Physical fitness and performance of daily activities in persons with intellectual disabilities and visual impairment
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General Discussion
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Summary and General discussion

General purpose of this study
Being physically fit and active is important for good health, well-being, and participation in and quality of life. However, this is not self-evident for persons with severe or profound intellectual and visual disabilities (SPIVD) due to the combination of these limitations. With the lack of sufficient physical activity, the risk of additional health problems is high. Due to their lower cognitive skills, visual impairments, limited motor skills, and comorbidity, measuring physical fitness in persons with SPIVD is problematic. Fitness tests developed for the general population cannot easily be applied to individuals with ID or SPIVD. Feasible, reliable, and valid measurement instruments for measuring physical fitness and interventions for improving physical fitness in persons with SPIVD are lacking.

The conducted studies provide insight into the impact of visual impairment on ADL-performance, the validity of the mBBS, physical fitness over a long-term period, applicability of muscle strength measurements, and the feasibility and effects of PRT in persons with (SP)IVD. The participants of the conducted studies varied from persons with (severe) intellectual and visual disabilities (S)IVD to persons with (severe of profound) intellectual disabilities (SP)IVD and persons with severe or profound intellectual and visual disabilities (SPIVD).

Summary
Many persons with SPIVD also have visual impairment. It is not clear whether these individuals require more support in their daily functioning than their peers without visual impairment. Therefore, the impact of visual impairment on ADL-performance in persons with SPIVD was examined in Chapter 2. In this study, 120 persons with severe/profound ID and 120 with severe/profound ID and visual disabilities participated. All of the participants could walk without or with slight restrictions. To measure the ability of performing ADL, the Barthel Index questionnaire (BI) and the Comfortable Walking Speed (CWS) were used. It was found that, for individuals with severe or profound ID, an additional visual impairment only slightly affected the ADL-performance. The level of motor skills, the level of ID, and presence of a visual impairment each led to lower BI-scores. Limited motor skills (GMFCS Levels 2 or 3) and profound ID-level resulted in lower
walking speed. Compared to persons with specific (chronic) health conditions, the participants in this study walked with low gait speed, and they had lower BI-scores compared to same-aged peers without severe/profound ID. These low gait speed and low BI-scores of persons with severe/profound ID may explain the limited influence of an additional visual impairment on gait speed and BI. It was concluded that an additional visual disability only slightly affects the ability to perform ADL in persons with severe/profound ID.

The modified Berg Balance Scale (mBBS) is an adapted balance scale that has been proven to be a feasible and reliable test for persons with ID and visual impairment. However, the validity of the mBBS to measure balance for this group is yet unknown. Therefore, the aim of the study in Chapter 3 was to determine the concurrent and predictive validity of the mBBS in adults with (SP)IVD as these individuals may have decreased balance and may be at risk for falling. In this study, 55 participants performed the mBBS, the Center of Gravity test (COG), and the Comfortable Walking Speed test (CWS). Additionally, the Barthel Index questionnaire (BI) was filled in by the participants’ residential caretakers in order to gain insight into the ability to perform ADL. To monitor the participants’ number of falling incidents, a monthly registration calendar was recorded. It was found that, for persons with (SP)IVD, the validity of the mBBS to predict balance and for predicting risk of falling was not sufficient. Scores of the mBBS were strongly related to BI and ADL-performance and, to a lesser extent, balance. It was found that the COG and the CWS were significant predictors of fall incidents and that the mBBS had no additional predictive contribution. In conclusion, the mBBS is not sufficiently valid to measure balance nor to predict falls for persons with (SP)IVD.

Persons with SPIVD have low physical fitness levels. Their life expectancy is increasing while daily functioning decreases with increasing age. For this group, physical decline begins at a much younger age compared to the general population. Insight into the physical fitness levels of this population measured over several years is necessary to track the course of physical fitness over a long-term period, to discover which components of physical fitness should be improved, and to gain insight into their need for support and care. The aim of the study in Chapter 4 was to examine changes in physical fitness levels of 55 individuals with SPIVD and GMFCS Levels 1 and 2 over a ten-year period. The participants performed the mBBS, the adapted Shuttle Run Test (aSRT), and...
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the six-minute walk distance test (6MWD). In addition, Body Mass Index (BMI) and waist circumference (Wcf) were measured. Due to different levels of motor skills, the participants with GMFCS Level 1 performed the aSRT and those with GMFCS Level 2 did the 6MWD. Over this ten-year period, BMI remained reasonably stable as well as Wcf except for the participants with GMFCS 1 whereby Wcf increased. In contrast to the general population, we observed a higher percentage of women being obese. Participants with GMFCS 1 improved on mBBS, and those with GMFCS 2 remained reasonably stable on mBBS. Cardiorespiratory fitness levels (aSRT and 6MWD) remained quite stable for both persons with GMFCS 1 and GMFCS 2 over this ten-year period. However, cardiopulmonary fitness levels were generally low for persons with SPIVD. In conclusion, for persons with SPIVD and GMFCS Levels 1 and 2, body composition and physical fitness levels are low but remained stable or improved slightly over a long-term period whereas waist circumference for persons with GMFCS 1 increased.

Persons with ID generally have low muscle strength particularly of the Quadriceps muscles. Until now, for persons with (SP)IVD, feasible and reliable instruments to measure strength are lacking. Also, the time frame that is necessary for persons with (SP)IVD to learn to adequately perform a strength test is currently unknown. The aim of the study in Chapter 5 was to examine the feasibility and reliability of three measurement instruments for Quadriceps strength in persons with moderate to severe ID and visual impairment (S)IVD and the degree of the association between these tests. For a period of five weeks, 29 persons with (S)IVD performed the Minimum Sit to Stand Height Test (MSST), the Leg Extension test (LE) and, the 30 seconds Chair Stand test (30sCS) within one session once per week. The feasibility, the learning period, and the reliability of these three methods was established. It was found that all three of the measurement instruments were feasible. Also, it was determined that no learning period was required for the 30sCS, four practice sessions were needed for MSST, and five for the LE in order to adequately perform the tests. All three methods had sufficient test re-test reliability. The moderate to sufficient correlations between the MSST, the LE, and the 30sCS revealed that the tests are complementary. It was concluded that the MSST, LE, and 30sCS are feasible methods for measuring muscle strength in individuals with (S)IVD with an acceptable learning period and a sufficient test re-test reliability. If Quadriceps strength is the primary outcome for a training program, it is recommended to use the LE test as a measuring instrument in persons with (S)IVD. However, if functional aspects
such as measuring the performance or level of ambulatory activities are deemed important, then the MSST (flexibility and strength) and 30sCS (muscle endurance and strength) are of added value for obtaining insight into clients’ ambulatory abilities as well as their need for support.

Just as with persons with ID, it is expected that individuals with (SP)IVD have less muscle strength as they may not move sufficiently due to their severe limitations. Progressive resistance training (PRT) is considered to be safe for individuals experiencing a wide range of health conditions and disabilities. However, for individuals with (SP)IVD, it was unknown whether this is a feasible and effective method to improve muscle strength. The feasibility and the effect of PRT on Quadriceps strength in individuals with (S)IVD is described in a multiple-case study in Chapter 6. Over a ten-week period, eight persons with (S)IVD participated two or three times per week in a PRT-program for Quadriceps strength. The feasibility and the effect of PRT on Quadriceps strength and participants’ personal goals were examined. Quadriceps strength was measured in Week 1, Week 5, and Week 10 with the 1RM leg extension test (LE), and the participants’ personal goals were measured with Goal Attainment Scaling (GAS) in Week 1 and Week 10. It was ascertained that participants attended more than 85% of the PRT sessions and trained up to the final 80% of their 1RM, indicating sufficient compliance. None of the participants missed a training session due to lack of motivation. Moreover, all participants experienced pleasure performing the PRT program and expressed a desire to continue participating in training sessions. Quadriceps strength increased significantly by nearly 80%, and the participants’ personal goals were achieved. It was concluded that PRT is a feasible and potentially effective method for increasing Quadriceps strength as well as achieving personal goals in persons with moderate to severe ID and visual impairment with GMFCS Level 1.

**Implications**

It is important to mention that not all individuals with SPIVD are residing in specialized institutions for this group but regularly within organizations for persons with ID that are not specifically aimed at individuals with additional visual impairments. Persons with SPIVD often demonstrate less initiative to communicate or perform activities due to their visual impairment. If it is not known whether a visual impairment is present, this could
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easily lead to underestimation of the wishes and skills of the person in question. Therefore, sufficient attention is important for the timely diagnosis of the presence of and the degree of a visual impairment that can be offered by two expertise centers in the Netherlands. With their expertise, they are also able to provide education and advice about the support and accompanying guidance that is needed as persons with SPIVD require specific attention and support in their daily activities, living skills, communication, initiative, and social skills. Within the facility where the studies were conducted, fortunately, increasing attention is being paid to a healthy lifestyle with sufficient physical activity. An explicit recommendation to all institutions for individuals with ID and eventually visual impairment or other vulnerable groups is to integrate sufficient exercise as part of daily support.

**Measuring and monitoring physical fitness**

Persons with SPIVD have low physical fitness levels. However, these low levels often remain unnoticed along with a gradual decline in their physical fitness. If those involved in the care of persons with SPIVD do not notice this, necessary interventions may not be initiated to prevent further deterioration or improve physical fitness. This can be prevented by annually measuring and thus monitoring physical fitness in persons with SPIVD.

It is first essential that all who are involved in the daily care of persons with SPIVD, such as direct support and care givers including physicians, physiotherapists and gymnastics instructors, are aware of the low fitness levels in this group. In addition, it is important to include physical fitness in, e.g., care plans and dossiers in a clear and accessible way. Furthermore, physical fitness should be a regular element of the curricula of the educational programs for these professions in order to increase awareness and knowledge as well as provide a support base so that physical fitness becomes (even) more of a fixed component of the daily care of this group.

With respect to monitoring physical fitness, a first step has been made in measuring Quadriceps strength in persons with (S)IVD and GMFCS Levels 1 and 2 (Chapter 5). Using the MSST, the LE, and the 30sCS, it is possible to gain insight into their Quadriceps strength, ambulatory skills, and consequently their need for support. A next step is to
actually use these methods annually to reliably determine Quadriceps strength for this group as a condition for ambulatory activities and participation (Figure 1, page 11). Muscle strength can be monitored by scheduling these measurements every year for persons with SPIVD to be able to detect a decrease over a period of time with the aim to intervene in time. In addition to this, sufficient muscle mass is proven to be important for healthy body composition. Regarding body composition of persons with SPIVD, BMI and Wcf are generally measured regularly. Because a lower BMI with a high Wcf may also indicate less muscle mass, it appears to be important to also measure fat-percentage annually in addition to BMI and Wcf.

To monitor physical fitness in a larger group, the MSST, the LE, and the 30sCS or similar methods may also be feasibly applicable for individuals with more severe and profound ID and visual impairment and for those who are more limited in their motor skills, for example, GMFCS Level 3. However, in the future, it is of interest to investigate whether adapted methods need to be developed for those individuals. In addition, it is expected that, in addition to these measurements for Quadriceps strength, comparable methods for measuring muscle strength of other major muscle groups in the upper and lower extremities are also applicable for persons with (SP)IVD. Measurements that require a movement in one fixed direction and measurements that require a functional movement might possibly be feasible with a certain learning period.

**Improving and maintaining physical fitness**

It was demonstrated that PRT is potentially effective for improving muscle strength and other components of physical fitness for persons with (S)IVD and GMFCS Level 1. These improvements will probably be beneficial for activities such as transfers, standing, walking (gait speed), stand-up, climbing stairs, and cycling which may increase ADL-performance and participation and reduce risk factors for all-cause mortality.

Despite the small study group, it is very likely that PRT is also applicable for persons with more severe and profound ID and visual impairment and for those who are more limited in their motor skills. However, for the future, it is important to take a next step and evaluate the applicability of PRT or other interventions aimed at improving physical fitness for persons with more severe ID and limited motor skills. If necessary, adapted
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programs can be developed for those individuals. Another continuation of the conducted study is to carry out a larger study with a control group in order to gain insight into the effects of PRT in persons with SPIVD. It is likely that, besides PRT of the Quadriceps muscles (Chapter 6), it is also possible for persons with SPIVD to improve all major muscle groups in the upper and lower extremities with PRT. This is important as it is recommended by the American College of Sports Medicine that all major muscle groups should be trained intensively for better health benefits.\(^3\)

Although there is still a need for further research, a first step has been made with promising results after PRT for improvement in Quadriceps strength and the achievement of personal goals (Chapter 6). Considering these achievements, it appears to be necessary that training programs or sports be scheduled as a permanent element in the weekly program of persons with SPIVD just as with other day-spending activities. This may be required to improve or prevent deterioration of their physical fitness. However, this is not yet the case in the daily support of this group. A condition for achieving this might be changing the focus to the abilities of persons with SPIVD rather than to their limitations regarding training programs and sports. In addition, it is important that those involved in the care of this group are aware of the exercise opportunities in order to provide better health conditions for this group. Moreover, awareness is needed that persons with SPIVD are capable of participating in training programs and might experience it as being fun to push their personal and fatigue limits and thus really make progress on physical fitness. Therefore, it is recommended to adopt a positive or stimulating attitude regarding sports for persons with SPIVD, knowing that training is necessary due to their low physical fitness and their ability to improve this through training. In addition to the attitude of support persons, it is important to take into account the stimulating and motivating influence of training in a group and training in a stimulating environment that is focused on sports.

From the study that was conducted in Chapter 6, it was discovered that all of the participants experienced pleasure in training/ sports and that interaction increased between participants and between participants and the supervisors. These are all very important factors that are beneficial for personal factors such as motivation and probably for an increase in participation. In addition, self-confidence in exercise and in daily life may also increase due to strength training/sports as well as positive behavioural
changes, increase in initiative, and daring to push boundaries which might be conditioned for being more active or increasing ADL-performance and participation. Related to the abovementioned factors, the awareness and, therefore, the actual stimulating influence of all of the involved professionals and peers of persons with SPIVD is decisive for actually accomplishing progress on those personal factors in this group.

In general, however, the basic attitude towards pushing boundaries and training with this vulnerable group can generally be characterised by cautiousness. It is recommended that physiotherapists and gymnastics instructors actually train individuals with SPIVD with the associated pushing of boundaries including fatigue limits when possible aiming at improving muscle strength and physical fitness. To accomplish this, it is essential that parents, direct support, and caregivers encourage this group to exercise. Furthermore, physical fitness, strength training and other interventions to improve the physical fitness of persons with ID or ID with visual impairment, should be a regular part of the curriculum of studies such as physiotherapy or gymnastics instructor. By gathering knowledge about these specific target groups with their concerns and possibilities and the opportunities to actually train these individuals, future professionals have a certain basic knowledge that is needed for adequately guiding this group of individuals. As it is necessary to push boundaries, including the fatigue limit, to improve the physical fitness of these groups, knowledge about this is very important in order to provide high quality care.

The question, however, is to what extent the results obtained by PRT will be maintained for this group in the long term if it is not possible to schedule sports as a permanent component in the weekly program of persons with SPIVD. In general, it is difficult to maintain achieved fitness levels and to prevent deterioration without a fixed continuous training program. This will not be different for persons with SPIVD. To maintain achieved fitness levels, environmental factors such as the facility, parents/ legal representatives, direct support/ care givers, and also physiotherapists and gymnastics instructors play an important role because they are involved in the daily care of persons with SPIVD. For example, achieved improved gait speed as a result of an intervention might be retained by direct support and care givers stimulating walking whenever possible in the daily life of persons with SPIVD. This may require a different focus on daily care and awareness of their important role in maintaining physical fitness in this population. On the other hand, it is crucial that physiotherapists and gymnastics instructors are also aware of this and
ensure proper knowledge transfer to the care providers and guide them in how physical fitness levels can be maintained in the daily lives of their clients. For example, teach them to stimulate and guide clients in walking on a treadmill and guide them in how to stimulate a client’s walking pace during the daily walking moments. A multidisciplinary collaboration appears to be necessary to develop strategies to stimulate gait speed in persons with SPIVD during daily care. In this way, improving or maintaining gait speed as part of physical fitness can become a permanent element of the daily care of this group.

Regarding PRT, it is of interest to gain insight into the long-term effects of strength training and to monitor the period after an intervention when clients no longer participate in an intervention. Additionally, it is important to gain insight into the needs to maintain the effects of a training program. For example, is it necessary to continually incorporate a fixed frequency of training into daily life in order to prevent them from reverting back to their earlier lifestyle patterns? What does it take to prevent this possible relapse? Are factors such as having sufficient time or a fixed time to exercise a condition decisive for retaining the achieved results or are other environmental factors such as exercising in a sporting environment or training in a group decisive for this?

Persons with (SP)IVD are likely to be encouraged to continue exercising because of the effect of group dynamics, a stimulating environment in which it is clearly the intention to train or practice, and through challenging training instruments, just like the general population. This makes it important for an organization for persons with (SP)IVD to create a sporting atmosphere with the pleasure of exercising together in order to guarantee a positive long-term effect.

**Transferring Improved physical fitness to ADL-performance and participation**

According to the ICF-model shown in Figure 1. (page 14), improved balance, gait speed, body composition, cardiorespiratory fitness, and Quadriceps strength are related to activities, ADL-functioning, and participation. The question, however, is whether improvement of these body functions will actually lead to being physically more active, improved ADL-functioning, and increased participation. In general, social support is an important mediator of successfully changing health habits. Since persons with SPIVD are (to a large extent) dependent on the support and care from others, environmental factors...
such as direct support and care givers are not only of influence, but even decisive, for actually becoming more active and exhibiting increased ADL-performance and participation. The institutional policy, the attitude of parents, direct support, and care givers with regard to increasing physical fitness, being active, ADL functioning, and participation of persons with SPIVD are particularly important to actually achieve this for this group. Additionally, practitioners such as physiotherapists and gymnastics instructors are part of these environmental factors and have an important role not only in improving the physical fitness of this group but also in the actual conversion of improved fitness into becoming more active, improved ADL-performance, and increased participation in daily life of persons with SPIVD. Together, these environmental factors may be pivotal in this. The ICF-model (Figure 1. page 14) reflects these environmental factors, however, not as a distinguished determining factor for the transfer of physical fitness to activity, ADL-functioning, and participation. Additionally, in Figure 2. page 15, the dotted arrows indicate that the direct relation between physical fitness and physical activity as well as participation is currently unknown for persons with SPIVD. Since the environmental factors seem to have a decisive influence on the transfer of physical fitness to physical activity as well as participation for this group, these factors are added as a determining component for the transfers in Figure 3.
Figure 3. Adapted integration of models and concepts of I: Schalock and III: Bouchard, expressing participation, quality of life, physical well-being, physical activity, physical fitness, and health, including environmental factors.

The research in this thesis demonstrated that it is possible to improve components of physical fitness with an intervention (Chapter 6) aimed at improving ADL-performance and participation. With this PRT program, Quadriceps strength improved, and personal goals were achieved, for example, climbing stairs. However, the achieved results from an intervention or treatment may not automatically lead to more activity or increased ADL-functioning and participation in daily life of persons with SPIVD. As mentioned above, environmental factors such as care providers are decisive in this regard given the guidance and supportive care that these persons require. Furthermore, with a lack of initiative and motivation, these individuals will not be inclined to be more active themselves, do new activities, push boundaries, or participate more in their daily life. Guidance and support from the environment are essential to accomplish this.

Also, regarding this topic, awareness is required from gymnastics instructors, physiotherapists, and direct support and caregivers that improved physical fitness in persons with SPIVD is no guarantee that they will actually perform more activities or that they will participate more actively in daily life. In this context, the professionals who are
directly responsible for or involved in the daily care of this group are designated to ensure that increased physical fitness is also reflected in being more active, improved ADL performance, and increased participation. In practice, this transfer/translation is often omitted, and old daily habits or familiar care quickly return. To prevent this and in order to develop an environment that is facilitating and motivating this group, gymnastics instructors and physiotherapists should have a supervising role in the transfer of achieved improved fitness levels to actually increased ADL-performance and participation. This supervising role could consist of providing feedback and training to direct support and caregivers in order to establish improvement of attitude and knowledge. For example, physical therapists could give advice to these individuals on how to use increased muscle strength during daily life such as picking up their own clothing from the floor or similar activities in different daily situations or brushing their teeth while standing rather than sitting, carrying groceries or raking the yard, motivating them to walk outside, how to guide clients properly, and how to stimulate a person to walk with a higher speed. In addition, the availability of materials such as a home trainer in a living room and encouraging its use are important possibilities to stimulate clients to be more active. Additionally, in daily reports, it should be noted to what extent a person had been sufficiently active during the day. This could help supervisors to actually ensure that this group moves sufficiently. It may be needed to investigate which conditions are necessary for direct support, care givers, and persons with SPIVD (like sufficient time, sufficient staff, and adequate stimulus) to implement sufficient exercise in the daily lives of persons with SPIVD. In short, there are many possibilities and opportunities regarding appropriate activities for individuals with SPIVD aimed at being more active, improved ADL performance, and increased participation. A plan of action should be made that is focused on how this increased physical fitness can result in clients becoming more active or being stimulated to perform tasks that are more difficult in daily life.

Communication between all disciplines involved with a person with SPIVD should be optimized and become a fixed component during multidisciplinary consultation. Perhaps a few professionals per discipline can have a pioneering role in this to ensure that this becomes a broad-based approach. In addition, Goal Attainment Scaling\(^7\) can also be used as an instrument to stimulate clients and those involved in order to actually increase ADL- performance and participation. In this thesis, a promising example of the use of GAS scores has been made in persons with (SJ)IVD.
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Lastly, as mentioned in the introduction, due to their need for support, self-care has a social context for persons with SPIVD and belongs to ‘participation’\(^8\). Therefore, it is important for all of those involved in the daily care of persons with SPIVD to focus on the social context of this care as being participation at times when help or support is provided. Awareness of this cooperation with each other and the social context of daily care might also be beneficial to improve participation opportunities for this group. By stimulating active engagement and involvement of persons with SPIVD in their daily care, daily activities, social contacts, and societal and leisure activities, participation might increase\(^8\).

**Aging**

Currently, individuals with ID are reaching older ages. Despite this increase in life expectancy, older persons with ID often have multiple health problems and an early functional decline\(^8\). The common understanding is that persons with ID are considered old after the age of 50 years due to this early onset of functional decline\(^9\)\(^-\)\(^11\). In this group, frailty occurs more often and to a more severe extent at a relatively young age compared to the general population and increases with age\(^9\)\(^,\)\(^10\)\(^,\)\(^12\). Moreover\(^,\)\(^13\) within the group with ID, frailty is more common in individuals with more severe ID due to the high degree of comorbidity\(^,\)\(^10\)\(^,\)\(^12\). Generally, frailty is described as a state of high vulnerability for adverse health outcomes at an older age\(^9\). Internationally, two operationalizations are commonly used to determine frailty, i.e., the frailty phenotype\(^13\) and the Frailty Index\(^14\). In older adults with ID, both proved to be feasible of which the Frailty Index appeared to be more applicable\(^12\). These instruments are probably also applicable to persons with SPIVD. For future research, therefore, it is important to determine the applicability of the frailty phenotype\(^13\) and the Frailty Index\(^14\) in order to annually monitor the level of frailty for this group. It is important to determine frailty in time to be able to intervene timely.

Since there is increasing attention being paid to frailty, first for the general population and now for persons with ID, it is important to focus more attention on this subject for individuals with SPIVD. Because physical fitness levels of persons with SPIVD are worrisomely low, which may affect the daily functioning of this group, research regarding frailty and how to determine it in this group needs to be developed. For persons with ID, a higher degree of frailty is predictive for decreased ADL-functioning and mobility and to an
increased need for care, use of medication, and mortality.\textsuperscript{9} Perhaps, the measuring instruments that were obtained to determine the physical fitness of persons with SPIVD could serve as a basis for the development of physical frailty and social/participation frailty indexes for this group. It is interesting to examine the possibilities of determining frailty in persons with SPIVD and for developing a paradigm for this. It is of interest to further investigate and develop this in conjunction with various experts from the field.

For the general population, frailty can be reduced or even restored with interventions.\textsuperscript{15,16} However, the higher the degree of frailty, the more difficult it is to reduce it.\textsuperscript{17} Therefore, it is recommended that the residential care facilities for persons with (SP)IVD and others with ID to measure health, fitness levels, and frailty annually throughout the life of the residents in order to be able to intervene in time. It should even be recommended that beginning at an earlier time, perhaps during childhood, might prevent these persons’ levels of physical fitness from diminishing. To gain insight into the influence of intervention programs on frailty and regarding the possibility of reducing frailty in persons with SPIVD, future research is recommended.

Recommendations

In this thesis, a start has been made in the field of measuring physical fitness and improvement of these levels with strength training and sports for persons with ID and visual impairment. Although it seems to be an important step, further research is required in order to gain additional detailed insight into this.

Recommendations for practice and education

The challenge is to annually measure physical fitness and to actually train at an appropriate level in order to improve it.

To achieve this, an approach is needed from all involved in persons with SPIVD from ‘care for’ to ‘care that’.

It is recommended to pay more attention to physical fitness and its improvement for persons with ID. Therefore, this should be a regular part of the curriculum of various studies, such as physiotherapy and gymnastics instructor, so that future professionals
have a certain basic knowledge about this specific target group with their concerns and opportunities.

Since persons with (SP)IVD have worryingly low fitness levels, it is recommended to monitor these levels as an integral part of care, annually and lifelong, regarding: body composition; cardiorespiratory fitness and gait speed; muscle strength and endurance; balance and ADL-performance. With this monitoring, the necessary care can be coordinated better and deterioration signaled with the aim to intervene in time.

It is recommended to implement progressive resistance training for all major muscle groups in upper and lower extremities for individuals with (SP)IVD.

Recommendations for research

For future research, it is recommended to gain insight into training and related physiological processes specifically for persons with severe or profound ID, whether there is a ceiling to improve their physical fitness, and which type of training is most beneficial for improved ADL-performance.

As the risk for being frail is high for individuals with (SP)IVD, future research is recommended that is aimed at developing an applicable frailty index for persons with SPIVD, for example, a physical frailty index and a social/participation frailty index. In addition, it is of interest to investigate the influence of an intervention on the reduction of frailty in this group.
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