Physical fitness and performance of daily activities in persons with intellectual disabilities and visual impairment
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Chapter 1

General introduction
Chapter 1

Outline of the Introduction

Sufficient physical fitness and physical activity are important for good health, general well-being, participation, and quality of life. However, for persons with (severe or profound) intellectual and visual disabilities (SP)IVD, sufficient exercise is not self-evident due to the combination of these limitations. This may reduce their ability to perform activities of daily living (ADL) and increase the risk of developing health problems. Therefore, it is important to gain insight into the level of the physical fitness of these persons. However, measuring physical fitness in persons with intellectual disabilities (ID) and, in particular, in persons with (SP)IVD is problematic due to their limited cognitive abilities, visual impairment, motor skills, and comorbidities; fitness tests that are developed for the general population cannot easily be applied to persons with ID or (SP)IVD. Therefore, the first steps have been taken to measure and map physical fitness of persons with SPIVD.

This introduction describes the characteristics of persons with SPIVD and their visual impairment as well as their locomotor skills. Furthermore, the conditions for and the actual ADL-performance and participation as well as aging and frailty in persons with (SP)IVD are displayed. Finally, the outline of the thesis is presented.
**Intellectual Disabilities**

In general, an individual’s intellectual level affects adaptive behavior. This is expressed in conceptual, social, and practical skills as well as in the ability to make self-determined choices. Individuals with an Intelligence Quotient (IQ) below 70 are defined as having a form of intellectual disability (ID). Four levels of ID are distinguished: mild, moderate, severe, and profound. These levels with the corresponding IQ and intellectual age are displayed in Box 1. Persons with ID have significant limitations regarding conceptual, social, and practical skills. The consequence may be that many opportunities that are available for the general population to participate in are not available for persons with ID. Especially persons with severe and profound ID require continuous support; are severely limited in self-care, continence, communication and mobility; and generally live in intramural institutions. According to the World Health Organization (WHO), approximately 1% of the European population has an ID. The prevalence of moderate to profound ID is almost 0.3-0.4% of the general population; this percentage is increasing probably due to the increasing life expectancy.

**Visual Impairments**

Visual ability is important for eye-hand coordination, neuromuscular function, and locomotor skills. These are essential for daily functioning. In individuals with ID, the prevalence of visual impairment and blindness is considerably higher compared to the general population. The severity of visual impairments is related to the severity of ID. That is, the prevalence of visual

<table>
<thead>
<tr>
<th>Classification</th>
<th>Light perception</th>
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<tr>
<td>Normal vision</td>
<td>0.8 - 1.2</td>
</tr>
<tr>
<td>Slightly limited sighted</td>
<td>0.3 - 0.8</td>
</tr>
<tr>
<td>Partially sighted</td>
<td>0.12 - 0.3</td>
</tr>
<tr>
<td>Severely partially sighted</td>
<td>0.05 - 0.12</td>
</tr>
<tr>
<td>Socially blind</td>
<td>0.02 - 0.05</td>
</tr>
<tr>
<td>Blind</td>
<td>&lt; 0.02</td>
</tr>
<tr>
<td>Totally blind</td>
<td>None</td>
</tr>
</tbody>
</table>

**Motor Skills**

<table>
<thead>
<tr>
<th>GMFCS</th>
<th>Limitations in</th>
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<tr>
<td>Level 1</td>
<td>Gross motor skills</td>
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<td>Level 2</td>
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<td>Level 5</td>
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</tbody>
</table>
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Impairments in persons with severe or profound ID is 92%. Therefore, persons with both visual impairment and intellectual disabilities are particularly at risk for experiencing limitations regarding ADL-functioning. The classification of visual impairment is further specified by visual acuity, field of view, and light perception. Most definitions are based on both visual acuity and visual field. A visual acuity of 0.1 (6/60) means the ability to see objects is at a six meter distance whereas a normal eye can see at a 60 meter distance. Normal vision is described as 1 (6/6) and a normal visual field is 160°-170° degrees horizontally. If the visual field is less than 30° around the central vision, it usually leads to significant limitations in visual functioning. Visual impairment is defined as a visual acuity between 0.05 (3/60) and 0.3 (6/18) in the best eye with available correction such as a lens or glasses and/or a field of view less than 30° but more than 10° around the central axis. Blindness is defined as visual acuity less than 0.05 (3/60) in the best eye after correction with a lens or glasses and/or a field of view of 10° or less around the central axis. If the visual acuity is good, there may still be a (severe) limitation in the field of vision (e.g., tunnel vision). A field of view less than 10% is classified as (social) blindness. Rehabilitation or specialized care is indicated if there is a request for help and the visual acuity (best corrected) is <0.3 (6/18) (<0.25) or with a visual field of less than 30 degrees. Box 1 displays the generally used classifications of visual impairments. The estimated number of adults with SPIVD in the Netherlands varies between 10,000 and 15,000 which corresponds to approximately 0.05-0.08% of the Dutch population. These adults have an IQ of less than 35 and visual acuity of less than 0.3 (6/18).16

Motor Skills

Individuals with SPIVD often have limited motor skills, and approximately 65% of this group has locomotor disabilities. To gain insight into the locomotor skills of persons with SPIVD, the Gross Motor Function Classification System (GMFCS) is generally used. The GMFCS is a five-level system that classifies the severity of motor disabilities in persons with intellectual and physical disabilities. Persons classified at Level 1 can generally walk without restrictions but tend to have limitations in more advanced motor skills such as running and jumping. Persons with a Level 2 classification can walk with slight restrictions and do not spontaneously increase their speed during walking. They
have limitations while walking in their daily living environment and outdoors. Persons with GMFCS Level 3 can walk with the help of walking devices but are limited in walking in their living environment and outdoors. Those with GMFCS Level 4 are able to propel themselves with limitations but must be transported outdoors or in the living environment. To be able to continue independently, an electric wheelchair may be used. Finally, for persons classified at Level 5, propulsion is seriously impeded despite the use of resources.\textsuperscript{18,19} The GMFCS levels and the corresponding limitations are depicted in Box 1. This thesis is primarily focused on persons with SPIVD who are classified at GMFCS Levels 1 or 2, thus persons who are able to walk without devices.

\textbf{Conditions for ADL-performance and Participation}

Important conditions for performing daily activities are muscle strength, muscle endurance, flexibility, cardiorespiratory fitness, and body composition.\textsuperscript{20} Individuals with low abilities for these are at risk for developing medical problems, chronic diseases, and all-cause mortality.\textsuperscript{1,20-22} For persons with SPIVD and GMFCS Level 1 and those with Level 2, the recommended components for measuring physical fitness are body composition, cardiorespiratory fitness, muscle strength, and balance.\textsuperscript{2} It was ascertained that older adults with ID have poor balance, muscle strength, and endurance as well as slow gait speed.\textsuperscript{23,24} Persons with visual impairments generally have decreased balance.\textsuperscript{11,25} This also applies to individuals with ID who exhibit decreased balance during both standing and walking\textsuperscript{26} and consequently have an increased risk factor for falling.\textsuperscript{27-32} Especially ambulatory living persons with ID are more at risk of falling,\textsuperscript{29,33} which manifests primarily during walking.\textsuperscript{34,35} For individuals with ID, fall incidents occur more indoors in a familiar environment than outdoors.\textsuperscript{36} Poor mobility\textsuperscript{28,37} and inactivity are associated with a higher risk for falling\textsuperscript{38} as well as (among others) decreased balance,\textsuperscript{37} low gait speed,\textsuperscript{39} intellectual disabilities, visual impairments, polypharmacy,\textsuperscript{27,28,40} decreased ADL functioning,\textsuperscript{28} decreased muscle strength, and endurance.\textsuperscript{37} As with older adults whereby fall incidents are a significant cause of morbidity and mortality,\textsuperscript{41} individuals with ID have a high incidence of falls and fall-related injuries,\textsuperscript{29-32} and the degree of hospitalization due to an injury that is mostly caused by falls is twice as high compared to the general population.\textsuperscript{32}
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It is important to identify persons who are particularly at risk for falls in order to be able to develop and implement interventions designed to improve balance and to decrease fall risk. To assess balance and risk for falling, the Berg Balance Scale (BBS) is an applicable instrument for the general population as well as for adults with ID.\textsuperscript{42-44} However, for individuals with SPIVD, the BBS was not feasible because a number of tasks appears to be too difficult to execute.\textsuperscript{45} Therefore, the BBS was recently adapted into the modified Berg Balance Scale (mBBS).\textsuperscript{45} For individuals with severe intellectual and visual disabilities (SIVD), the mBBS appeared to be a feasible and reliable measurement method.\textsuperscript{45} However, since it is adapted specifically for persons with SIVD, it is not possible to compare outcomes with other populations.\textsuperscript{45} Furthermore, the concurrent validity and the predictive validity of the mBBS in individuals with ID and visual impairment has not yet been established.

Gait speed is a predictor of locomotor disabilities, ADL functioning, falls, health-related institutionalization, and hospitalization for older adults in general.\textsuperscript{39} According to the ‘Health, Aging and Body composition study’ (Health ABC), individuals with a gait speed lower than one meter per second have low gait speed.\textsuperscript{39} The speed of one meter per second is determined as the cut-off point for predicting short-term mortality.\textsuperscript{39} Balance, gait speed, and muscle strength can be improved with an intervention program for individuals with ID, which also decreases fall rate and fall related injuries.\textsuperscript{46,47}

For ambulatory activities such as rising from a chair, walking at an appropriate speed, and climbing stairs, a sufficient leg strength is needed.\textsuperscript{48} Loss of muscle strength influences these activities in daily living (ADL)\textsuperscript{49} and health-related quality of life.\textsuperscript{50} Moreover, weakness of the Quadriceps muscles is a predictor of mortality\textsuperscript{51} as it is one of the first muscles that degenerates due to inactivity.\textsuperscript{52} Individuals with ID have less muscle strength compared to persons without ID.\textsuperscript{53} Being less physically active appears to be one of the most important factors for lower voluntary activation levels in persons with ID.\textsuperscript{54} Their lower muscle strength seems to be related to a central nervous system failure to activate motor units and to some abnormal intrinsic muscle properties.\textsuperscript{54} Therefore, it is expected that individuals with SPIVD have less muscle strength as well. From previous studies, it is known that persons with SPIVD have low physical fitness levels, such as cardiorespiratory fitness, compared to persons with ID,\textsuperscript{2,23} however, until
now, it was not possible to actually measure the muscle strength of persons with SPIVD because a feasible and reliable measurement instrument for this is not available.

Improvement of muscle strength is related to positive changes in functional activities for adults with Down Syndrome and in work-related skills of individuals with intellectual disabilities. For persons with ID and Down Syndrome, positive effects on physical fitness have been achieved with exercise programs. In addition, improvement of muscle strength and endurance can be achieved with progressive resistance training in individuals with Down Syndrome. However, until now, it is unknown whether such exercise programs aimed at improving muscle strength are applicable for individuals with SPIVD.

Individuals with ID have additional comorbidities twice as often compared to the general population and are of increased risk of getting health problems such as diabetes, high blood pressure, low physical fitness, and obesity. These increased health risks are partly due to a lack of physical activity. Both physical inactivity and increased BMI are risk factors for the onset of cardiovascular diseases. In addition, waist circumference as an indicator of abdominal fat is also an important predictor of cardiovascular health risks and type 2 diabetes. Furthermore, a higher BMI is related to reduced balance and postural stability. Low cardiorespiratory fitness is an important risk factor for cardiovascular diseases and mortality. Due to chronotropic incompetence and physical inactivity, persons with ID have low cardiorespiratory fitness levels. These lower levels begin at a young age and decrease further due to the process of aging. Another determining factor for low cardiorespiratory fitness levels in persons with ID is the muscle strength of the lower limbs. Individuals with ID have low physical fitness levels over their lifetime, and persons with severe or profound ID both with or without a visual disability have even lower physical fitness levels. Their degree of dependency increases with older age.

**ADL-performance and Participation**

Participation in society is an important aspect of the quality of life. It is defined as ‘involvement in a life situation’ in which a higher degree of participation is related to a contributory attitude of the social environment. Persons with severe ID are at risk of
impaired participation.\textsuperscript{80,81} The WHO International Classification of Functioning, Disability and Health (ICF) describes the relation between body functions and structures as well as activities and participation.\textsuperscript{4} The ICF-framework for individuals with SPIVD with GMFCS Levels 1, 2, and 3 is specified in Figure 1. According to the framework, intellectual level, visual ability, and physical fitness components such as balance, strength, cardiorespiratory fitness, and body composition belong to ‘body functions and structures’. These components are conditional for ‘activities’ such as understanding, visual functioning, transfers, standing, walking, stand-up, climbing stairs, and cycling which subsequently influence the degree of participation in self-care, work, daily activities, leisure activities, sports, family, and social functioning.

\textbf{Figure 1.} ICF Framework specified for individuals with SPIVD with GMFCS levels 1, 2, and 3.

Due to the combination of ID severity, visual impairment, and limitations of motor skills, persons with SPIVD are limited in undertaking daily activities such as living skills,
communication, initiative, and social skills.\textsuperscript{13} Because of their need for support, self-care
has a social context for persons with SPIVD, and therefore, this belongs to ‘participation’
\textsuperscript{82} rather than to ‘activities’ which is more common for the general population. For this
reason, self-care and daily activities are categorized under the heading ‘participation’ in
Figure 1 where active engagement and involvement in daily activities is considered an
important aspect of participation for persons with SPIVD.\textsuperscript{82} Furthermore, for this
population, the interdependencies between several concepts\textsuperscript{1,3} were integrated into an
adapted model, as shown in Figure 2.\textsuperscript{2} In this Figure, \textit{I} refers to the concept of Schalock
regarding the quality of life of persons with ID,\textsuperscript{3} and \textit{III} refers to the concept of Bouchard
concerning the relation between physical fitness, physical activity, and health.\textsuperscript{1}
Specifically, the mutual relation of the concepts quality of life, participation, physical well-
being, physical fitness, physical activity, and health are expressed in this figure.\textsuperscript{2} The
dotted arrows, however, indicate that the direct relation between physical activity /
physical fitness and participation in persons with SPIVD is currently unknown.\textsuperscript{2}

\textbf{Figure 2. Integration of models and concepts of \textit{I}: Schalock\textsuperscript{3} and \textit{III}: Bouchard,\textsuperscript{1}
expressing participation, quality of life, physical well-being, physical activity, physical
fitness, and health.}\textsuperscript{2}
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The ability to perform ADL is an operationalization of daily functioning for the general population as well as for persons with ID. ADL-functioning influences the required level of care and independence as well as the quality of life. For persons with ID, the degree of dependence is greater in addition to their often-reduced motor skills and mobility. Moreover, ADL-performance is important as a predictor for hospitalization and mortality. To measure the ability to perform ADL, the Barthel Index (BI) is a generally accepted instrument also for persons with ID. In addition, comfortable walking speed (CWS) is considered to be a reflection of the ability to perform ADL. Due to several combinations of disabilities, it is reasonable to expect that ADL-functioning and participation of persons with SPIVD is decreased compared to persons with ID without visual impairment. However, until now, no knowledge is available concerning the impact of visual impairment on ADL performance of persons with ID.

Aging and Frailty

The proportion of aging individuals with ID is increasing steadily within the population with ID. Furthermore, the life expectancy of persons with ID is increasing and is approaching that of the general population which is the result of improved quality of residential and health care. Although individuals with ID reach a higher age, it has long been a common understanding to classify them as “old” after 50 years of age due to the early onset of functional decline. Also, frailty appears to be more prevalent and more severe in relatively young individuals with ID compared to the general population which may affect the quality of life with aging. In the context of healthy aging, it is important to obtain suitable and feasible measuring instruments to measure these domains throughout the years in individuals with SPIVD. However, no data are available for these persons about trends in time with regard to aging and whether early signs of aging also apply to this group.

Content of the thesis and research questions

This thesis aims to obtain further insight into the validity and predictive value of the modified Berg Balance Scale (mBBS) and the feasibility and reliability of muscle strength measurements in order to measure balance and muscle strength and to improve or
maintain physical fitness and ADL-functioning in persons with SPIVD. With these measurement instruments, risk groups can be identified, physical fitness as the basis for ADL-functioning can be mapped, the level of required care can be determined, and intervention programs aimed at optimizing muscle function as conditions for ADL-functioning and participation can be developed, implemented, and evaluated.

ADL-functioning and participation influence the quality of life\(^3,85\) in which ADL performance is an important measure for the required level of care of persons with SPIVD.\(^85\) Therefore, it is important that the influence of a visual impairment on the ability to perform ADL is investigated. The impact and the degree of ADL-functioning of additional visual impairment on persons with severe or profound intellectual disabilities is examined in Chapter 2.

The modified Berg Balance Scale (mBBS) has been proven to be feasible and reliable for individuals with SIVD.\(^45\) However, the validity of the mBBS is currently unknown.\(^45\) It is of interest to examine the validity of the mBBS for persons with SIVD as both persons with ID and those with visual impairment exhibit decreased balance.\(^11,25,26\) Moreover, for persons with ID, these visual deficits are identified as a potential risk factor for falling.\(^31\) Therefore, it is important to investigate the concurrent criterion as well as predictive validity of the mBBS in individuals with SIVD in order to gain additional insight into the relationship between balance, mobility, ADL performance, and prevalence of falls in persons with SIVD (Chapter 3).

Due to improved care, life expectancy increases for individuals with ID.\(^89,95\) To gain insight into the process of aging in individuals with SPIVD with respect to physical fitness, it is necessary to monitor their physical fitness during aging. By measuring individuals with SPIVD over a period of several years with regard to body composition and physical fitness levels, insight can be gained into their physical fitness during aging (Chapter 4).

Muscle strength contributes to mobility which more generally affects quality of life\(^96\) whereas the strength of the lower limbs is more specifically important for ambulatory activities.\(^48\) Loss of muscle strength may lead to a decrease in daily activities\(^49\) and worse health-related quality of life.\(^50,97\) Furthermore, Quadriceps weakness is a predictor of mortality\(^61\) since it is among the first muscles to degenerate due to inactivity.\(^52\) Persons with ID have low muscle strength, in particular of the m. Quadriceps,\(^98-100\) and it is reasonable to expect that individuals with SPIVD also experience this. However, it is
unclear whether current measurement instruments are applicable for this group. Therefore, it is important to obtain a feasible and reliable measurement instrument for Quadriceps strength in persons with SPIVD (Chapter 5).

Improvement in muscle strength has been positively associated with changes in functional activities in adults with Down Syndrome\textsuperscript{47,55} and in work-related skills in persons with ID.\textsuperscript{56} A threshold for Quadriceps strength concerning common tasks in daily life was determined\textsuperscript{101} in which higher force production is associated with better functional performance in the general population\textsuperscript{102,103} as well as in persons with ID.\textsuperscript{53,104} Therefore, it is important to investigate the possibilities of improving Quadriceps strength in individuals with SPIVD. Progressive resistance training (PRT) was found to be safe to apply to persons with a range of health conditions and disabilities.\textsuperscript{105} Several studies found that PRT can improve upper-limb and lower limb muscle endurance as well as strength in individuals with Down Syndrome.\textsuperscript{59-61} However, for individuals with SPIVD, current knowledge of the effects of implementing PRT is limited. Therefore, it is important to gain insight into the feasibility as well as the effect of a PRT program of the Quadriceps muscles in persons with SPIVD (Chapter 6).
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Progressive resistance training (PRT) was found to be safe to apply to persons with a range of health conditions and disabilities.\(^105\) Several studies found that PRT can improve upper-limb and lower limb muscle endurance as well as strength in individuals with Down Syndrome.\(^59\)-\(^61\) However, for individuals with SPIVD, current knowledge of the effects of implementing PRT is limited. Therefore, it is important to gain insight into the feasibility as well as the effect of a PRT program of the Quadriceps muscles in persons with SPIVD (Chapter 6).

References


Chapter 1


Chapter 1


Chapter 1


Chapter 2

The impact of visual impairment on the ability to perform Activities of Daily Living for persons with severe/profound intellectual disability

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