Measuring physical fitness in persons with severe or profound intellectual and multiple disabilities
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Chapter 1

Introduction
Outline of the introduction

The introduction describes the characteristics of persons with severe or profound intellectual disabilities (ID), as well as the consequences in functioning of additional visual impairments. Firstly, this introduction exposes the various health threats associated with severe or profound ID and/or visual impairments. Next, an examination of the theoretical framework of this thesis is put forward. Finally, both the research questions and the outline of the thesis will be briefly described.

Intellectual disabilities

Persons with ID have significant limitations in both intellectual functioning and adaptive behaviour as expressed in conceptual, social, and practical skills [1]. Intellectual disability is a condition that affects people’s ability to make self-determined choices. In addition, people with intellectual disabilities are in danger of being excluded from many situations and opportunities usually available to people not suffering from ID [1]. Based on the WHO population prevalence estimate, the prevalence of ID in the population of Europe is about 1% [2].

The ICD-10 (World Health Organization, WHO) [3] distinguishes four levels of ID: mild (IQ 50-69), moderate (IQ 35-49), severe (IQ 20-34) or profound (IQ under 20). Adults with severe ID have an intellectual age from 3 to 6 years, which is likely to result in a continuous need for support. Adults with profound ID have an intellectual age below 3 years, which results in serious limitations in self-care, continence, communication and mobility [3].

Intellectual disabilities and visual impairment

In all subgroups with ID, prevalence of visual impairment and blindness are significantly higher, compared to the general Dutch population [4]. The severity of the visual impairment is related to the severity of ID. Moreover, prevalence of visual impairments in persons with severe or profound ID is 92% [5]. As the combination of ID and visual impairment is even more detrimental, thereby creating less opportunity for compensation [6], the combination of visual impairment with ID aggravates problems in daily functioning [7].

Health threats associated with ID and/or visual impairments

Research has shown individuals with ID to have twice as much health problems and significantly higher levels of co-morbidity when compared to the general population [8]. As an example, prevalence of neurological problems in persons with ID is 15%, versus 5% in the general population [8]. Moreover, 75% of the persons with severe or profound ID also suffer from locomotor disabilities [9], while adults with mild or moderate ID score significantly lower than a control group without ID on all sensorimotor tests [10]. Also, Shinkfield et al. [11] reported that individuals with mild or moderate ID display inadequacies both in perception as in motor-reproduction.

In addition, those classified with ID are more prone to experience lifestyle related diseases such as diabetes mellitus II or cardiovascular diseases [8, 12, 13]. These persons often suffer from overweight [14, 15, 16] or malnutrition [17]. Obesity in women and underweight in both men and women are also known to be more common in adults with ID than in the general population [12]. Furthermore, Mc Guire et al. [13] found that 68% of their ID sample was overweight or obese. In the Netherlands, over 40% of adults with an intellectual disability were shown to have
overweight [15]. This prevalence is similar to that in other countries [14, 16]. Moreover, persons with ID are often not sufficiently active to achieve health benefits [14, 16, 18, 19], and more than 50% of the persons with ID of all age categories in Europe have a sedentary lifestyle [20]. As a consequence, these persons may have poor physical fitness [14, 16].

Similar to individuals with ID, persons with visual impairments display poor performance on locomotor skills [21] and have low levels of habitual activity [22], resulting in poor physical fitness when compared to the control group, in this case persons with normal eyesight [23, 24]. Furthermore, persons displaying a combination of severe or profound intellectual disability and a visual impairment are particularly at risk to develop deficits in both locomotor skills as in daily functioning [7]. The combination of these findings puts forward the suggestion that persons having severe or profound intellectual and visual disabilities are likely to display insufficient physical fitness.

**Terminology relating to persons with severe or profound ID**

A wide range of terms is being used to describe persons having a combination of severe or profound intellectual and additional disabilities. The persons studied in this thesis have severe or profound intellectual as well as visual disabilities. In general, the study population is referred to as persons with severe or profound intellectual and multiple disabilities (SPIMD). In the studies examining a population consisting in majority of persons with severe intellectual disabilities, the term severe intellectual and multiple disabilities (SIMD) is used. In the studies examining a population consisting in majority of persons with profound intellectual disabilities, the term profound intellectual and multiple disabilities (PIMD) is used. The term ‘multiple’ indicates locomotor disabilities, neurological problems, sensory disabilities, and/or problems with food ingestion.

As locomotor skills may influence protocols for measuring physical fitness, it is useful to classify persons with severe or profound ID according to their locomotor skills. The Gross Motor Function Classification System (GMFCS) [25] is a five-level system used to classify the locomotor skills of people with physical disabilities and is also applicable for persons with ID. Participants with a “Level I” classification can generally walk without restrictions but tend to have limitations in some more advanced motor skills. Participants with a “Level II” classification can walk with slight restrictions and do not spontaneously increase their speed during walking. Participants with a “Level III” are only able to walk with walking devices and have restrictions in walking outside as well as in their living environment. Participants with a “Level IV” have limited mobility, but might be able to stand during transfers. Usually they use a wheelchair, which they may drive themselves by hand or by assistive technology. Participants with a “Level V” classification generally have very limited mobility, even with the use of assistive technology. These participants always use a wheelchair.

It is often assumed that persons with profound ID automatically have low locomotor levels and are not able to walk. However, the ability to walk varies considerably in persons with severe ID as well as in persons with profound ID. For example, 75 percent of persons with severe ID is able to walk at least with walking devices (GMFCS I-III), whereas 25 percent is not able to walk (GMFCS IV-V). Moreover, 56 percent of persons with profound ID is able to walk at least with walking devices (GMFCS I-III), whereas 44 percent is not able to walk (GMFCS IV-V). Thus, contrary to common beliefs, it is necessary to perform research in persons with severe or profound ID yet ranging in GMFCS levels from I to V.
Physical fitness and persons with both severe or profound ID and visual impairment

As a sufficient physical fitness level and physical activity improve health [26], and sufficient health in turn improves well-being and quality of life [27, 28, 29], it is imperative to gain comprehensive insight into the physical fitness of persons with SPIMD. However, the feasibility and reliability of physical fitness measurements and tests in participants with SPIMD have until now not been properly scrutinized, resulting in little reliable knowledge on the physical fitness levels and locomotor skills of persons with SPIMD.

Due to limitations both in intellectual functioning as in adaptive behaviour related to SPIMD, the level of health-related physical fitness is difficult to quantify in a feasible and reliable manner [1]. Therefore, improving feasibility of physical fitness tests in persons with SPIMD needs to be prioritized. Persons with SPIMD are not accustomed to the assessments, have difficulty comprehending what is required of them [30] and often cannot understand instructions [3]. Furthermore, persons with visual disabilities cannot see how test tasks need to be performed [4], hence showing them how to perform the task at hand is useless. In general, if a participant does not understand the tasks within a certain test, the test will automatically fail to provide a realistic impression of the capabilities of the participant, rendering the test invalid. Thus, test instructions for persons with SPIMD require our special focus.

Other factors of influence when determining the feasibility, reliability and validity of physical fitness tests in persons with SPIMD are the prevalence of locomotor disabilities and motivational problems. Adapted test procedures and specific inclusion criteria are required because persons with intellectual, visual, and locomotor disabilities are not able to stand straight or to stand at all [31]. Also, persons with SPIMD are often not motivated to exert themselves fully, which necessitates adjustments to and familiarization with test protocols.

Since physical fitness is related to physical activity [26], it is important to gain insight into the physical activity level in persons with SPIMD. However, as almost 40 % of SPIMD population is simply not able to walk, walking fails to be an adequate representation of a person's overall activity level [32].

Moreover, the presumed low levels of activity in persons with such profound disabilities are often not accurately presented by measurement devices, like activity monitors, which are relatively insensitive [32]. Heart rate monitoring may be an indicator of activity levels assuming a relationship between activity intensity and heart rate [33, 34]. Heart rate monitoring appears to be sufficiently valid for creating broad physical activity categories (e.g. highly active, somewhat active, sedentary) [35]. However, a proper method for dating heart rate patterns in persons with PIMD, as well as the proper correlation between heart rate monitoring and activity levels for this specific group have so far not been examined.
Theoretical framework of the study

International Classification of Functioning, Disability and Health

Physical fitness is related to health [26] which in turn is related to participation [36]. Since participation for persons with ID is important, it is necessary to describe the relation between health and participation for this specific group as well [6].

The International Classification of Functioning, Disability and Health [36] is a commonly used model for various target groups in the field of health care. The concept of participation is defined within the framework of the ICF [3]. Kiestra [6] described participation in persons with a profound intellectual and visual disability as the extent to which someone can take part in or has influence on situations and contexts that are important to him or her, or are considered to be important to him or her by his or her representative or personal coach. This includes situations such as living habits, daily activities, leisure activities, recreation, sports, etc. The level of participation is linked to the abilities of performing the activities in question. In figure 1 the physical fitness components and their related activities are integrated into the model of the ICF to show their relation.

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**Figure 1.** ICF model with physical fitness components and their related activities.
Health, physical fitness, physical activity and quality of life

Several models and concepts have been developed to describe quality of life, participation, physical well-being, physical fitness, physical activity, health and their mutual relatedness. To illustrate the connections between these concepts, a combination of three models is made, which is shown in Figure 2.

Figure 2. Integration of models and concepts of participation, quality of life, physical well-being, physical activity, physical fitness, and health [1, 26, 27, 28, 29]. I. refers to the description of the model of Shalock in the text; and III refers to the model of Bouchard in the text.

I. First, Schalock et al. [1] provided a concept of quality of life within the international field of intellectual disabilities. Most quality of life concepts share the following common features: general feelings of well-being, feelings of positive social involvement, and opportunities to achieve personal potential [1]. In this model, physical well-being is incorporated as one of the seven domains that contribute to quality of life. Furthermore, quality of life is considered to be an outcome measure of participation [36].

II. Second, we incorporated the following statement into the model: sufficient health improves well-being and quality of life as well [27, 28, 29].

III. The third part of our model reflects the Toronto model, which describes the relation between physical fitness, physical activity and health. Both sufficient physical fitness and physical activity improve health [26]. Physical activity is defined as any body movement produced by skeletal muscles that results in energy expenditure [37], while physical fitness is defined as the ability to perform physical activity, depending on a specific set of attributes that people have or achieve (The American College of Sports Medicine, ACSM) [38]. However, only physical activity which reveals heart rates of more than 55% of the heart rate reserve during 5 days in a week, may gain profit for physical fitness [39]. Health is defined as a state of complete physical, mental and social well-being, and is a positive concept emphasizing social and personal resources, as well as physical capacities [40]. As far as we know, the direct relation between physical activity / physical fitness and participation in persons with SPIMD is still unknown, as indicated by the dotted line.
Components of physical fitness

The attributes of physical fitness can be defined differently for different target groups [U.S. Centers for Disease Control and Prevention] and therefore, physical fitness for persons with SPIMD needs to be described. Hilgenkamp et al. [42] stated that “physical fitness describes how “fit” a person physically is to cope with the demands set by his or her environment” and described physical fitness for older people with ID in a model (table 1) [U.S. Centers for Disease Control and Prevention; 26, 41, 42].

Based on this model, the required attributes of physical fitness for persons with SPIMD are described by caregivers, professionals and scientists in the field of SPIMD. Coordination, reaction time and muscle endurance are considered irrelevant attributes for individuals with such limited cognitive and physical skills.

Caregivers of persons with profound intellectual, visual and locomotor disabilities (profound intellectual and multiple disabilities, PIMD) often describe the quality of daily movements in terms of ‘flexibility’ or ‘stiffness’. Since muscular flexibility is one of the defined physical fitness components for persons with PIMD, muscle tonus or level of spasticity may be used as outcome measures to objectify the concepts of ‘flexibility’ and ‘stiffness’.

Hence, the required attributes of physical fitness for persons with SPIMD are body composition, cardiorespiratory fitness, balance, muscle strength and muscle flexibility (table 1).

Table 1. Model of components of physical fitness for older persons with ID [U.S. Centers for Disease Control and Prevention; 26, 41, 42].

<table>
<thead>
<tr>
<th>Health-related physical fitness</th>
<th>U.S. Centers for Disease Control and Prevention</th>
<th>Physical fitness of older adults with ID (Hilgenkamp et al. 2010)</th>
<th>Physical fitness of persons with PIMD</th>
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<tbody>
<tr>
<td>Motor</td>
<td>Coordination</td>
<td>Coordination</td>
<td>Balance</td>
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<td></td>
<td>Reaction time</td>
<td>Reaction time</td>
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<td>Balance</td>
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<td>Muscular</td>
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<td>Flexibility</td>
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<td>Cardiorespiratory</td>
<td>Cardiorespiratory fitness</td>
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<td>Morphological</td>
<td>Body composition</td>
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<td>Metabolic</td>
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Aims and research questions of this thesis

Until present, the feasibility and reliability of physical fitness measurements and tests for participants with SPIMD are unknown. Consequently, knowledge of the physical fitness levels and locomotor skills of persons with SPIMD is scarce. Yet, only with feasible and reliable tests the evaluation of a specific training intervention aimed at promoting physical fitness can be objectively established. The main aim of the research reported in this thesis is to examine the feasibility, the validity and the reliability of physical fitness tests in individuals with SPIMD.

This research addresses the following research questions:
1. Are body composition measurements in participants with SIMD and GMFCS levels I and II feasible and reliable? If so, what are the outcomes of the body composition measurements in these participants [chapter 2]?
2. Are waist circumference measurements in participants with PIMD and GMFCS levels IV and V valid and reliable [chapter 3]?
3. Are the 6 Minute Walking Distance (6MWD) and the adapted Shuttle Run Test (aSRT) in persons with SIMD and GMFCS levels I and II feasible and reliable [chapter 4]?
4. Are the feasibility, validity and test-retest reliability of the adapted Shuttle Run Test (aSRT) protocol performed on a treadmill for persons with SIMD and GMFCS level I sufficient [chapter 5]?
5. Is the modified Berg Balance Scale (mBBS) in persons with SIMD and GMFCS levels I and II feasible and reliable [chapter 6]?
6. Are the Modified Ashworth Scale (MAS) and the Modified Tardieu Scale (MTS) in persons with PIMD and GMFCS levels IV and V feasible and reliable [chapter 7]?
7. What is the level of physical activity of persons with PIMD based on heart rate patterns when compared to ACSM guidelines of healthy physical activity? Differ heart rate patterns according to group differences, days, time of day and is it possible to establish adherent classification in heart rate height and patterns? Is there a relation between heart rate patterns and observed level of activity in persons with PIMD? What is the influence of covariates such as gender, age, and common co-morbidity (motor disabilities, spasticity and sensory disabilities) on heart rate patterns [chapter 8]?

Outline of the thesis

Chapter 2 addresses the feasibility and the test-retest reliability of body composition measures in participants with SIMD. Anthropometric measurements are widely used to reliably quantify body composition and to estimate risks of overweight in both healthy subjects as in patients. However, information about the reliability of anthropometric measurements in participants with severe intellectual and visual disabilities is lacking.

Chapter 3 deals with the validity and reliability of measuring waist circumference in persons with PIMD. Waist circumference as an indicator of abdominal fat is an important predictor of health risks. It is unknown whether waist circumference can be measured validly and reliably when a participant is in a supine position. This assumption however is a critical one when international standards for healthy subjects are applied to persons with PIMD.

Chapter 4 seeks to address the cardiorespiratory component of physical fitness. Cardiorespiratory fitness can be divided into functional exercise and aerobic capacity [26].
Therefore, a study is put forward with the purpose of examining the feasibility and test-retest reliability of both the six-minute walking distance test (6MWD) as an adapted shuttle run test (aSRT) in persons with SIMD.

Chapter 5 examines the feasibility, validity and reliability of the adapted Shuttle Run Test performed on a treadmill, in persons with SIMD. Sufficient balance is necessary to perform daily activities. Chapter 6 discusses a study with the purpose of determining the feasibility and reliability of the modified Berg Balance Scale (mBBS) in persons with SIMD.

The Modified Ashworth Scale and the Modified Tardieu Scale Muscle examine muscle tonus or level of spasticity. The purpose of the study described in Chapter 7 was to determine the feasibility, the test-retest reliability and interrater reliability of the Modified Ashworth Scale and the Modified Tardieu Scale in persons with PIMD.

Reliably quantifying physical activity levels in persons with SPIMD is important, but also difficult in persons who are not able to walk. Heart rate monitoring may be an indicator of activity levels. Chapter 8 describes heart rate monitoring and heart rate patterns of persons with PIMD. Furthermore, this chapter examines the relative activity of persons with PIMD when compared to ACSM guidelines of healthy physical activity, as well as the correlation between heart rate patterns and level of activity for this specific target group. Finally, the influence of covariates such as gender, age, and common co-morbidity on heart rate height are examined and participants are classified according to heart rate height during physical activity.

Chapter 9 summarizes the main findings and puts them in perspective. Implications and recommendations for further research, methodological analyses and clinical practice are given.
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