%) | 1.83 (0.67-5.04) | 0.240 |
| No | | 24 (66.7%) | 33 (78.6%) | | |
| Functional Ambulation Classification (FAC) | 75 | | | | |
| Dependent for supervision | | 2 (5.6%) | 3 (7.7%) | 1 | |
| Independent level surface only | | 9 (25%) | 11 (28.2%) | 1.23 (0.17-9.02) | 0.840 |
| Independent | | 25 (69.4%) | 25 (64.1%) | 1.50 (0.23-9.76) | 0.671 |
| Berg Balance Scale (BBS) | 75 | 47.7±6.5 (30-55) | 45.8±7.3 (27-55) | 1.04 (0.97-1.11) | 0.250 |
| Timed Up and Go Test (TUGT, s) | 75 | 16.9±6.6 (9.4-37.8) | 17.8±9.1 (9.7-47.3) | 0.99 (0.93-1.05) | 0.646 |
| Functional Reach (FR, cm) | 74 | 15.7±8.7 (4-40) | 13.4±8.1 (1-26) | 1.03 (0.98-1.09) | 0.250 |
| Single Leg Stance (SLS, s) | 75 | 3.7±4.5 (0.0-21.6) | 3.7±4.9 (0.0-22.6) | 1.00 (0.91-1.10) | 0.966 |
| Ten Meter Walking Test (TMWT, s) | 75 | 11.7±3.9 (6.7-22.8) | 12.7±5.6 (7.1-34.3) | 0.95 (0.86-1.01) | 0.362 |

| | | | | | |
|---|---|---|---|---|---|
| Gait speed (m/s) | 75 | 0.93±0.26 (0.44-1.50) | 0.88±0.26 (0.29-1.40) | 2.17 (0.37-12.83) | 0.395 |
| Physical Activity Scale for the Elderly (PASE) | 70 | 93.75±69.27 (2.25-257.71) | 55.58±57.73 (0.00-219.50) | 1.01 (1.00-1.02) | **0.021**** |
| Raven's Coloured Progressive Matrices (RAVEN) (general IQ) | 59 | 20.52±1.10 (10.00-32.00) | 19.36±1.08 (10.00-32.00) | 1.04 (0.95-1.13) | 0.450 |
| 'NEuropsychologische Testserie voor Oudere Licht verstandelijk gehandicapten' (NETOL) | | | | | |
| Visuo-spatial memory task | 64 | 4.79±0.36 (1.00-8.00) | 3.74±0.37 (1.00-8.00) | 1.28 (1.00-1.64) | **0.051*** |
| Visuo-motor task | 69 | 6.73±0.25 (3.00-8.00) | 5.75±0.31 (1.00-8.00) | 1.46 (1.05-2.03) | **0.023**** |
| Visual-search task | 69 | 9.18±0.53 (2.00-14.00) | 9.23±0.50 (2.00-14.00) | 0.99 (0.85-1.16) | 0.911 |
| Visuo-contructive task | 74 | 19.71±0.69 (4.00-22.00) | 19.28±0.69 (2.00-22.00) | 1.03 (0.92-1.15) | 0.656 |
| Adolescent Adult Sensory Profile (AASP) | 74 | | | | |
| Poor perception of sensory stimuli | | 2.10±0.62 (1.00-3.43) | 2.33±0.73 (1.00-4.00) | 0.59 (0.29-1.19) | **0.143*** |
| Sensation seeking | | 3.02±0.60 (2.00-4.57) | 2.70±0.56 (1.00-3.86) | 2.77 (1.14-6.69) | **0.024**** |
| Sensitivity to sensory stimuli | | 2.03±0.61 (1.00-3.30) | 2.01±0.69 (1.00-3.80) | 1.04 (0.51-2.11) | 0.910 |
| Sensation avoiding | | 2.00±0.67 (1.00-3.43) | 2.05±0.81 (1.00-4.57) | 0.84 (0.45-1.58) | 0.594 |
| Adult Behaviour Checklist (ABCL) | 75 | | | | |
| Depression | | 0.36±0.34 (0.00-1.40) | 0.43±0.31 (0.00-1.40) | 0.47 (0.11-2.05) | 0.318 |
| Anxiety | | 0.61±0.46 (0.00-1.67) | 0.58±0.43 (0.00-1.67) | 1.22 (0.43-3.45) | 0.710 |
| Attention problems | | 0.50±0.41 (0.00-1.71) | 0.62±0.35 (0.00-1.33) | 0.44 (0.13-1.54) | **0.198*** |
| Hyperactivity-Impulsiveness | | 0.59±0.47 (0.00-1.83) | 0.44±0.40 (0.00-1.33) | 2.30 (0.78-6.82) | **0.132*** |

Values are represented as mean±SD (range) or n (%), OR (95% CI) = odds ratio with 95% confidence interval, p *<0.2, **<0.05, ***<0.01.
The BBS has a maximal score of 56, the higher the better motor functioning. The higher the PASE Score the more active. The higher the scores on the RAVEN and the NETOL the better the cognitive functioning. The higher the AASP and the ABCL the more prevalent the behavioural aspect.

Each of the variables that differed between the fallers and non-fallers were entered into a multiple logistic regression analysis (see Table 5.2). This analysis revealed that severity of ID, physical activity, visuo-motor capacity, attention problems, and hyperactivity-impulsiveness were significantly and independently associated with falling, accounting for 56% of the variance. Overall, persons with mild ID and persons who were physically active were more prone to falling. In addition, with respect to cognition and behaviour, hyperactive persons, persons with better visuo-motor capacity, and persons with good attentional focus had a higher fall risk.

## Indoor versus outdoor fallers

The indoor fallers were significantly older (mean age 70.4±10.5 vs. 60.8±5.5 years; p=0.016), less active (mean PASE score 54.4±56.8 vs. 135.4±65.8; p=0.036), and less depressed (ABCL depression 0.1±0.1 vs. 0.4±0.3; p=0.025) than the outdoor fallers. Furthermore, the indoor fallers performed significantly worse on almost all clinical balance and gait tests except the FR (the p-values ranged from 0.020 to 0.036). The other potential risk factors did not differ significantly between the indoor and outdoor fallers.

Because the indoor fallers differed significantly from the outdoor fallers with respect to balance and gait capacity and physical activity, and because these factors are known to play an important role in the exposure to fall risk, we analysed their mutual relationships further. Because the Berg Balance Scale (BBS) assesses both static and dynamic balance and has an established cut-off score for increased fall risk (a BBS score of 45),[42] this measure was used to measure motor capacity. With respect to physical activity, the Physical Activity Scale for the Elderly (PASE) was used to distinguish high-active and low-active subgroups using a cut-off value of 70, which is the mean score for elderly persons in the general population.[33]

**Table 5.2** The adjusted odds ratio (OR) of the variables for the risk of falling within one year using multivariate logistic regression (full sample n=63)

| Independent variable | Adjusted OR | 95% CI | p-value |
|---|---|---|---|
| Severity ID (mild) | 7.80 | 1.87-32.57** | 0.005** |
| Physical Activity Scale for the Elderly (PASE)[1] | 1.13 | 1.00-1.26* | 0.045* |
| Visuo-motor task | 1.68 | 1.09-2.61* | 0.020* |
| Attention problems | 0.02 | 0.00-0.36** | 0.008** |
| Hyperactivity-Impulsiveness | 102.59 | 5.42-1943.48** | 0.002** |

[1]PASE, per units of 10 points, p *<0.05, **<0.01.

Figure 5.2 shows the distribution of fallers and non-fallers for four subgroups based on high and low motor capacity and high and low physical activity. In addition, the locations of the falls (indoors or outdoors) are shown.

Group I represents active persons with low motor capacity and contains only two persons, both of whom were fallers (100%). Group II represents active persons with high motor capacity (n=25). This group contained a high percentage of fallers (64%). Group III represents persons who were physically inactive and had low motor capacity (n=20) and contained the lowest percentage of fallers (25%) among the four subgroups. Group IV represents persons with high motor capacity but who were physically inactive (n=21); this group contained 38% fallers. The differences in the percentage of fallers among the groups were significant ($\chi^2(3)=9.70$; p=0.02). In Group III the largest proportion of falls occurred indoors (60%), whereas in Group II the largest proportion of the falls occurred outdoors (56%). In Group IV the amount of indoor and outdoor falls was comparable.



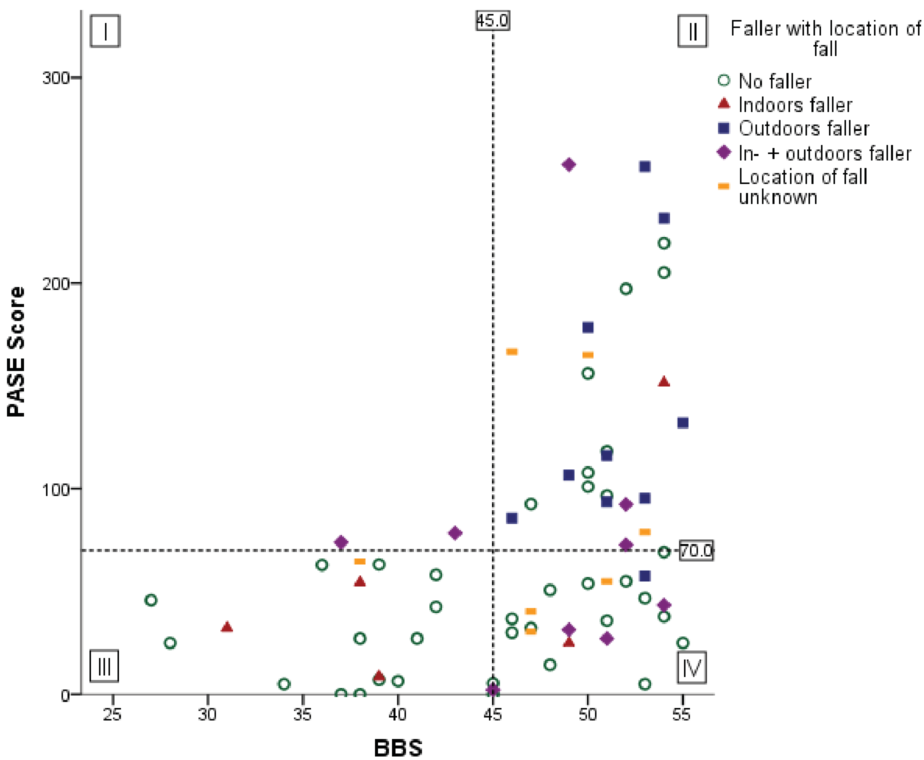


**Figure 5.2** Level of motor function vs activity level in the fallers and non-fallers, with location of falls.

## Discussion

To the best of our knowledge, this is the first prospective study to investigate risk factors for falling among elderly persons with mild-to-moderate intellectual disabilities (ID). Falls occurred in 46% of the participants, and the fall rate was 1.00 falls per person per year. These numbers are higher than what has been reported for the general elderly population (33% fallers, with an estimated fall rate of 0.45-0.65 falls per person per year).[2,3] The most important risk factors for falling among persons with mild-to-moderate ID were (mild) severity of ID, (high) physical activity, (good) visuo-motor capacity, (good) attentional focus, and (high) hyperactivity-impulsiveness; together, these risk factors accounted for 56% of the risk of falling. As in the general elderly population, the persons who fell indoors differed from those who fell outdoors. The outdoor fallers in our study were younger, had better motor capacity, and were more physically active than the indoor fallers.

Hyperactivity and impulsive behaviour were more prevalent among fallers than non-fallers, which is consistent with the findings of Hale et al., who reported movement impulsiveness among fallers with ID.[15] Hyperactivity was also identified as a risk factor for injuries among persons with ID.[43] Other well-known risk factors for falling in the general population, like co-morbidities and medication use, could not differentiate the fallers from the non-fallers with ID. Although the numbers of co-morbidities and medication use were high, they did not differ significantly between the fallers and non-fallers in our study. Furthermore, we found no difference between fallers and non-fallers with respect to their balance and gait, even though this is considered the most important risk factor for falling among the general population.[44] Our participants with ID, however, performed considerably worse on all clinical balance and gait tests compared to their peers in the general population.[29] Remarkably, the persons who had mild ID, were physically active, and had relatively few visuo-motor and attention problems had the highest risk of falling. These counterintuitive results might be explained by a higher level of exposure to fall hazardous situations and/or less protection by their caregivers. We hypothesise that persons with moderately severe ID and poor motor capacity are more likely to be protected by their caregivers, thus limiting their exposure to potentially dangerous situations.[43] This notion is consistent with previous studies that reported that higher levels of mobility and independent ambulation are risk factors for falling among persons with ID.[6,10,15] This hypothesis is also supported by our finding that the subgroup of participants with relatively good motor capacity and high physical activity (Group II) had a relatively high percentage of fallers. Indeed, persons with mild ID are often more independent than persons with more severe ID,[45] and as such, they are generally more prone to falling.[9] Unfortunately, we were unable to test the hypothesis that protection by caregivers was higher for the persons with the observed risk factors, as we did not question the caregivers regarding their protective attitude towards the participants. Overall, the emerging picture suggests that the observed risk factors represent a complex interplay between personal factors (motor capacity, functional independence, impulsiveness, attentional focus, and cognition) and environmental factors (exposure, protection, etc.). Therefore, future research should focus on the relationship between these personal and environmental factors.

Our analysis of the differences between indoor and outdoor fallers further supports the notion of a highly complex relationship between the various types of fall risk factors. Compared to the participants who fell only indoors, the outdoor fallers were significantly younger, had better motor function, and were more physically active. These results are consistent with a recent report conducted among older persons in the general population, which found that the outdoor fallers had a faster gait speed, better balance capacity, and were more physically active than indoor fallers.[19] These results indicate that different fall risk assessments and prediction models are needed to identify people in the various subgroups of persons with ID who are at risk of falling. Identifying such subgroup-specific fall risk models was beyond the scope of the present study and remains a subject for future research.

Despite these incompletely understood interactions between personal and environmental factors that contribute to the risk of falling among older persons with ID, the high fall rates that were reported (particularly among more active individuals) emphasise the need for taking measures to prevent falls. In the general elderly population, exercise interventions have been shown to be most effective at preventing falls.[46] Previous research has revealed that exercise programs can improve balance and increase strength among persons with ID.[47,48] These improvements may enable them to move more safely within their personal and environmental context. Although we did not identify poor motor function as a risk factor for falling, we believe that exercise can reduce the incidence of falling among persons with ID, given this group's high prevalence of mobility problems compared to the general population.[12,49] Indeed, a recent study by our group provided the first evidence to support the notion that an exercise program can improve motor function and reduce the number of falls among persons with ID.[50] In designing future programs to reduce the incidence of falls among persons with ID, we recommend to take into account the risk factors identified in the present study as well.

A strength of our study was that fall incidents were recorded prospectively for one year using a monthly fall calendars, with both the participant and the caregiver being responsible for recording the fall data. Using this approach, we minimised recall bias and the likelihood of failing to record fall incidents, which is a common problem in retrospective studies.[17]

Furthermore, standardised baseline assessments using validated tests were performed for each participant in order to directly assess the level of functioning, and this approach is generally more reliable than using chart reviews.[51]

The selection of our study participants has some limitations with respect to our ability to generalise our results to the total ID population. First, we only included ambulatory participants with mild-to-moderate ID, as the assessments are not considered feasible for use in people with more severe physical and/or cognitive disabilities. Second, persons with epilepsy were excluded from this study because falling during an epileptic seizure has a different cause than falling that is related to ID and aging. Nevertheless, retrospective studies have revealed that epilepsy can be an important risk factor for falling among persons with ID.[6,7,10,11,16,52] More research that includes persons with more severe ID and/or epilepsy is needed in order to fully understand the risk factors for falling within the entire ID population.

This study was also limited by the feasibility of the cognitive assessments. Only 36% of the participants were able to complete the entire set of cognitive tests. In particular, the ANT – in which the participants needed to operate a computer – was difficult for many participants, as they often seemed unable to understand how their action (pushing a button) was related to the tasks on the computer screen. Thus, we may have missed (aspects of) cognitive functioning as a potential fall risk factor; for example, poor executive functioning has been found to increase the risk of falling among the elderly in the general population.[53,54] To understand better the role of cognitive functioning in the risk of falling among persons with ID, more feasible cognitive tests are needed. For the study population at hand, we recommend the use of pencil-and-paper tests rather than computer tasks.

Because elderly persons with ID are more prone to falling than their peers,[41] and because the identified risk factors cover multiple domains, it is important to be aware of the complex interplay between multiple factors involved in falling. Multifactorial screening procedures that are tailored to persons with ID must be developed and administered by a multidisciplinary team (e.g. a physician and a physical therapist) within the habitat of the person with ID.

In conclusion, our study revealed that elderly persons with mild-to-moderate ID fall more frequently than the general elderly population. The most important risk factors for falling among persons with mild-to-moderate ID were the severity of ID, physical activity, visuo-motor capacity, attention problems and hyperactivity-impulsiveness. Fallers tended to be more physically active, had milder ID, had higher visuo-motor capacity, and had more hyperactivity-impulsiveness and better attentional focus than non-fallers. This somewhat surprising pattern of risk factors suggests that a complex interplay between personal and environmental factors underlies the aetiology of falls among elderly persons with ID. We recommend further research on the development of multifactorial screening procedures and individually tailored interventions to prevent falling among persons with ID.

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# Appendix

Baseline assessment

| | |
|---|---|
| ***Clinical assessments*** | |
| Mobility | Berg Balance Scale (BBS) |
| | Functional Reach (FR) |
| | Timed Get Up and Go Test (TUGT) |
| | Single Leg Stance (SLS) |
| | Ten Meter Walking Test (TMWT) → Gait Speed |
| | Functional Ambulation Classification (FAC) |
| Cognition | The Raven's Coloured Progressive Matrices (RAVEN) (General Intelligence Quotient) |
| | The 'Amsterdamse Neuropsychologische Taken' (ANT) |
| | Reaction Time (Baseline Speed) |
| | Memory (Memory Search Object 1 Key) |
| | Sustained Attention (Sustained Attention Object 1 Key) |
| | Divided Attention (Response Organisation Arrows) |
| | The 'NEuropsychologische Testserie voor Oudere Licht verstandelijk gehandicapten' (NETOL) |
| | Visuo-spatial memory task (Cirkelspan forwards) |
| | Visual-search task (Poppelreuter) |
| | Visuo-motor task (Draw from a model) |
| | Visuo-contructive task (Synthesis puzzles) |
| ***Questionnaires*** | |
| Activity level | Physical Activity Scale for the Elderly (PASE) |
| Sensory-motor abilities | Adolescent Adult Sensory Profile (AASP) |
| | Poor perception of sensory stimuli |
| | Sensation seeking |
| | Sensitivity to sensory stimuli |
| | Sensation avoiding |
| Behaviour | Adult Behaviour Checklist (ABCL) |
| | Depression |
| | Anxiety |
| | Attention problems |
| | Hyperactivity-Impulsiveness |
| ***Chart review and interview*** | |
| Demographic characteristics | Gender |
| | Age (years) |
| | Body Mass Index (BMI = weight/length$^2$) |

*Appendix continues on next page*

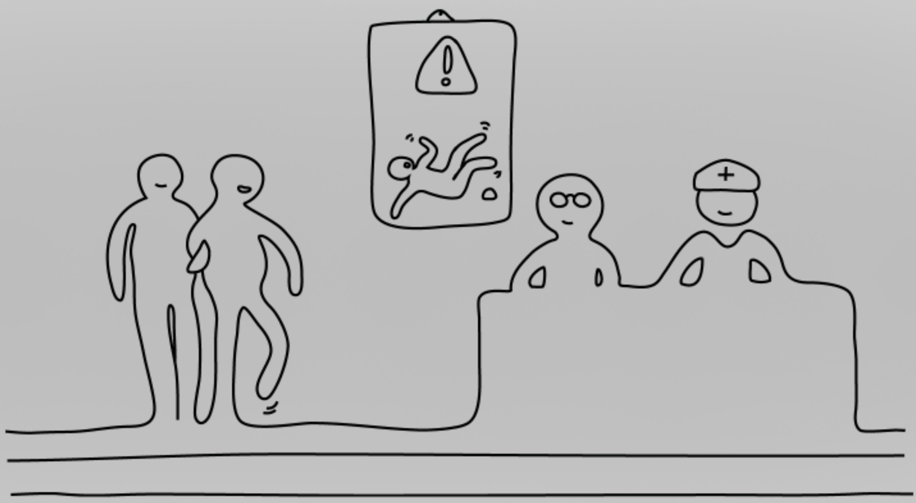
**Appendix** *Continued*

| | |
|---|---|
| ***Chart review and interview*** | |
| | ID related characteristics |
| | Aetiological diagnosis (Genetic cause, Brain damage, Unknown cause) |
| | Severity of ID (mild, moderate) |
| | Living facility (Central setting, Community based, Independent) |
| | Safety Habitat |
| | Occupation |
| | Duration work (hour/week) |
| | Exposure to falls work |
| | Sports |
| | Duration sports (min/week) |
| | Exposure to falls sports |
| | Help in Activities of Daily Life (ADL) |
| | Use of walking aids |
| | Type of walking aid |
| | History of falls in previous year |
| | Number of retrospective falls in previous year |
| | Fear of falling |
| Medication use (according to ATC index of WHO)[40] | Number of medication (Polypharmacy)<br>Psychotropic drug use |
| Co-morbidities (based on Rigler et al., 2002)[39] | Number of co-morbidities<br>Visual problems<br>Hearing problems |

5

# PART III

## Falls prevention in persons with ID



# Chapter 6

# Falls prevention in persons with intellectual disabilities: Development, implementation, and process evaluation of a tailored multifactorial fall risk assessment and intervention strategy

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## Abstract

In the general elderly population, multifactorial screening of fall risks has been shown to be effective. Although persons with intellectual disabilities (ID) fall more often, there appears to be no targeted screening for them. The aim of this study was to develop, implement, and evaluate a falls clinic for persons with ID. Based on guidelines, literature, and expert meetings, a falls clinic for persons with ID was developed. In total, 26 persons with ID and a fall history participated in the study. Process evaluation was conducted with evaluation forms and focus groups. Fifty interventions (0–8 per person) were prescribed. The (para)medical experts, clients, and caregivers described the falls clinic as useful. Advice for improvement included minor changes to clinic content. Logistics were the largest challenge for the falls clinic, for example organizing meetings, completing questionnaires prior to meetings, and ensuring that a personal caregiver accompanied the person with ID. Furthermore, the need for a screening tool to determine whether a person would benefit from the falls clinic was reported. In conclusion, the falls clinic for persons with ID was considered feasible and useful. Some minor content changes are necessary and there is a need for a screening tool. However, logistics concerning the falls clinic need improvement. More attention and time for multifactorial and multidisciplinary treatment of persons with ID is necessary. Implementation on a larger scale would also make it possible to investigate the effectiveness of the falls clinic with regard to the prevention of falls in this population.

## Introduction

Persons with intellectual disabilities (ID) are at increased risk for falls and fall-related injuries.[1-4] Previous retrospective studies investigating falls in persons with ID have demonstrated percentages of fallers ranging from 34% to 70% in their study populations.[1,2,5,6] In our prospective study in older adults with mild to moderate ID, during which falls were registered with monthly fall registration calendars for 1 year, 45% of the participants reported a fall, with a fall rate of 1.00 falls per person year.[7] In comparison, in the general elderly population, one-third of elderly persons fall each year, with estimated fall rates between 0.45 and 0.65 falls per person year.[8-12] It is estimated that 50-60% of injuries in persons with ID are caused by falls.[2,3,13,14] Injury-related visits to emergency departments and hospital admittances in persons with ID are primarily due to falls.[15]

Because of this high number of falls and injuries, falls prevention is very important in persons with ID. In fact, fall prevention has become even more important for this population because the life expectancy of persons with ID is increasing,[16,17] resulting in more age-related problems such as reduced mobility,[18] which is associated with falls. Multifactorial interventions to prevent falls are the most effective in the general elderly population.[9,19] A study by Chang et al. showed that multifactorial fall risk assessment and management programs resulted in a fall rate reduction of 37%.[20] However, a recent meta-analysis showed a non-significant decrease of 9% in the number of fallers after multifactorial assessment.[21] This discrepancy is probably related to the differing approaches: programs that consisted only of assessment and referral to usual care for treatment were not effective in reducing falls. In contrast, programs that incorporated management of identified risk factors were effective.[21,22] This emphasizes the importance of carrying out the prescribed interventions; that is, the risk assessment may be thorough and complete, but if the interventions resulting from this multifactorial assessment are not followed, falls will not be prevented. Indeed, a recent study in which participants immediately received the interventions was effective in reducing falls and fear of falling.[23]

Existing multifactorial fall risk assessments have not paid specific attention to persons with ID. It may be that physicians in general falls clinics have difficulty determining the appropriate approach for caring for this target group and their specific problems. Fall risk factors in persons with ID are largely comparable to those identified in the general elderly population, including older age, visual deficits, medication use, and co-morbidities.[2,3,5,6,14,24-26] However, there are also specific risk factors related to the specific conditions of persons with ID (e.g., epilepsy).[2,3,6,25] Additionally, risk factors such as cognitive impairment, co-morbidities, balance and gait problems (impaired mobility), and higher medication use are more prevalent in persons with ID.[12,18,27-33] Furthermore, for existing falls clinics, persons with ID often have to travel far and the unfamiliar environment may hamper them with regard to optimal performance.

Thus, there is a need for an effective multifactorial fall risk assessment and intervention strategy: a falls clinic specifically tailored to persons with ID.[14] The falls clinic should be run by physicians and therapists experienced in working with this target group. Furthermore, the travel distances required for participants should be as brief as possible.

The aim of the present study was to develop such a multifactorial fall risk assessment and fall preventive intervention strategy for persons with ID. A second aim was to implement this falls clinic in service providers for persons with ID and perform a process evaluation.

## Methods

### Participants

Participants were selected from a study on fall risk factors in persons with ID. In that study, 86 persons with mild to moderate ID were recruited from three service providers for persons with ID in The Netherlands. Participants had to be at least 50 years old, able to walk independently for at least 10 m, and able to understand simple instructions. Epilepsy was an exclusion criterion in the original study because coming to the floor or lower level due to an epileptic seizure, which might be seen as a "fall," has a different cause than falling related to ID and aging.

In the original study, 82 of the participants registered their fall incidents with monthly fall registration calendars. Persons who reported a fall in the original study were invited to participate in the current study for the falls clinic.

The regional medical ethical committee approved the study. Informed consent was obtained from the participants and, if applicable, their legal representatives.

### Development of the falls clinic

A falls clinic was developed for persons with ID based on guidelines for falls prevention and falls clinics in the general elderly population, meetings with experts in the field, and literature on fall risks in persons with ID and the general elderly population. A flow chart depicting falls clinic organization is presented in Figure 6.1.

For the falls clinic, participants were first invited for a meeting with a physician specialized in persons with ID ("ID physician"). The participant and his/her personal

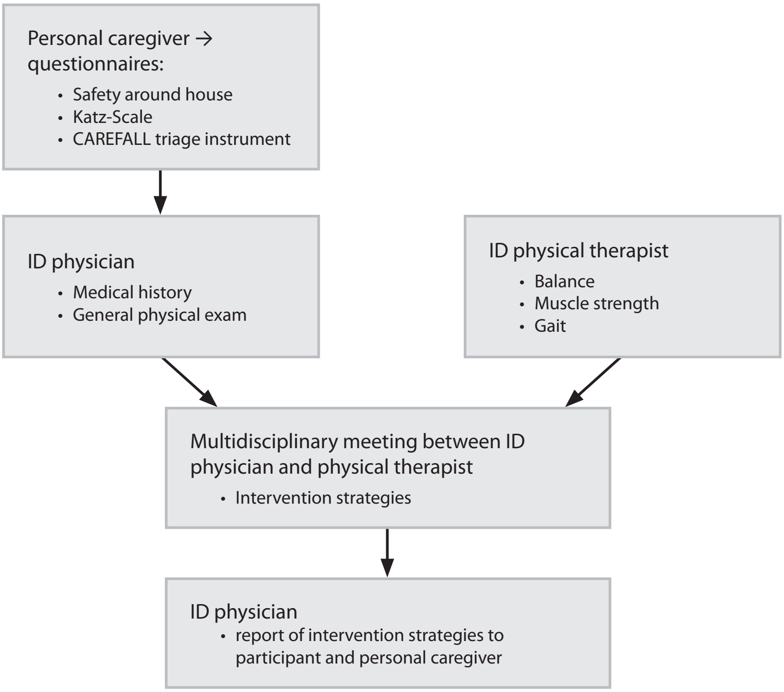


**Figure 6.1** Flow chart for organization of falls clinic for persons with ID.



caregiver were asked to complete three questionnaires before the meeting to provide additional information for the ID physician. These were questionnaires on safety in and around the house (checklist 'halt u valt,' www.veiligheid.nl), activities of daily life (ADL) functioning (Katz scale)[34], and fall circumstances (the CAREFALL triage instrument (CTI))[35]. The ID physician took a medical history for each participant, focusing on medication use, ADL functioning, number of falls and fall circumstances, and risk factors for falls. A general physical examination was also performed, including assessment of each participant's blood pressure, vascular system, neurological system, mobility, and coordination.

On a different day, participants were examined by a physical therapist with experience in working with persons with ID. The physical therapist examined muscle force, balance (Berg Balance Scale, Timed Up and Go Test, Functional Reach),[36-38] reaction to (un)expected balance disturbances, walking pattern, use of walking aids, and endurance (3-min walking test).

The ID physician and physical therapist both worked at the participants' living facility, so the participants did not need to travel far for the meetings. A (personal) caregiver accompanied each participant during all examinations.

After the consultations, the ID physician and physical therapist had a multidisciplinary meeting during which they discussed possible interventions to prevent the participant from suffering future falls. An overview of possible intervention strategies related to the investigated risk factors was developed for the study and made available to the ID physician and physical therapist (see appendix). Subsequently, the ID physician discussed these intervention strategies with the caregiver and participant in the form of a structured interview.

## Process evaluation

### Evaluation forms

After each assessment at the falls clinic, the ID physician and physical therapist were asked to complete an evaluation form. On this form, the ID physician and physical therapist indicated how much time was needed for the different elements of the falls clinic: screening, multidisciplinary meeting, and meeting with the client and caregiver. For each element of the screening, the ID physician and physical therapist were asked to score on a 5-point Likert scale (1=totally disagree to 5=totally agree) whether the objective of that element was clear, all important aspects were included, and the element was treated sufficiently. Furthermore, the ID physician and physical therapist were asked to state which items were not feasible and whether there were items that should be added or deleted from the screening form. The form had space for extra comments about the process. Finally, the ID physician and physical therapist were asked to indicate which interventions were recommended to the participant and the caregiver.

The caregivers and the participants were also asked to evaluate the falls clinic. They were asked whether the goal of the study on the falls clinic was clear and the meetings were experienced as pleasant. They were also asked for their opinions about the duration of the meetings. Because the effectiveness of a falls clinic depends on compliance with the recommended interventions, the evaluation was performed at 1 and 6 months after the meeting during which they had discussed the suggested interventions based on the assessments. It was evaluated whether the recommended interventions had been performed, whether the participant understood why the interventions were needed, and whether the interventions had an effect. If an intervention was not followed, the caregivers and participants were asked to indicate the reason.

### Focus groups

After completing all individual assessments, interventions and process evaluations, two focus groups were held to discuss the content and process of the falls clinic and make recommendations for its future implementation. The focus group was designed to provide an opportunity for all to discuss various topics and express their opinions rather than achieve general agreement.[39] Each focus group had a standardized protocol of the points to be discussed. The focus groups were chaired by an interviewer and the researcher was present for questions regarding the study. Furthermore, a secretary took minutes for the focus groups. These minutes were sent to all participants, who were asked whether they agreed with the content (member check). One focus group consisted of the ID physicians and physical therapists; another group consisted of the caregivers and participants.

### Falls registration

Participants registered their falls with monthly fall registration calendars during the 1-year follow-up. The fall rate (number of falls per person year) was determined from this information. Because the participants had also registered their falls for at least 1 year during the original study, the fall rate after the falls clinic could be compared with the fall rate in the period prior to the falls clinic.



# Results

## Participants

Of the 82 participants who registered their falls during the original study on fall risk factors in persons with ID, 39 reported at least one fall and were invited to participate in the current study. Three persons were too ill to participate, and three participants and five legal representatives were not willing to participate. Two participants dropped out after they signed informed consents, one due to health problems and one who did not want to visit the physician and physical therapist. Thus, in total, 26 participants were seen at the falls clinic. A flow chart of participants is presented in Figure 6.2. The baseline characteristics of the participants who visited the falls clinic are presented in Table 6.1.

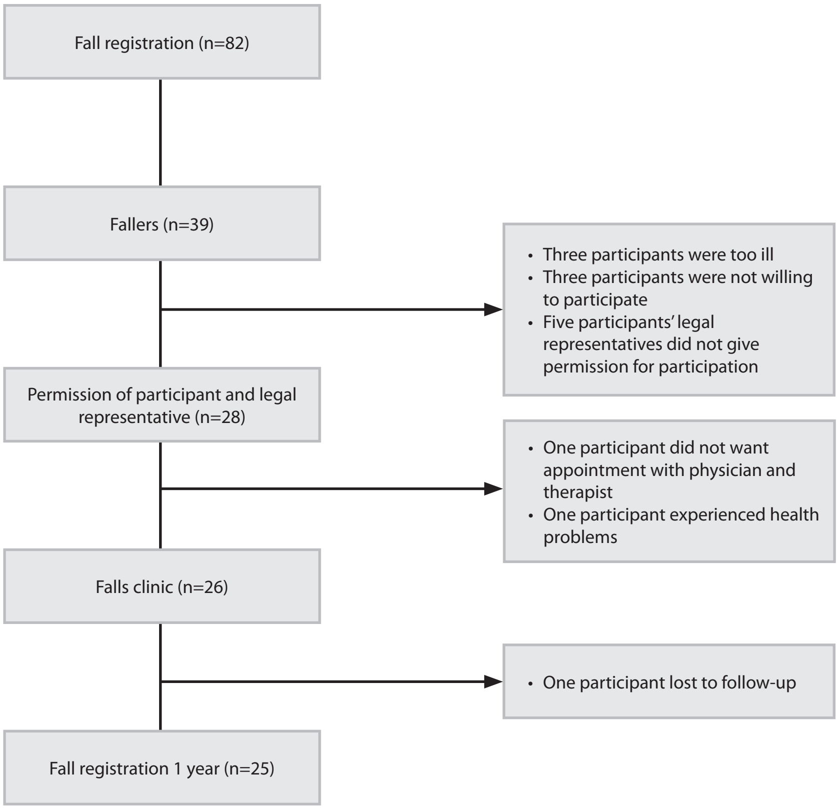


**Figure 6.2** Flow chart of participants in the study.

## Falls clinic

### Meetings

Meetings were planned after the informed consent was signed. Thereafter, it took an average of 36.0 days (standard deviation (SD)=29.9, range 3-128) before the meeting with the ID physician took place, 40.5 days (SD=20.3, range 5-82) until the meeting with the physical therapist, 80.4 days (SD=41.9, range 10-154) until the multidisciplinary meeting occurred, and 95.7 days (SD=48.5, range 14-182) until the results of the falls clinic were provided to the participants and their legal caregivers.

Because of the design of the study, in which all fallers from the entire study period of the original study were invited, the time between the last fall and the meeting with the ID physician was often long: on average, 7.1 months (SD=5.7, range: 0-22).

**Table 6.1** Participant characteristics (n=26)

| Characteristics | |
|---|---|
| Sex [male:female (n)] | 12:14 |
| Age [years, mean (SD), range] | 60.8 (5.6), 53-73 |
| Weight [kg, mean (SD)] | 75.8 (14.8) |
| Height [m, mean (SD)] | 1.65 (0.11) |
| Cause [n (%)] | |
| Genetic cause | 3 (12%) |
| Brain damage | 4 (15%) |
| Unknown cause | 19 (73%) |
| Level of ID [n (%)] | |
| Mild | 17 (65%) |
| Moderate | 9 (35%) |
| Co-morbidity [n (%)] | |
| Visual | 12 (46%) |
| Musculoskeletal | 9 (35%) |
| General | 9 (35%) |
| Digestive | 5 (19%) |
| Cardiac | 5 (19%) |
| Hearing | 4 (15%) |
| Respiratory | 4 (15%) |
| Psychosocial/Behavioural | 3 (12%) |
| Cancer | 2 (8%) |
| Neurologic | 2 (8%) |
| Incontinence | 1 (4%) |
| Diabetes | 1 (4%) |
| Medications [n (%)] | |
| Nervous system | 14 (54%) |
| Psychotropic medicine | 9 (35%) |
| Cardiovascular system | 7 (27%) |
| Alimentary tract and metabolism | 5 (19%) |
| Dermatological | 5 (19%) |
| Genito-urinary system/sex hormones | 3 (12%) |
| Musculoskeletal system | 2 (8%) |
| Respiratory system | 2 (8%) |
| Blood and blood forming organs | 1 (4%) |
| Systemic hormonal preparations | 1 (4%) |
| Sensory organs | 1 (4%) |
| Type of living facility [n (%)] | |
| Community-based group homes | 24 (92%) |
| Supported independent living situation | 2 (8%) |
| Day activity [n, hours per week, mean (SD)] | |
| (Paid) Work | 18, 29.1 (7.5) |
| Arts and crafts at day activity centre | 7, 19.1 (11.4) |
| Retired | 1, 0 |
| Sport activity [min per week, mean (SD)] | 39.5 (35.9) |

SD, standard deviation.

The duration of the meeting with the ID physician was on average 88.4 min (SD=20.0, range 60-120) and with the physical therapist, 84.0 min (SD=20.9, range 30-120). The duration of the multidisciplinary meeting varied from 5 to 45 min (mean=21.7, SD=10.2). For four participants, the ID physician choose to report the results of the falls clinic by e-mail instead of a personal meeting or phone call. The duration of the remaining meetings to discuss the results with the caregiver and participant varied from 10 to 60 min (mean=24.4, SD=12.8).

### Interventions

Fifty interventions were prescribed to the participants, ranging from 0 to 8 per person (see Table 6.2). For 11 of the 26 participants, no intervention was prescribed. On average, 1.9 (SD=2.3) interventions were prescribed per participant, including medication adjustments, changes in diet, physical therapy, advice about ADL; orthostatic hypotension; urine incontinence; shoes; walker use; and cycling, referrals to a general practitioner (GP); ID physician; ophthalmologist; or rehabilitation physician, and advice about safety in the house regarding lighting.

For one participant, the caregivers did not provide information on the follow-up of the interventions after 1 and 6 months. For another participant, this information was not received after 6 months, despite several reminders by mail and phone. For the other participants, the percentages of interventions performed after 1 and 6 months are reported in Table 6.2. After 1 month, 52% of the interventions were performed or were ongoing; this increased to 85% after 6 months.

The reasons why 15% of the interventions were not performed are as follows:

- In one case in which a walker was advised, the family and caregivers did not think the participant would benefit from the intervention.
- For the dual energy X-ray assessments (DXA), one appointment was planned later, one participant did not want the examination, one participant had a new caregiver who was unaware of the advised intervention, and of one participant the evaluation form was not returned after 6 months.
- The ID physician/general practitioner was not consulted about the pain complaints of one participant because the complaints resolved.
- In one case of advice to check joint mobility, the caregiver assumed that the ID physician would contact the participant, but this had not happened during the 6-month follow-up period.

**Table 6.2** Prescribed interventions after fall risk assessment

| Intervention | No. of participants | Performed after 1 month | Performed after 6 months |
|---|---|---|---|
| None | 11 | n.a. | n.a. |
| Medication: reduction in anti-psychotics | 2 | 100% | 100% |
| Changes in diet (calcium and/or more fluid) | 5 | 100% | 100% |
| Safety in the house | 1 | 0% | 100% |
| Physical therapy | 6 | 80% | 100% |
| Advice on: | 14 | 54% | 91% |
| Orthostatic hypotension | 4 | 75% | 100% |
| Activity during the day | 4 | 66% | 100% |
| Shoes | 2 | 0% | 100% |
| Walker use | 2 | 50% | 50% |
| Urinary incontinence | 1 | 100% | 100% |
| Cycling | 1 | 0% | 100% |
| Referral | 22 | 36% | 72% |
| ID physician/GP: | 17 | 29% | 64% |
| High blood pressure | 5 | 80% | 100% |
| Orthopedic shoes | 3 | 0% | 100% |
| DXA | 4 | 0% | 0% |
| Calcium and vitamin D | 1 | 0% | 100% |
| Check vital sensibility | 1 | 0% | 0% |
| Diabetes | 1 | 100% | 100% |
| Pain | 1 | 0% | 0% |
| Joint complaints | 1 | 0% | 0% |
| Ophthalmologist | 4 | 75% | 100% |
| Rehabilitation physician | 1 | 0% | 100% |

ID, intellectual disability; GP, general practitioner; DXA, dual-energy X-ray assessment.

Overall, the caregivers and participants reported that the 50 interventions were helpful, except for two:

- In the first case, although the participant understood the importance of his new adjusted shoes, he was not willing to wear the new footwear.
- In the second case, a participant received advice about orthostatic hypotension, but the complaints of dizziness did not resolve.

### Process evaluation

Although there were some problems with receiving the information, ultimately, all evaluation forms from the ID physicians and physical therapists were returned. Only one caregiver and participant evaluation form was not returned.

**Table 6.3** Process evaluation of the fall clinic (n=26 fallers) by ID physicians and physical therapists (percentages of the scores)

| | ID physician | | | | | Physical therapist | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | 1 | 2 | 3 | 4 | 5 | 1 | 2 | 3 | 4 | 5 |
| Design falls clinic | | | | | | | | | | |
| Clear | 0 | 0 | 4% | 96% | 0 | 0 | 0 | 0 | 100% | 0 |
| All important aspects included | | | | | | | | | | |
| Yes | 0 | 9% | 0 | 91% | 0 | 0 | 4% | 0 | 96% | 0 |
| Intervention strategy scheme | | | | | | | | | | |
| Clear | 0 | 20% | 4% | 76% | 0 | 0 | 4% | 12% | 85% | 0 |
| Complete | 0 | 4% | 4% | 92% | 0 | 0 | 0 | 16% | 84% | 0 |
| Multidisciplinary meeting | | | | | | | | | | |
| Clear | 0 | 0 | 3% | 96% | 0 | 0 | 0 | 12% | 88% | 0 |
| Complete | 0 | 0 | 8% | 92% | 0 | 0 | 0 | 12% | 88% | 0 |
| Meeting participant and caregiver to report interventions | | | | | | | | | | |
| Clear | 0 | 0 | 8% | 92% | 0 | n.a. | | | | |
| Complete | 0 | 0 | 12% | 88% | 0 | n.a. | | | | |

Scores on Likert scale: 1: totally disagree, 2: disagree, 3: neutral, 4: agree, 5: totally agree.

### Satisfaction

Both the ID physicians and the physical therapists were positive about the falls clinic process and content, with the median scores on the evaluation form being 4 on the 5-point Likert scale (5=totally agree; see Table 6.3). The design was reported to be clear, with all important aspects dealt with, and the intervention strategy scheme and forms for the multidisciplinary meeting and meeting on intervention strategies with participants and caregivers were reported to be clear and complete. All the separate elements were scored as being well-treated (all median scores of 4).

One ID physician mentioned that the falls clinic was rather extensive, while another mentioned that, although the falls clinic was extensive, it was complete and relevant, and nothing should be removed. One physical therapist mentioned that she was able to safely perform the assessments without assistance, and another stated that the meetings were shorter than expected.

The caregivers and participants also reported positively on the process of the falls clinic (median scores 4; see Table 6.4). The importance of the falls clinic was clear to participants and caregivers, the meetings with the ID physician and physical therapist were experienced positively, and the duration of the meetings was perceived as appropriate and sufficient.

### Suggestions for improvement

Important comments from the ID physicians and physical therapists were that the personal caregiver was often not present at the meetings, although this was explicitly requested. Furthermore, the caregivers were asked to complete a set of questionnaires on fall circumstances, safety in the house, and ADL functioning, and these often were not completed. Reasons for these issues included changes in personnel and the length of time between inclusion in the study (when they received the questionnaires) and the

**Table 6.4** Process evaluation of the fall clinic (n=26 fallers) by participants and caregivers

| | 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|---|
| Importance of fall clinic clear | 0 | 8% | 0 | 72% | 20% |
| Meeting ID physician was pleasant | 0 | 0 | 12% | 80% | 8% |
| Meeting physical therapist was pleasant | 0 | 0 | 13% | 78% | 9% |
| The duration of the meetings was too long | 0 | 24% | 40% | 32% | 4% |
| The duration of the meetings was too short | 9% | 45% | 45% | 0 | 0 |

Scores on Likert scale: 1: totally disagree, 2: disagree, 3: neutral, 4: agree, 5: totally agree.

actual meeting. Additionally, certain aspects of medical history were often unknown to the caregivers, participants, and physicians.

The ID physician reported the (near) impossibility of assessing sensibility as part of the neurological examination. Generally, verbal instructions during physical examinations appeared to be hard to understand for some participants.

### Focus groups

In the first focus group, three ID physicians and six physical therapists from all three service provider facilities participated. They generally confirmed the results of the process evaluation. The collaboration between ID physicians and physical therapists was evaluated positively. The participants agreed that at present, there is no tradition of multidisciplinary teamwork by physicians, allied health professionals, and caregivers in healthcare for persons with ID in their organizations. ID physicians and physical therapists mentioned that the falls clinic should get more attention, which would make it easier to arrange the necessary meetings and ensure that the correct caregivers accompanied the person with ID. Furthermore, ID physicians and physical therapists stated that the policy regarding falls (for each service provider) should be clearer and more readily available to them. The ID physician and physical therapist focus group advised development of a checklist to be completed by the caregivers after each fall incident to indicate whether the person who fell should be seen at a falls clinic. They also agreed that more persons could benefit from the falls clinic, such as persons with epilepsy, severe behavioral problems, and lower levels of ID. Although such persons were excluded from the present study, the falls clinic protocol was used on several occasions for these persons as well and was considered helpful.

In the second focus group, two participants and six caregivers from two of the three service providers participated. They all reported that they were more aware of fall dangerous situations because of the falls clinic. They also agreed on the need for a checklist. They mentioned that the advices and results of the falls clinic were not always clearly reported back to them. They confirmed that there was a need for a well-established falls clinic that could easily be contacted with a single phone number. The falls clinic should be readily accessible, as in the present study, by having the meetings at the service provider's facility.

## Falls registration

On average, the participants collected fall data before the falls clinic over 21.8 months (SD=3.9, range 15-29) and reported 3.0 falls (SD=2.0, range 1-7). Overall, the fall rate was 1.78 falls per person year.

After the falls clinic, one person was not able to use the fall calendar correctly and did not receive assistance from his caregivers. For five participants, the falls clinic was planned later in the study period, so they were not able to complete the entire follow-up period of 1 year (1 person, 9 months; 3 persons, 10 months; 1 person, 11 months). All available fall registrations were included in the analysis of the fall rate. Fourteen participants (54%) reported a fall in the year after the falls clinic (range 1-8), yielding a fall rate of 1.37 falls per person year.

## Discussion

The aim of this study was to develop, implement, and evaluate a multifactorial fall risk assessment and intervention strategy for persons with ID. This study showed that a complex intervention such as a falls clinic was feasible for persons with ID. Moreover, the falls clinic was perceived as useful by ID physicians, physical therapists, participants with ID, and their caregivers. Some minor changes in the clinic content were considered necessary, and the logistics involved in presenting the falls clinic need improvement to implement it on a larger scale.

To successfully implement complex interventions one relevant prerequisite is the inclusion of the correct persons. In the present study, all persons who had reported a fall in the original study on fall risk factors in persons with ID were eligible. As a result, persons who had fallen a long time ago and/or only once were included. For some of the participants, the ID physician and physical therapist thought that it was not necessary to screen the person at the falls clinic. This might explain why no intervention was prescribed for several persons. It indicates the need for a checklist that can be completed after each fall incident to identify persons at risk for falls who would benefit from the falls clinic. The need for such a checklist was also emphasized in both focus groups. With such a checklist falls will be registered and documented for systematic evaluation of whether further action is needed. However, such a checklist does not yet exist for persons with ID.

For the general elderly population, it is advised that persons should be seen at a falls clinic when they have fallen at least once in the prior year, with at least one of the following factors: unknown cause of fall, four or more risk factors for falls, or recurrent falls.[40] Other guidelines state that it is best to ask about falls in the previous year and the existence or suspicion of mobility problems for the case finding of elderly persons at risk of falls.[12,41-47] For future implementation of the falls clinic it would be helpful to develop a checklist to identify persons with ID that are at risk for future falls.

For future implementation of a falls clinic, more attention is needed for the questionnaires that caregivers must complete and more time is needed for the personal caregivers to accompany the participants. Another possibility might be having family members accompanying the participants to the fall clinic, because family members often have good knowledge of the medical history of the participants.

One of the main difficulties reported in this study was planning the different meetings. On average, it took more than 3 months from inclusion in the study to the meeting for discussing the results of the fall clinic with the participant and caregiver. It is possible that the problems related to the falls change within 3 months. The major barrier was arranging the multidisciplinary meeting. It took 40 days on average after both specialists had seen the participant for them to discuss their findings. It seems that service providers for persons with ID are not currently accustomed to working in multidisciplinary teams, and this was mentioned by members of the focus group. Although the importance of multidisciplinary meetings was recognized in the study, it appears that the cultural, organizational, and economic environment of many service providers makes it difficult to implement new interventions. Several interventions are often needed to achieve real changes in the daily practice routines of professionals and caregivers.[48,49]

Direct management of identified risk factors is important for a fall clinic to be effective.[21,22] Our study showed that after 6 months, 85% of the prescribed interventions had been realized or were being executed. Even though they all had a fall history, 11 of the 26 participants received no intervention. Six of them reported no falls in the follow-up period and probably would not have needed the referral to the falls clinic. However, five participants did report further falls (two persons had one fall, and the other three had two, four, and eight falls, respectively). Interestingly, they were all seen by the same ID physician. This indicates that the professionals involved in the falls clinic should be carefully selected and educated.

Advantages of the falls clinic for persons with ID as developed in this study were that it was readily accessible, close to the living facilities, and with physicians and therapists experienced in working with the target group. However, due to the necessary changes related to the abilities of persons with ID, the falls clinic was not as extensive as a general falls clinic. As a result, referrals to specialists will be necessary for more complex problems. Another limitation of the present study was that the group size was too small to perform a valid effect evaluation. However, our study indicates that the falls clinic may be effective in the prevention of falls based on a 23% decrease in fall rate after referral to the falls clinic.

In conclusion, the proposed falls clinic for persons with ID is feasible and was seen as useful by professionals, participants, and caregivers. Some minor changes in the content are necessary and development of a checklist to identify the persons at risk for future falls is highly recommended. The logistics of the falls clinic primarily need improvement. More attention and time for multifactorial and multidisciplinary treatment of persons with ID is necessary. When this can be organized, implementation of the falls clinic on a larger scale should be feasible and will result in the possibility of investigating (cost)effectiveness in the prevention of falls in persons with ID.

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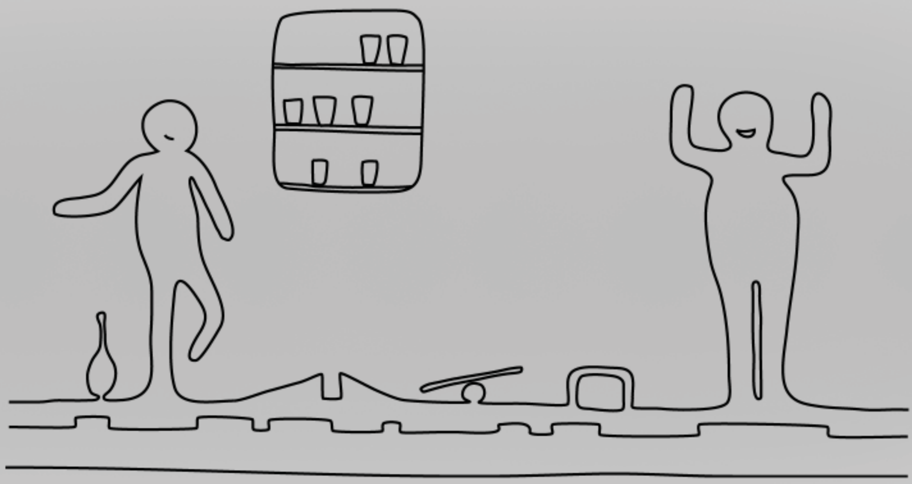
# Appendix

Intervention strategies (multifactorial screening on fall risk)

| | Reason assessment | Intervention |
|---|---|---|
| *ID physician* | | |
| **Anamnesis** | **Find out causes and circumstances of falls and risk factors for new falls Tractus anamneses** | **On indication of extra diagnostics, treatment, and if necessary, referrals** |
| Medication | Control accuracy, side effects, polypharmacy, psychotropic medication | Adjust medication use |
| Nutrition | Malnutrition | Dietary advice |
| Daily activity | Activity level | Activate |
| Vision | - Acute decline<br>- Poor vision (with glasses)<br>- Cataract | Adjust glasses/refer to ophthalmologist |
| Incontinence | Urge-incontinence | Lifestyle advices/medication (adjustments)/incontinence material/if necessary, referral to urologist |
| Smoking/alcohol/drugs | Detect excessive use | Lifestyle advices |
| Dentures | Bad dentures or eating problems | Referral to dentist |
| Seizures / cardiac problems | In case of syncope with:<br>- Unknown cause<br>- Someone with a history of cardiac problems or<br>- When cardiac problems are suspected | Lifestyle advice; referral to neurologist or cardiologist |
| Dizziness | Determine the cause | Lifestyle advices or medication (adjustments) |
| Activity level | Decline | Activate; adjust daily activity |
| Cognition | Decline | Adjust care and environment, medication if necessary and/or referral to psychologist |
| Behavior | Changes | Consider psychological diagnostics |
| Osteoporosis | Detect risk factors | Anti-osteoporosis medication; lowering other medication; DXA if necessary DXA; hip protector; referral to rheumatologist |
| Safety in and around house | Detect fall risk factors | Adjust; possible referral to occupational therapist |
| Katz scale | ADL functioning | Expand care/ADL training |

| Physical examination | Screening | On indication extra diagnostics, treatment and if necessary referrals |
|---|---|---|
| Blood pressure | Orthostatic hypotension | Lifestyle advice or medication (adjustments) |
| Neurological exam | - Asymmetric muscle weakness<br>- Changes in apraxia, ataxia en aphasia<br>- Sensibility problems | Referral to neurologist |
| Psychological functioning | Depression | Referral to psychologist |
| ***Physical therapist*** | | |
| **Anamnesis** | **Focus on mobility, strength, and balance** | **Therapy aimed at mobility, strength, and/or balance** |
| Hand grip strength | Measure for muscle strength | Idem |
| Berg balance scale | Balance | Idem |
| Timed Up and Go Test | Balance | Idem |
| Nijmegen gait analysis scale | Walking pattern | Idem |
| 3minute walking test | Condition | Idem |
| Reaction | Sensory motor integration | Advices client and staff |
| Walking aid | Control | Adjust or obtain aid |
| Shoes | Control | Adjust or obtain good shoes/ orthopedic shoemaker |
| Extra on referral: psychologist | | |
| Depression scale | Depression | Behavioral therapy and/or medication |
| DSDS/DSVH | Dementia | Behavioral therapy; adjustment in living situation; possibly medication |

DSDS, Dementia Scale for Down Syndrome; DSVH, Dementie Schaal voor mensen met een Verstandelijke Handicap.



# Chapter 7

# Obstacle course training can improve mobility and prevent falls in people with intellectual disabilities

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## Abstract

**Background:** Persons with Intellectual Disabilities (ID) constitute a special-needs population at high risk of falling. This is the first study to evaluate whether obstacle course training can improve mobility and prevent falls in this population.

**Methods:** The intervention was implemented as part of an institution-wide health care improvement plan aimed at reducing falls at a residential facility for people with ID. It comprised an annual screening of each resident for his or her individual fall risk. Subsequently, the group of ambulatory persons with a moderate to high fall risk (N=39) were offered 10-session obstacle course training to improve their balance and gait abilities. Mobility was assessed pre-intervention, mid-term and post-intervention with the Performance Oriented Mobility Assessment (POMA), the Timed Up and Go (TUG) and the 10-meter walking test. The number of falls was compared between the year before and after intervention.

**Results:** The number of falls decreased by 82% ($p<0.001$). POMA scores significantly improved from pre-intervention to mid-term (mean difference±SD, 1.8±2.9, $p=0.001$), from mid-term to post-intervention (2.0±2.9, $p<0.001$), and from pre-intervention to post-intervention (3.8±4.3, $p<0.001$). Participants completed the 10-meter walking test faster at the post-intervention compared to the pre-intervention assessment (difference±SD, 2.1±5.1 sec, $p=0.022$). TUG scores did not improve significantly.

**Conclusions:** The present study provides preliminary evidence for the effectiveness of obstacle course training in improving mobility and preventing falls in people with ID. As falls are a significant health concern in this population, further research is advocated to provide conclusive evidence for the suggested beneficial effects of exercise interventions.

## Introduction

Falls are an important health care issue as they can lead to serious injuries and have important psychosocial consequences, like fear of falling and loss of independence.[1-3] Persons with intellectual disabilities (ID) constitute a specific group at particularly high risk of falling, but also with a very high proportion of falls resulting in injuries.[4-8] Falls even represent the leading cause of injury (50-60%) in this population.[9] Along the same line, people with ID are more likely to visit emergency departments (odds ratio 1.69) and be admitted to hospital (odds ratio 1.76) for fall-related injuries, when compared to the general population.[10] These falls and the related injuries have a great impact on the individuals who fall, but also on their environment, health services and the community.

Mobility problems have been identified as the most important risk factor for falls in the general elderly population.[11-14] A recent review reported that poor balance and gait capacities, as two key factors underlying mobility impairments, are very common in the population with ID, which suggests their important role in persons with ID as well. They generally start at young age and remain present during the entire lifespan, with a relatively early occurrence of age-related decline in balance and gait capacities.[15] Furthermore, consistent with fall circumstances in the general population, walking has also been reported as the most common activity leading to falls in a group of ambulatory older persons with ID,[16] which also supports a key role for mobility problems in the etiology of falls in this population.

Because of the high incidence and the impact of falls in the population with ID, many studies have emphasized the importance of developing and evaluating falls prevention programs for this specific group.[4,5,7,9,17-19] To the authors knowledge, however, no such intervention has been designed and evaluated yet. In the general elderly population there is overwhelming evidence for the effectiveness of multi-modal exercise programs in reducing the risk of falls.[20,21] It has been demonstrated that exercise programs can also improve balance, gait and muscle strength in persons with ID.[15] Hence, exercise interventions also seem to be a promising strategy in the management of falls in the population with ID.

The Nijmegen Falls Prevention Program (NFPP) is one such exercise program that has been shown to reduce fall rates and increase balance confidence in healthy elders[22] and in persons with osteoporosis[23]. The original NFPP consists of obstacle course training, walking exercises and the practice of fall techniques. The aim of this study was to evaluate the effectiveness of the obstacle course training from the NFPP in persons with ID. The primary outcome was mobility, as measured with clinical balance and gait tests. Furthermore, the effectiveness of the program was evaluated with regard to the number of falls in the year before and after the intervention.

# Methods

## Study design and participants

The intervention was implemented as part of an institution-wide health care improvement plan aimed at reducing the number of accidental falls at a residential facility for people with ID (IQ<70). The plan was implemented in 2007 and comprised an annual screening of each resident (N=247 at the time of implementation) for his or her individual fall risk with the use of a purpose-designed checklist, which included 10 risk factors of falls (Table 7.1). The checklist was composed from the literature in the general older population on fall risk factors and assessment strategies.[24-28] The outcome of this checklist provided a starting point when determining individual risk reduction strategies.

This paper is confined to the group of persons with a moderate (4-6 risk factors present) to high fall risk (7-10 risk factors) who were offered a 10-session exercise intervention to improve their balance and gait abilities (Table 7.2). The primary focus in selection was on

**Table 7.1** Fall risk factors included in initial screening and number of participants and non-participants with medium and high risk scoring on each of the items

| | Participants* (N=39) | Non-participants (N=62) |
|---|---|---|
| 1. Fall History – Has fallen within the last 3 months | 26† | 15† |
| 2. Environment – Environmental factors caused falls (e.g. uneven surface, poor lighting, lack of space to maneuver) | 20† | 16† |
| 3. Medications – Is on 4 or more different categories of medications (e.g. sedatives, anti-depressants, analgesics) | 29 | 45 |
| 4. Sensory Deficits – Has at least one sensory deficit (sight, hearing, sensation) | 26 | 33 |
| 5. Mental/Behavioral State – Is confused, agitated or forgetful | 20 | 40 |
| 6. Balance and Gait – Has poor balance or gait problems | 28 | 34 |
| 7. Transfer ability – Independently transfers self | 37† | 45† |
| 8. Medical – Has medical problems (e.g. pain, arthritis) | 11 | 25 |
| 9. Elimination – Has periods of incontinence | 20 | 37 |
| 10. Equipment – Requires the use of mobility aids | 16 | 19 |
| **Number of fall risk factors, Mean±SD** | **6.2±2.0†** | **5.0±1.3†** |

*This group includes two persons scored as low fall risk.
†Significant difference between groups of participants and non-participants.

those individuals who were ambulatory and had a recent history of (near) falls, particularly those that had resulted in injuries. The vast majority of the participants had ID due to perinatal or acquired brain damage, or due to unknown causes. Exclusion criteria were related to the person's inability at a functional and cognitive level to participate in the program and the testing measurements (e.g. behavioral resistance to the testing and participation despite the fact that they would have the ambulatory skills to participate) and medical complications. As this study comprised an analysis of routinely collected data in the context of this health care improvement plan, no informed consents had to be obtained from the participants or their legal representatives (as confirmed by the Institutional Review Board).

## Intervention

The exercise intervention was derived from the Nijmegen Falls Prevention Program (NFPP).[22] The original NFPP (5 weeks, 10 sessions) consist of three elements; an obstacle course (50% of the total time), walking exercises to simulate walking in crowded environments (20%) and the practice of fall techniques (30%). It was delivered as a group-based program. In the present study, it was chosen to deliver the program on an individual basis (with two staff to one participant), as training in groups was considered too burdensome, both for the staff and for the participants. As a second adjustment, only the obstacle course was applied, as the other elements were either deemed not feasible in the target population (practice of fall techniques), or unsuitable for individual training (walking exercises). The obstacle course training aimed to improve balance, gait and coordination. The obstacle course stations were designed to simulate potentially hazardous situations and activities of daily living (e.g. walking over uneven surfaces, stepping over obstacles, picking up an object from the floor). In agreement with the protocol of the original NFPP, the level of complexity was gradually enhanced by adding secondary cognitive and motor task that had to be performed simultaneous with the obstacle course. The final program comprised a total of 10 weekly obstacle course sessions of approximately 30 minutes each. The training was delivered by a physiotherapist, a mobility therapist and physiotherapy and occupational therapy assistants. If deemed necessary, the participant wore a safety belt to facilitate staff in preventing falls during the execution of the exercises.

## Data collection

As a standard clinimetric evaluation, a number of tests were conducted pre-intervention, at mid-term (i.e. after five training sessions) and post-intervention. The Performance Oriented

Mobility Assessment (POMA) was conducted to assess balance and gait capacity,[29] which tests was previously found a valid and reliable tool for detecting fall risk in the population with ID.[30] The other tests were the Timed Up and Go (TUG) to assess mobility,[31] and the 10-meter walking test to assess comfortable speed.[32]

With respect to falls, the facility has implemented (in the year 2002) a falls monitoring procedure. Incident reports as well as 24-hour reports from the homes were collected and analyzed by the risk and utilization manager on a daily basis. A fall was defined as unintentionally coming to rest on the ground or a lower surface.[33] If the person was lowered or assisted to the floor by staff or family this was not regarded as a fall. Confirmed fall incidents were entered into a database on an individual level. This allowed us to identify each participant's number of falls both in the year before and after the intervention. In addition, the number of fall-related fractures sustained were determined over a 3-year period prior to intervention and a 2-year period post intervention.

### Statistical analysis

Scores on the POMA, TUG, and 10-meter walking test were compared with an analysis of variance (ANOVA) for repeated measures (pre-intervention, mid-term, and post-intervention), with post-hoc paired t-tests. As the fall data were not normally distributed, a Wilcoxon signed-rank test was applied to compare the numbers of falls between the year before and after participation. Due to the low numbers of fall-related fractures, these values were only reported descriptively. The alpha level was set at 0.05.

## Results

A total of 99 persons were identified as being at moderate to high fall risk, of whom 37 took part in the intervention. The remaining 62 persons were excluded because they were non-ambulatory (n=15), or otherwise not willing or capable to participate. Two persons with a low fall risk were also included; one with a falls history prior to the 3 months as included in the checklist, the other because staff deemed him to benefit from the intervention as well. Compared with non-participants, participants more often had a history of falls, more often fell due to environmental hazards, were more able to transfer independently (cf. being ambulatory), and had a larger overall fall-risk.

The characteristics of the participants are presented in Table 7.2. Between the pre-intervention and mid-term assessments, two persons refused to continue with participation in the intervention, two persons were unable to complete the intervention due to an increase of medical complications and one person was found not suitable for the obstacle course and placed in an alternative program. Hence, 34 persons (87.2%) completed all 10 sessions. The POMA and 10-meter walking test could be conducted in all the participants, whereas TUG data could not be obtained reliably in 2 participants because of behavioral problems. Complete fall data were available for 38 persons.

The results on the clinical tests are shown in Table 7.3. The statistical analysis yielded significant main effects of time on the POMA ($F(2,66)=20.727$, $p<0.001$) and the 10-meter walking test ($F(2,66)=3.748$, $p=0.029$). Significant improvements were observed in POMA scores from pre-intervention to mid-term ($p=0.001$), from mid-term to post-intervention ($p<0.001$), and from pre-intervention to post-intervention ($p<0.001$). Participants completed the 10-meter walking test faster at the post-intervention compared to the pre-intervention assessment ($p=0.022$). TUG scores did not improve significantly ($F(2,62)=1.274$, $p=0.287$).

**Table 7.2** Participant characteristics

| | |
|---|---|
| Sex, M:F | 21:18 |
| Age (y), Mean±SD | 55.1±10.7 |
| Length (m), Mean±SD | 1.61±0.12 |
| Body mass (kg), Mean±SD | 67.4±12.6 |
| BMI (kg/m$^2$), Mean±SD | 26.0±4.2 |
| Diagnosis, N | |
| Down syndrome | 2 |
| Brain damage (perinatal or acquired) | 14 |
| Unknown cause | 23 |
| Severity ID, N | |
| Mild | 9 |
| Moderate | 7 |
| Severe | 21 |
| Profound | 2 |

BMI, body mass index; ID, intellectual disability.

**Table 7.3** Results (mean±SD) of the clinical balance and gait tests

| | Pre-intervention | Mid-term | Post-intervention |
|---|---|---|---|
| POMA score | 18.5±4.1 | 20.3±4.0* | 22.3±4.0*† |
| 10 m walking test (s) | 14.4±6.4 | 13.2±4.2 | 12.3±4.7* |
| TUG (s) | 20.2±6.0 | 19.8±6.6 | 18.6±6.3 |

POMA, Performance Oriented Mobility Assessment; TUG, Timed Up and Go.
*Significantly different from pre-intervention, †significantly different from mid-term, $p<0.05$.

In the year prior to participation, a total of 131 falls were recorded in the group of participants. The median fall rate was 2 falls per person (range 0-29). In the year post intervention, 23 falls were recorded, with a median fall rate of 0 falls per person (range 0-4), which was a significant reduction compared to pre-intervention (82%, $p<0.001$). The participants sustained 12 fall-related fractures over a 3-year period prior to the intervention. In the 2 years following the intervention only 3 fractures were reported.

## Discussion

This study was the first to evaluate the effectiveness of obstacle course training on mobility and falls in individuals with ID. The obstacle course training was derived from the NFPP, which program has previously been proven effective in reducing falls in healthy older individuals and people with osteoporosis.[22,23] The results demonstrated that compared to the baseline assessment, POMA scores and walking speed improved significantly, in parallel with a substantial reduction in the rate of falls. Importantly, the number of fall-related fractures decreased as well, which demonstrates that both severe and non-severe falls were prevented. These findings confirm the effectiveness of the obstacle course training as a specific element of the NFPP.

The finding that an obstacle course training can improve mobility skills in persons with ID is in line with previous studies. For instance, Carmeli and co-workers demonstrated that a 25-week treadmill walking program was effective in improving balance and muscle strength in older persons with Down syndrome.[34] Improved walking abilities were demonstrated in a group of individuals with mild to moderate ID after a 12-week program including balance and weight bearing exercises.[35] Balance and gait impairments are well-known risk factors of falls in the general older population. These impairments are also highly prevalent in persons with ID, which suggests their implication in the elevated fall risk in this group as well.[15,36] In our group of participants, the average scores on the POMA and TUG were indeed indicative of a high fall risk, as based on the cut-off scores determined in the general older population (>14 sec for TUG and <19 for POMA). The observation that the present intervention did not only improve mobility (albeit non-significantly for TUG scores), but also resulted in a lower number of falls provides further evidence for mobility-related fall-risk factors in this population. It remains for future studies to elucidate their exact role in the aetiology of falls in persons with ID.

In the general older population, poor mobility is not only associated with higher fall risk, but also with physical inactivity.[37] Inactivity has previously been identified as an important problem among persons with ID[38,39] and the promotion of physical activity was identified as the single most effective strategy to improve health in this special needs population.[40] Encouraging people to become more physically active, however, may lead to larger numbers of falls and injuries.[41] We therefore raise the suggestion to consider improving mobility skills, for instance with the presently described obstacle course training, prior to the promotion of physical activity in persons with ID.

Another finding of note was the applicability of the clinical tests in the present sample with a preponderance of severe ID. This is in line with the report of Chiba et al., who also found that the POMA could be completed by most of their participants, even those with severe or profound ID.[30] These observations add to the reported feasibility in persons with mild to moderate ID of clinical balance and gait tests that have originally been developed for the general older population.[42,43]

The present study involved a within-subjects analysis of clinimetric and fall data that were collected in the context of an institution-wide health care improvement plan to prevent accidental falls. Consequently, an inherent limitation was that no control group was included that received either no or a sham intervention. Furthermore, it cannot be excluded that other elements of the plan (e.g. elimination of environmental hazards or staff education) have also contributed to the decreased fall rates. The reduction for the participants to the obstacle course training, however, was much larger than the reduction observed for the population of residents at large (23%) in the same time period. Furthermore, the participants were not partaking in any other form of exercise or recreational program other than their regular activities of daily living. This present finding therefore suggests that the obstacle course training importantly contributed to the reduced fall risk of the participants. Although these results are promising, further research is needed to establish the effectiveness of falls prevention exercise programs in this special needs population, preferably involving randomized controlled trials.

Another limitation of the present study was that the intervention was not suitable for a substantial number of persons with moderate or high fall risk, due to them being non-ambulatory or having other problems impeding participation. It remains an open question whether and how the risk of falling may be reduced in these persons.

In conclusion, the present study provides preliminary evidence for the effectiveness of obstacle course training in improving mobility and preventing falls in people with ID. As falls have been identified as a significant health concern in this special needs population, further research is advocated to provide conclusive evidence for the suggested beneficial effects of exercise interventions.

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# Chapter 8

# Summary and general discussion

## Summary

The number of persons with Intellectual Disabilities (ID) who are receiving care is increasing in the Netherlands. Furthermore, as a result of an increased life expectancy, age-related problems become more prominent in the care for persons with ID. One of the major age-related health problems is falling. It is commonly known that persons with ID are at a higher risk of falls and fall-related injuries than their mentally healthy peers. However, the reason for this increased fall risk is still elusive. Therefore, the main aim of this thesis is to determine the most important risk factors for falls in elderly persons with ID and to investigate interventions to prevent future falls. Special attention is given to the relationship between falls and mobility problems (problems in balance and gait), since these have shown to constitute the most important risk factor for falls among elderly in the general population.

Chapter 1 is a general introduction and provides background information about persons with ID and their health. Particularly, the problem of falls and the risk factors for falls in this population are addressed as well as the lack of scientific data in this area. This void of knowledge inspired three service providers for persons with ID (Dichterbij, Siza and Pluryn) and the Radboud University Medical Centre in the Netherlands to start a series of studies on (risk factors for) falls and falls prevention in elderly persons with ID. At the end of chapter 1, the objectives and outline of this thesis are described. In the first part (Chapters 2 and 3), balance and gait problems in persons with ID are studied; in the second part (Chapters 4 and 5), falls and risk factors for falls in persons with ID are investigated, while in the third part of this thesis (Chapter 6 and 7) the possibilities for falls prevention in this population are dealt with.

### Part I: Balance and gait problems in persons with ID

In Chapter 2 a literature review on balance and gait problems in persons with ID is described. The objective of this review was (1) to critically appraise the available literature on balance and gait characteristics, (2) to study the consequences of balance and gait problems in relation to falls, and (3) to find evidence for the trainability of balance and gait capacity in persons with ID. A systematic search identified 48 articles that were included in the review. The literature has consistently reported that balance and gait capacities are affected in persons with ID compared to their age-matched peers. These problems start at a relatively young age and show a relatively early occurrence of age-related decline. Based on these results a conceptual model has been suggested in which the lifelong development of mobility in the ID population is compared to the general population. Regarding the second

objective, the literature has shown that, although the relationship of balance and gait problems with falls has not yet been thoroughly investigated in persons with ID, there is preliminary evidence for the notion that these problems are important risk factors in the ID population as well. Finally, the literature has indicated that balance and gait capacity is potentially trainable in persons with ID, suggesting that falls may be prevented through ID-specific exercise interventions.

The aim of the study described in Chapter 3 was to determine the feasibility of frequently used clinical balance and gait tests in older persons with mild to moderate ID and to examine whether these tests are able to show limitations in balance and gait capacities in the ID population compared to age-matched peers in the general population. To this end, the following clinical balance and gait tests were administered in 76 older persons with mild to moderate ID and 20 healthy controls: the Berg Balance Scale (BBS), the Functional Reach test (FR), the Timed Up and Go Test (TUGT), the Single Leg Stance (SLS) and the Ten Metre Walking Test (TMWT). Furthermore, it was aimed to identify the most important determinants of balance and gait disability in persons with ID. This study showed that it was feasible to conduct standard clinical balance and gait tests in older persons with mild to moderate ID. Balance and gait performance of persons with ID was significantly worse compared to older persons in the general population. Age, Body Mass Index (BMI), fear of falling, number of co-morbidities and body sway were associated with balance and gait performance in persons with ID, whereas sex, aetiological diagnosis, severity of ID, number of medication and use of psychotropic drugs were not.

## Part II: Falls and risk factors for falls in persons with ID

Chapter 4 presents the results of a prospective study on fall rate, fall circumstances and consequences of falling in older persons with mild to moderate ID. Eighty-two individuals with mild to moderate ID participated. Falls were registered for one year with monthly fall registration calendars to determine the fall rate (mean number of falls per person year). Information on fall circumstances and consequences was obtained from questionnaires completed by caregivers and study participants after each fall. These questionnaires asked about the date, time, location, direction and cause of falls and their consequences, such as fractures and other injuries needing medical attention. The fall rate in this sample was 1.0 fall per person per year. Thirty-seven participants reported at least one fall (range 1-6). Sex and age were not related to falls. Most falls occurred while walking (63.3%), outside (61.7%) and in familiar environments (88.9%). Importantly, 11.5% of the falls resulted in severe injuries, approximately half of which were fractures. Thus, the circumstances and consequences of falls in persons with ID were comparable to those of the general elderly population, but the fall rate was substantially higher.

Chapter 5 describes the first prospective study to investigate risk factors for falls in elderly persons with mild to moderate ID. Seventy-eight ambulatory persons with mild to moderate ID participated. This longitudinal cohort study involved extensive baseline assessments, followed by a one-year follow-up on fall incidents. The baseline assessments consisted of clinical measurements of mobility and cognition, questionnaires regarding sensorimotor abilities, activity level and behaviour, and a medical chart review regarding demographic characteristics, medication use and co-morbidities. Falls occurred in 46% of the participants and the fall rate was 1.0 falls per person per year. The most important risk factors for falls were (mild) severity of ID, (high) physical activity, (good) visuo-motor capacity, (good) attentional focus and (high) hyperactivity-impulsiveness, which together explained 56% of the fall risk. This pattern of risk factors suggests a complex interplay of personal and environmental factors in the causation of falls in elderly persons with mild to moderate ID.

## Part III: Falls prevention in persons with ID

In part III two types of interventions to prevent falls in persons with ID were explored. Chapter 6 describes a multifactorial screening procedure, the so-called "Falls Clinic for persons with ID". The aim was to develop, implement, and evaluate a falls clinic for this population. Based on guidelines, literature, and expert meetings, a targeted falls clinic was developed. Twenty-six persons with ID and a fall history participated. A process evaluation was conducted using evaluation forms and focus groups. Fifty interventions (0-8 per person) were prescribed. The medical and allied health experts, persons with ID and caregivers rated the falls clinic as useful. Advice for improvement included minor changes to its clinical content, whereas logistics appeared to be the biggest challenge for the falls clinic, i.e. organizing meetings, completing questionnaires prior to meetings, and ensuring that caregivers accompanied the persons with ID. Furthermore, the need for a screening tool to determine whether a person would benefit from the falls clinic was reported. In conclusion, the falls clinic for persons with ID was considered feasible and useful, although logistics needed improvements. In addition, more attention and time for multifactorial and multidisciplinary treatment of persons with ID was considered necessary. Implementation on a larger scale would make it possible to also investigate the effectiveness of the falls clinic with regard to the prevention of falls in the ID population.

Chapter 7 is a report of a study that evaluated whether an obstacle course training could improve balance and gait capacity and prevent falls in persons with ID. The applied obstacle course training used was derived from the "Nijmegen Falls Prevention Program". This program was developed for healthy elderly persons and has shown to be effective in reducing the number of falls in the general population. A group of ambulatory persons with ID and a moderate to high fall risk (N=39) was offered a 10-session obstacle course training to improve their balance and gait capacities. Mobility was assessed pre-intervention, mid-term and post-intervention with the Performance Oriented Mobility Assessment (POMA), the Timed Up and Go Test (TUGT) and the Ten Metre Walking Test (TMWT). The number of falls was compared between the year before and after intervention. The number of falls decreased by 82%. POMA scores significantly improved from pre-intervention to mid-term, from mid-term to post-intervention, and from pre-intervention to post-intervention. Participants completed the TMWT faster at the post-intervention compared to the pre-intervention assessment, but TUGT scores did not improve significantly. Thus, this study provides preliminary evidence for the effectiveness of obstacle course training to improve balance and gait capacity and to prevent falls in people with ID. As falls are a significant health concern in this population, further research is warranted to obtain more conclusive evidence for the beneficial effects of exercise interventions in persons with ID.

# General discussion

In this general discussion the main results as summarized above are further elaborated on. First, the risk factors for falls and the interplay between these factors are addressed. Then mobility problems and their effect on falls in persons with ID are discussed in relation to the use of fall preventive interventions in the ID population. After considering the most important strengths and limitations of the present research, some logistic recommendations are given for performing future research in persons with ID. Finally, the clinical implications of the results of this thesis are addressed.

## Fall risk in ID: a multidimensional model

This thesis comprises the first prospective study on risk factors for falls in elderly persons with mild to moderate ID. The results of this study reveal a complex interplay of personal and environmental factors in the aetiology of falls in the ID population.[1] Particularly in this population fall risk seems to depend not only on a person's capacities and motor behaviour, but also on the support and protection from the environment. The multidimensional framework regarding human functioning in persons with ID (Figure 8.1),[2] as introduced in the general introduction of this thesis, may help to better understand this complex interplay of risk factors for falls in persons with ID.

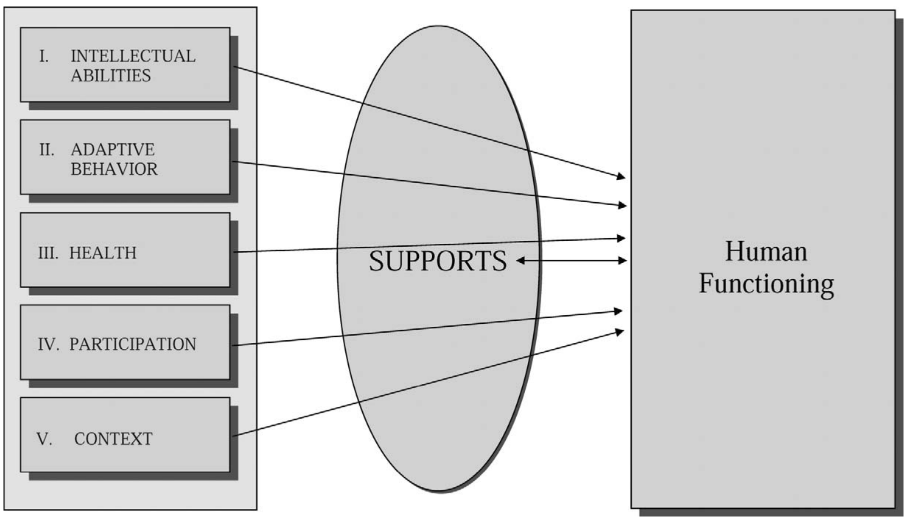


**Figure 8.1** Conceptual framework of human functioning.[2]

The fall risk factors that were identified in the prospective study are present in the different dimensions of human functioning in this model. Intellectual abilities (dimension I) were related to fall risk since persons with mild severity of ID appeared to have a higher fall risk than persons with moderate ID. Adaptive behaviour (dimension II) also had an influence on fall risk. This dimension covers the collection of conceptual, social and practical skills that have been learned and are performed by people in their everyday lives.[2] Identified risk factors for falls in this dimension were (good) visuo-motor capacity, (good) attentional focus and (high) hyperactivity-impulsiveness. Health (dimension III) is a state of complete physical, social and mental well-being.[3] It was expected that health-related factors, such as co-morbidities, would also be of influence on fall risk in person with ID, however, this was not confirmed in the prospective study. Participation (dimension IV) refers to the individual functioning in society. The prospective study indicated that persons with ID who were more physically active were at an increased risk of falls. Finally, context (dimension V) includes the environmental and personal factors that represent the complete background of an individual's life. For example, we investigated whether sex, age, occupation, sports, living facility and safety habitat were of influence on the risk of falls, but this was not the case. Lastly, support refers to the resources and strategies that aim to promote the development, education, interest, and well-being of a person.[2] The model shows that the five dimensions do not influence human functioning, or more specifically fall risk, independently, but that they exert a combined effect in interaction with the level of support.

The large influence of support on human functioning in persons with ID helps us to better interpret the results of our study. At first sight, it seems counterintuitive that persons who had mild ID, were physically active, and had relatively few visuo-motor and attentional problems showed the greatest risk of falls.[1] On second thought, however, this pattern of results can be explained by a higher level of exposure to fall hazardous situations and/or less protection of persons with mild disabilities by their caregivers. Persons with moderately severe ID and poor motor capacities are more likely to be protected by their caregivers and/or living situation, which would limit their exposure to potentially dangerous circumstances. This notion has previously been addressed by Sherrard et al.[4] Although (over)protection may reduce falls and fall-related injuries in daily life, a drawback of such a protective care strategy may be that individuals with ID are less challenged in their daily lives, allowing them less chance to learn new skills and improve their quality of life. Moreover, the physical inactivity that inevitably accompanies a protective care strategy will probably speed up the age-related decline of physical and mental capacities and gradually induce a greater dependency on others.

Although the attitude of the caregivers towards the participants was not investigated in the prospective study, it seems that the amount and form of support is of crucial importance in the risk for falls in persons with ID. Future research should, therefore, focus on the relationship between the level of individual functioning and environmental factors such as exposure and protection in persons with ID.

## Mobility problems and falls prevention in persons with ID

Because mobility (e.g. balance and gait) problems are known to be the most important risk factors for falls among elderly in the general population[5-7] special attention was given to the relationship between falls and mobility problems in persons with ID. Persons with ID have a higher fall risk compared to the general elderly population.[8-11] In line with this notion, the prospective study in this thesis showed that the fall rate was higher in persons with ID.[1,12] Furthermore, other studies in this thesis showed that persons with ID have impaired balance and gait capacities compared to their age-matched peers and that these problems are present at a younger age.[13,14] Therefore, it is likely that mobility problems have an important influence on fall risk in the ID population as well. Surprisingly, as mentioned above in relation to the multidimensional model, the dimension health, including mobility problems, was not associated with fall risk in the prospective study.[1] Here too, this counterintuitive result may be explained by the fact that the individuals with the poorest balance and gait capacities received the most support, which may have prevented them from falling.

Even though mobility problems were not identified as risk factors for falls in the prospective study, the study on obstacle course training in this thesis appeared to be effective to improve motor functioning and reduce the number of falls in elderly persons with ID.[15] Other studies have also shown that exercise programs can improve balance and strength in persons with ID,[16,17] which improvements may allow them to more safely operate within their environment. Exercise interventions may therefore reduce the risk of falling in persons with ID, despite the fact that poor motor functioning was not identified as a risk factor in the prospective study. Perhaps such interventions are effective through influencing other risk factors than mobility problems that are possibly related to fall risk, for instance visuo-motor capacity and attentional focus. To provide further evidence for the effectiveness of fall preventive exercise programs in the ID population, more research is needed preferably based on randomised controlled trials.

This thesis also showed that a multifactorial screening and intervention strategy, such as a falls clinic, is feasible and helpful in the care for persons with ID.[18] For future fall preventive interventions, it is recommended to pay attention to the complex interplay of personal and environmental risk factors for falls in the ID population, as identified in the prospective study.[1] A wider implementation of falls clinics for persons with ID would make it possible to evaluate their effect on fall prevention in the ID population on a much larger scale. Furthermore, caregivers, medical and allied health experts and persons with ID indicated the need for a checklist that can be completed after each fall incident to identify persons at risk for future falls who might benefit from either visiting a falls clinic or participating in an exercise program.[18] With such a checklist, all falls can be registered and documented for systematic evaluation and to determine whether further action is needed.

Although in the prospective study 56% of the variance in fall incidence in elderly ambulatory persons with mild to moderate ID could be explained,[1] there was still a substantial part of the variance that could not be accounted for by the identified risk factors. Thus, future prospective research should try to optimize the explanation of fall risk in the ID population, for instance by including more factors related to individual psychological profile (e.g. impulse regulation, anger, fear) as well as support.

## Strengths and limitations

The prospective study in this thesis was the first to use monthly fall registration calendars in combination with fall incident questionnaires in persons with ID. This method has been recommended by the Prevention of Falls Network Europe (ProFaNe)[19] and is generally more reliable than collecting data from retrospective reports, medical records, or client records as was done in previous studies in persons with ID.[8,9,20,21] Indeed, retrospective collection of falls often leads to an underestimation of fall rate.[22,23] In the prospective study, the risk of recall bias or missing fall incidents was further minimized by making both the participant and the caregiver(s) responsible for recording the fall data. Still, it cannot be excluded that some falls were missed, since their detection was dependent on self-report.

The participant's level of functioning was objectively measured by using a standardized baseline assessment. This assessment always occurred in an environment that was familiar to the participant (e.g. at home or at the day activity centre) and was performed by a trained professional. In addition, in the majority of the assessments, a familiar therapist or caregiver was present.[1] These circumstances most likely contributed positively to the validity of the functional assessments.

Despite careful selection, the applied baseline tests were not always feasible in our study sample. For instance, the feasibility of the cognitive assessments, especially those using the computer, were problematic. Only 36% of the participants were able to adhere to the entire set of cognitive tests.[1] Therefore, some aspects of cognitive functioning might have been missed as a potential fall risk factor. Furthermore, the measurement of sensibility using a tuning-fork was often not possible since many participants could not distinguish the sensation of pressure from the fork and its vibration. Therefore, only the sensibility data obtained with the Adult Adolescent Sensory Profile (AASP) were used. It was initially intended to measure leg strength with a dynamometer that was fixed to a chair. However, since most participants did not understand the test instructions, these dynamometer data were regarded as invalid. Instead, information about whether an individual was able to get up from a chair without using the hands was used as a measure of leg strength.

Because not all of the tests administered during the baseline assessments were considered feasible for persons with more severe physical or cognitive disabilities, only ambulatory participants with mild to moderate ID were included in the studies reported in this thesis. Furthermore, persons with epilepsy were excluded, because falling as a result of an epileptic seizure was considered as a completely different problem than falling related to ID and ageing.[1] Because of this selection of participants, the results of this thesis cannot be generalized to the entire population of persons with ID, but only provide information about falling in elderly persons with mild to moderate ID.

### Logistic recommendations regarding future research in persons with ID

Scientific research is a rather new area in the care for persons with ID. In the Netherlands, the research conducted in this area has been fragmented over many themes lacking coordination.[24] It has been acknowledged that performing research in the ID population is quite challenging.[25] Also in the studies that constitute this thesis, several logistic problems were encountered, based on which experience it is warranted to give some recommendations for the design of future studies in this target group.

First, the studies in this thesis made use of a focus group of family members of persons with ID and professionals from all the service providers involved in the research consortium. They gave advice on how the study procedures would best fit into the daily routines of the three service providers. Furthermore, they advised on how the burden on the participants could be kept as low as possible without compromising the research goals.

The preparatory phase of empirical studies in the ID population is very important and time consuming. In working with persons with ID one depends on their cooperation as well as on the cooperation of various professionals, family members and legal representatives. It is crucial that all these stakeholders are informed timely and adequately and that their participation is made as easy as possible for them.

The inclusion of participants starts with the selection of eligible candidates by professionals working for the service providers. To this end, a checklist with in- and exclusion criteria was developed. In the present research, eligible participants and (if applicable) their legal representatives received information letters. Two versions were used: one for the representatives and one for the candidates. Members of the focus group and clients of the participating service providers should be involved in constructing these letters to optimize both the content and the formulations. The same is true for constructing the informed consent papers, since these have to be signed by both the participants and the legal representatives. In this process, the caregivers play a linking role between the legal representatives, the participants and the research team.

After inclusion data collection can start but, in order to do this properly, it is crucial that the participants feel comfortable enough to perform at the best of their abilities. In addition, it is important to minimize the travelling time for the participants. In the present research, the primary researcher paid a home visit before the start of the baseline measurements to get acquainted with the participant and to answer any remaining questions. In advance of this visit, a picture of the primary researcher was send to the participant. This picture was used in all further correspondence as a support for recognition. Another crucial success factor is to perform the assessments in or close to the home situation of the participants. In the studies of this thesis, the clinical assessments always took place in a familiar environment to minimize travelling time and to ensure that the participants felt comfortable. The latter goal was also pursued by the presence of a caregiver or physical therapist that was familiar to the participant.

Lastly, regular correspondence with the caregivers is very important. In the prospective study, this was not only essential to ensure correct and complete data collection on fall incidents, but also because many participants moved from group homes to community-based housing during the follow-up period.

## Clinical implications

The high prevalence of falls in persons with ID emphasizes the importance of regular screening on risk factors for falls in this population. Because these risk factors represent various dimensions of human functioning, it is important to have a multi-factorial, multi-disciplinary screening to investigate falls and prevent future falls in persons with ID. Such a multidisciplinary approach has been used in our falls clinic for ID. Though the falls clinic was considered feasible and useful, logistic issues needed improvement, for instance concerning the organisation of the multidisciplinary meetings. It seems that professionals working for service providers for persons with ID are currently not accustomed to working in multidisciplinary teams. Although the importance of multidisciplinary meetings was recognized, it appears that the cultural, organizational, and economic environment of many service providers makes it difficult to implement such new interventions. Thus, more time and attention to multifactorial and multidisciplinary assessment and treatment of persons with ID is crucial to improve their healthcare.

Another finding of the present research is that the level of motor functioning of elderly persons with mild to moderate ID can very well be assessed by a set of existing, commonly used, clinical balance and gait tests. Using these measures enables clinicians to objectively assess and evaluate the level of motor functioning in persons with ID.

Because the risk of falling in persons with ID is apparently determined by a complex interplay of personal and environmental factors, including the support a person with ID receives, the of role caregivers seems to be very important. (Over)protection may be a significant problem in this field, which may have serious drawbacks for those who are cared for. Many of these drawbacks probably remain invisible as they may be taken for granted and considered an inevitable consequence of the intellectual disabilities. This notion should be challenged by innovations in healthcare as well as by future research. Indeed, it is a common finding that older persons with ID exhibit very low activity levels.[1,26] In the general population, inactivity is associated with health problems such as a higher risk of obesity, cardiovascular disease and diabetes.[27,28] There is little reason to believe that persons with ID do not suffer from such risks when they remain too inactive. Therefore, caregivers and researchers should strive to determine the optimal activity level for various subgroups of the ID population.[29,30] An optimal activity level ideally combines maximal physical exercise without jeopardizing safety or increasing the incidence of falls and fall-related injuries. Being already a challenge in the population with mild to moderate ID, this will require an even greater effort for persons with more severe ID.

## Take home messages

- Fall rate in elderly persons with mild to moderate ID is higher than in elderly persons in the general population
- Fall risk factors in persons with mild to moderate ID represent a complex interplay between personal and environmental factors
- Commonly used clinical balance and gait tests are applicable in persons with mild to moderate ID
- Balance and gait capacity is affected in elderly persons with mild to moderate ID compared to elderly in the general population, but this may not be directly related to fall risk
- (Over)protection may underlie the observation that fall risk is greatest in persons with relatively good (cognitive) capacities and a relatively high activity level
- Fall preventive strategies have been developed and have shown preliminary effectiveness in the ID population
- More awareness of the fall incidence and regular screening on risk factors for falls is necessary in the daily care for persons with ID
- Multidisciplinary teamwork seems important to prevent falls in the ID population, however, until now such teamwork is not generally implemented in the Netherlands

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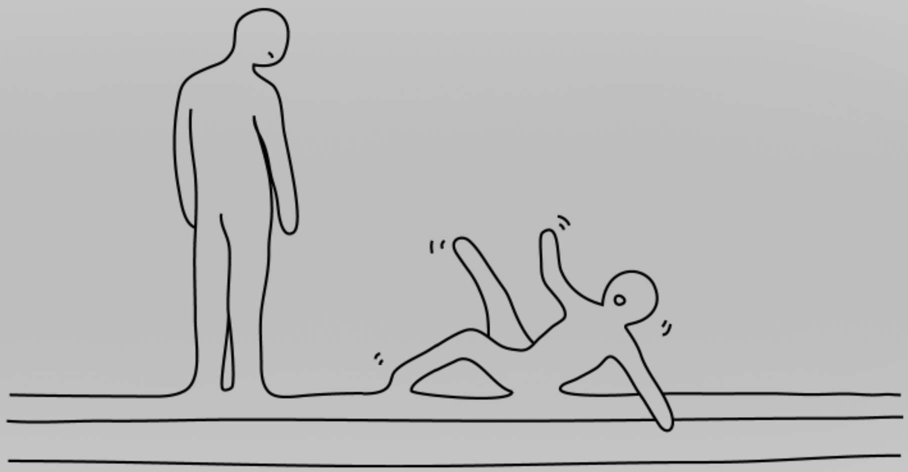
# Nederlandse samenvatting



## Hoofdstuk 1: Waar gaat dit boek over?

Het aantal mensen met verstandelijke beperkingen dat zorg nodig heeft in Nederland groeit. Deze mensen worden steeds ouder.

Als je ouder wordt kun je vaker vallen. Als je valt kun je gewond raken. Het is daarom beter niet te vallen.

Het is niet bekend waarom sommige mensen vallen en anderen niet.

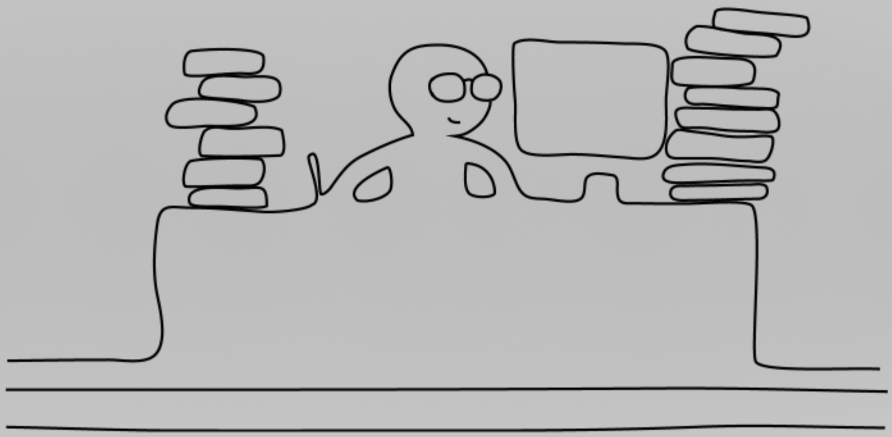
## Waarom hebben we dit boek geschreven?

We wilden graag weten waarom oudere mensen met verstandelijke beperkingen vallen. En ook wat je kunt doen om ervoor te zorgen dat zij minder vaak vallen.

We hebben ook onderzocht hoe goed het evenwicht van deze mensen is en hoe goed zij kunnen lopen. Bij ouderen zonder verstandelijke beperking blijkt een goed evenwicht heel belangrijk om niet te vallen.

## Wat staat er in de verschillende hoofdstukken?

- In hoofdstuk 1 staat algemene informatie over (oudere) mensen met verstandelijke beperkingen en hun gezondheid. Ook schrijven we daarin wat al bekend is over waarom deze mensen vallen.
- Hoofdstuk 2 en 3 beschrijven het evenwicht en lopen bij mensen met verstandelijke beperkingen.
- In hoofdstuk 4 en 5 beschrijven we hoe vaak en waarom mensen met verstandelijke beperkingen vallen.
- In hoofdstuk 6 en 7 zijn we op zoek gegaan naar twee manieren om ervoor te zorgen dat oudere mensen met verstandelijke beperkingen minder vaak vallen.



## Hoofdstuk 2: Dit is al bekend over het evenwicht en lopen bij mensen met verstandelijke beperkingen

### Wat wilden wij weten?

Wat is er al door andere mensen geschreven over het evenwicht en lopen bij mensen met verstandelijke beperkingen?

### Wat hebben wij gedaan?

- We hebben gezocht in tijdschriften, boeken en op internet.
- We hebben een overzicht gegeven wat anderen gevonden hebben.
- We hebben gekeken hoe het evenwicht en lopen zich ontwikkelen tijdens het leven van mensen met verstandelijke beperkingen.

### Wat zijn wij te weten gekomen?

- Het evenwicht en lopen bij mensen met verstandelijk beperkingen is minder goed dan bij leeftijdsgenoten.
- Het evenwicht en lopen ontwikkelt zich in jonge jaren minder snel en wordt in latere jaren eerder slechter bij mensen met verstandelijke beperkingen dan bij leeftijdsgenoten.
- Er zijn nog veel onderwerpen waarover nog niet zo veel is geschreven bij mensen met verstandelijke beperkingen, zoals:
  - welke gevolgen hebben het minder goede evenwicht en lopen voor het risico om te vallen?
  - kunnen het evenwicht en lopen worden verbeterd door training?
  - als evenwicht en lopen verbeteren, vallen mensen dan ook minder vaak?

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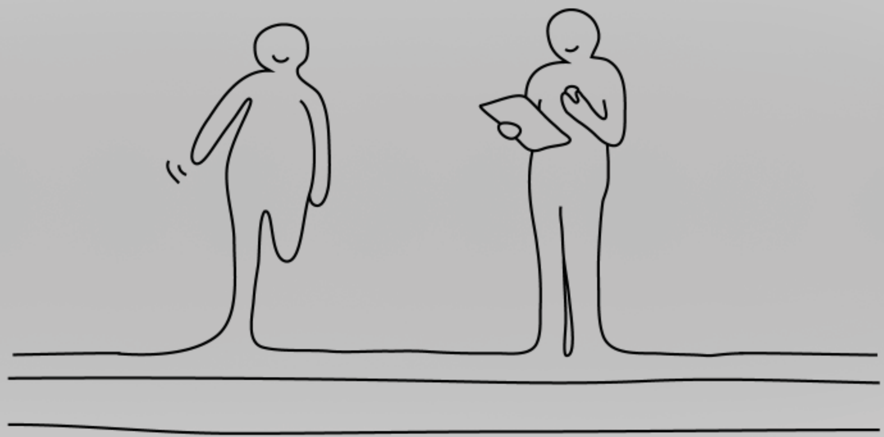


## Hoofdstuk 3: Testen van het evenwicht bij mensen met verstandelijke beperkingen

### Wat wilden wij weten?

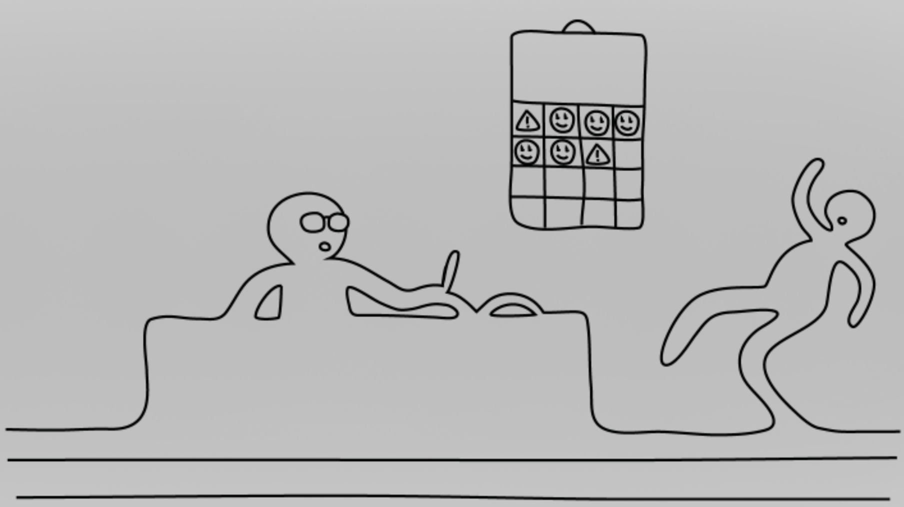
Hoe is het evenwicht van ouderen met verstandelijke beperkingen in vergelijking met leeftijdsgenoten?

### Wat hebben wij gedaan?

- We hebben verschillende testen gedaan om te kijken hoe goed het evenwicht is bij mensen met en zonder verstandelijke beperkingen.
- We hebben de volgende testen gebruikt;
  - Berg Balans Schaal (evenwicht)
  - Functional Reach (reiken)
  - Timed Up and Go (opstaan uit stoel en lopen)
  - Single Leg Stance (op één been staan)
  - 10-Meter Walking Test (10 meter lopen)
- Deze testen worden veel door fysiotherapeuten gebruikt. We hebben geen nieuwe testen gemaakt.
- We hebben de testen afgenomen bij 76 mensen met milde tot matige verstandelijke beperkingen en bij 20 mensen zonder verstandelijke beperkingen.
- Alle deelnemers waren 50 jaar of ouder.

### Wat zijn wij te weten gekomen?

- Testen die door fysiotherapeuten bij ouderen worden afgenomen kunnen ook worden afgenomen bij oudere mensen met milde tot matige verstandelijke beperkingen. Er hoeven dus geen nieuwe testen voor deze mensen te worden gemaakt.
- Mensen met verstandelijke beperkingen hebben een slechter evenwicht en lopen minder goed dan mensen zonder verstandelijke beperkingen.
- Hoe goed het evenwicht en lopen is bij mensen met verstandelijke beperkingen hangt af van de leeftijd, het aantal gezondheidsproblemen, de verhouding tussen lengte en gewicht (Body Mass Index: BMI), hoe stil iemand kan staan, en de angst om te vallen.



# Hoofdstuk 4: Vallen bij mensen met verstandelijke beperkingen

## Wat wilden wij weten?

- Hoe vaak en waar vallen mensen met verstandelijke beperkingen?
- Wat zijn de gevolgen van dit vallen?

## Wat hebben wij gedaan?

- Een jaar lang hebben 82 mensen met milde tot matige verstandelijke beperkingen van 50 jaar of ouder bijgehouden of ze vielen.
- Dit deden ze met een valkalender.
- Iedere dag plakten zij een sticker op de kalender.
    - Een gele  als ze niet waren gevallen.
    - Een rode  als ze wel waren gevallen.
- Ook schreven ze, samen met hun begeleider, in een weekboek op of ze gevallen waren.
- Als ze waren gevallen vulden ze nog in op een lijst wanneer, hoe, waar, en waarom ze waren gevallen en of ze zich pijn hadden gedaan.

## Wat zijn wij te weten gekomen?

- Oudere mensen met verstandelijke beperkingen vallen vaker dan andere ouderen.
- In totaal vielen 37 van de 82 deelnemers.
- Sommige mensen vielen maar één keer, terwijl anderen wel 6 keer in het jaar vielen.
- Deelnemers vielen gemiddeld één keer per persoon per jaar.
- Mensen vielen meestal als ze liepen in een bekende omgeving en vaak buiten.
- Een klein deel van de mensen die meededen had zich ernstig verwond, waarvan de helft een bot brak.
- De omstandigheden en de gevolgen van het vallen waren niet anders bij mensen met verstandelijke beperkingen dan bij andere ouderen.
- Bij mensen die vielen was er geen verschil tussen oud en jong of tussen man en vrouw.

# Hoofdstuk 5: Oorzaken voor vallen bij mensen met verstandelijke beperkingen

## Wat wilden wij weten?

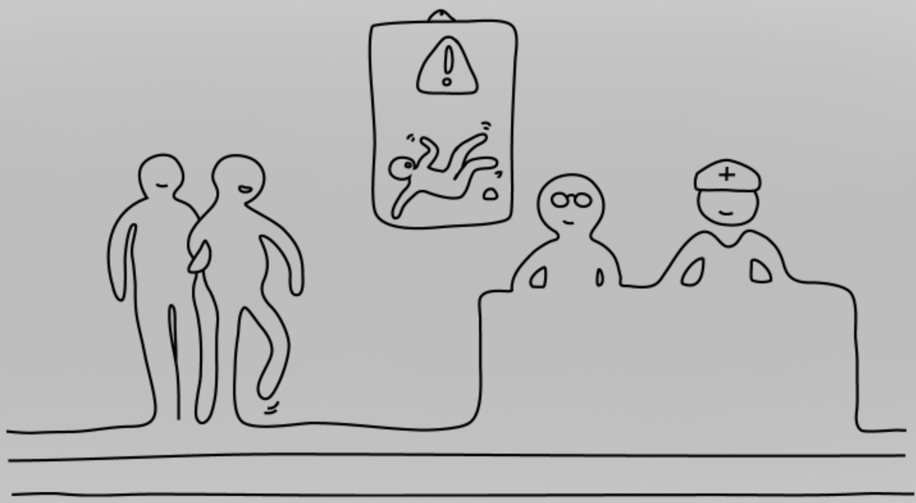
Waarom vallen mensen met verstandelijke beperkingen?

## Wat hebben wij gedaan?

- We hebben veel testen gedaan om bewegen, begrip, gedrag en gezondheid te meten.
- We hebben de testen afgenomen bij 78 mensen met milde tot matige verstandelijke beperkingen.
- Alle mensen die meededen waren 50 jaar of ouder.
- Hierna hebben de deelnemers een jaar lang bijgehouden of ze vielen.
- Dit deden ze met een valkalender, waarbij ze iedere dag een sticker plakten;
  - Een gele  als ze niet waren gevallen.
  - Een rode  als ze wel waren gevallen.

## Wat zijn wij te weten gekomen?

- Bijna de helft van de mensen die meededen vielen.
- Deelnemers vielen gemiddeld 1 keer per persoon per jaar.
- De kans om te vallen bleek groter als je een milde verstandelijke beperking hebt en heel actief bent.
- De kans om te vallen hing ook af van hyperactiviteit, hoe goed je kan afstemmen wat je ziet en wat je doet (bijvoorbeeld met natekenen), en aandacht.
- Daarnaast bepalen eigenschappen van de omgeving de kans om te vallen bij ouderen met milde tot matige verstandelijke beperkingen.



## Hoofdstuk 6: Het voorkómen van vallen door een valspreekuur

### Wat wilden wij weten?

Kunnen we door een valspreekuur vallen in de toekomst voorkómen bij mensen met verstandelijke beperkingen? Het valspreekuur is een onderzoek door arts en fysiotherapeut bij mensen die al eens zijn gevallen.

### Wat hebben wij gedaan?

- We hebben een handboek gemaakt met testen om de kans op vallen te onderzoeken.
- Ook hebben we in het handboek aangegeven wat je kunt doen om vallen te voorkómen.
- Dit handboek is gemaakt op basis van richtlijnen; wat er al eerder geschreven is en gesprekken met mensen die er veel van weten.
- Een arts en een fysiotherapeut hebben met het handboek 26 mensen onderzocht die waren gevallen.
- Daarna hebben de arts en de fysiotherapeut 50 behandelingen voorgeschreven. Bij sommige mensen die waren gevallen was geen behandeling nodig. De mensen die een behandeling kregen hadden één tot acht verschillende behandelingen nodig.
- We hebben aan artsen, fysiotherapeuten, verzorgers en mensen met een verstandelijke beperking gevraagd hoe zij het handboek en de werkwijze van het valspreekuur vonden.

### Wat zijn wij te weten gekomen?

- Iedereen vond het valspreekuur nuttig en goed te doen.
- Er zijn een paar aanpassingen aan het handboek gemaakt en er moet beter gecontroleerd worden of afspraken worden nagekomen.
- Iedereen was het er over eens dat bij mensen met verstandelijk beperkingen:
  - er meer tijd en aandacht nodig is om het risico op vallen te bepalen
  - verschillende behandelaars nodig zijn zoals een arts en fysiotherapeut
  - de behandeling om het vallen te voorkómen moet worden aangepast aan de persoon.

## Hoofdstuk 7: Het voorkómen van vallen door een hindernisbaan

### Wat wilden wij weten?

Kunnen we met een hindernisbaan vallen bij mensen met verstandelijke beperkingen voorkómen?

### Wat hebben wij gedaan?

- We hebben een training gegeven van 10 lessen met een hindernisbaan om evenwicht en lopen te oefenen.
- Deze training hebben 39 mensen met verstandelijke beperkingen gevolgd.
- Vooraf, halverwege, en achteraf hebben we gekeken hoe goed het evenwicht en lopen van de deelnemers was. Dit hebben we gedaan met de volgende testen:
    - Performance Oriented Mobility Assessment (test voor balans en lopen)
    - Timed Up and Go (opstaan uit stoel en lopen)
    - 10-Meter Walking Test (10 meter lopen)
- Ook hebben we onderzocht of mensen het jaar na de training minder vielen dan het jaar ervoor.

### Wat zijn wij te weten gekomen?

- Het aantal vallen verminderde zeer fors.
- Twee van de drie testen van evenwicht en lopen waren beter na de training dan ervoor.
- Bij deze groep mensen heeft de training met de hindernisbaan gezorgd dat mensen minder vielen en een beter evenwicht en lopen kregen.

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## Hoofdstuk 8: Alle hoofdstukken samen

## Wat zijn wij te weten gekomen in dit boek?

- Oudere mensen met milde tot matige verstandelijke beperkingen vallen vaker dan andere ouderen.
- Bij ouderen met milde tot matige verstandelijke beperkingen bepalen eigenschappen van de persoon én van de omgeving samen de kans om te vallen. Hoeveel ondersteuning mensen van hun omgeving krijgen is hierbij ook van belang.
- Mensen met een milde verstandelijke beperking vallen vaker dan mensen met een matige verstandelijke beperking. We denken dat dit komt doordat mensen met een milde verstandelijke beperking minder beschermd worden.
- Mensen met een verstandelijke beperking die actiever zijn vallen vaker, omdat zij vaker in een omstandigheid zijn waarin je kunt vallen.
- Testen die door fysiotherapeuten bij ouderen worden afgenomen kunnen ook worden gebruikt bij mensen met milde tot matige verstandelijke beperkingen. Er hoeven dus geen nieuwe testen voor deze mensen te worden gemaakt.
- Vallen bij mensen met verstandelijke beperkingen kunnen worden voorkómen door training met een hindernisbaan. We moeten nog uitzoeken welke mensen hiervoor het meest geschikt zijn.

## Wat is er goed gegaan en wat kan beter?

- We hebben veel testen gedaan bij mensen met verstandelijke beperkingen. Daarna hebben zij samen met hun begeleiders een jaar lang bijgehouden of ze vielen. Wanneer je later aan mensen vraagt of ze zijn gevallen, kunnen ze dit vergeten zijn. Dit gebeurt niet wanneer ze bij iedere val meteen een sticker plakken.
- We hebben testen afgenomen in een vertrouwde omgeving. Hierdoor hoefden de mensen die meededen niet zo ver te reizen en voelden ze zich beter op hun gemak.
- Niet alle testen konden goed worden afgenomen. Vooral de testen van het begrip waren moeilijk.
- We hebben alleen mensen van 50 jaar en ouder met milde en matige verstandelijke beperkingen die zelf konden lopen mee laten doen aan ons onderzoek.
- We hebben voor het onderzoek hulp gekregen van zorgverleners, waardoor we het onderzoek makkelijker en beter konden doen.
- We hebben de kans om te vallen bij oudere mensen met verstandelijke beperkingen beter kunnen verklaren, maar we weten nog lang niet alles.

## Hoe nu verder?

- Het is belangrijk dat er meer aandacht is voor vallen bij (oudere) mensen met verstandelijke beperkingen.
- Het zou goed zijn wanneer ouderen met verstandelijke beperkingen vroeg genoeg onderzocht worden op het risico om te vallen. Er kan dan mogelijk wat gedaan worden om het vallen te voorkómen.
- Het vallen bij mensen met verstandelijke beperkingen moet door verschillende zorgverleners samen worden onderzocht, omdat verschillende eigenschappen ervoor zorgen dat iemand valt.
- Welke behandeling iemand krijgt om het vallen te voorkómen zal per persoon moeten worden bekeken. Dezelfde behandeling zal niet bij iedereen helpen.

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# List of publications
# Dankwoord
# Curriculum Vitae

# List of publications

**Enkelaar L**, Smulders E, van Schrojenstein Lantman-de Valk H, Weerdesteyn V, Geurts ACH. Prospective study on risk factors for falling in elderly persons with mild to moderate intellectual disabilities. *Research in Developmental Disabilities*. 2013 Nov; 34(11):3754-3765.

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# Dankwoord

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## Curriculum Vitae

Lotte Enkelaar was born on April 14, 1980 in Wageningen, the Netherlands. After finishing secondary school (VWO) at the "Regionale Scholengemeenschap Pantarijn" in Wageningen, she started studying Health Science at the University of Maastricht. Her major program was Human Movement Science. Lotte became interested in the direct care to patients and therefore additionally studied Physical Therapy at the Hogeschool Zuyd in Heerlen.

During her education Lotte did an internship at the Rehabilitation Centre "De Hoogstraat" in Utrecht, where she performed a study on two measurement-scales to determine the motor functioning of young children with cerebral palsy. After her graduation for both studies in 2005 she got the opportunity to continue her work at the Rehabilitation Centre as a junior researcher. She was involved in two projects regarding longitudinal cohort studies of children with cerebral palsy, aged 0-5 and 5-9 years. In 2007 she started her PhD-project on falls in persons with Intellectual Disabilities (ID) at the Department of Rehabilitation of the Radboud University Nijmegen Medical Centre. The results of her PhD project are described in this thesis.

Last year Lotte has also been working as a project manager at the Department of Primary and Community Health Care of the Radboud University Nijmegen Medical Centre. This implementation project concerned translation of research results to persons with ID and their caregivers. Lotte is assistant Clinical Director FunFitness of the Special Olympics in the Netherlands. Furthermore, she is a member of the organizing committee of the yearly congress of the Dutch association of Physical Therapists for persons with ID (Nederlandse Vereniging van Fysiotherapeuten voor Verstandelijk Gehandicapten, NVFVG).

Currently Lotte works as a Physical Therapist at Bartimeus, a service provider for persons with visual and intellectual disabilities. In the future she hopes to combine her clinical work with research to ultimately improve the care for persons with ID.

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