Progressive resistance training for persons with intellectual disabilities and visual impairment
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INTRODUCTION

Muscle strength and muscle endurance are components of health-related physical fitness in addition to body composition, cardiorespiratory fitness and flexibility (American College of Sports Medicine (ACSM), 2013). Muscle strength contributes to mobility which affects quality of life (Brooks & Faulkner, 1994), and the strength of the lower limbs is important for ambulatory activities (Bassey et al., 1992). Loss of strength in these muscles may lead to a decrease in daily activities (Vinciguerra, Musaro, & Rosenthal, 2010) and diminished health-related quality of life (Mostert, Goris, Weling-Scheepers, Wouters, & Schols, 2000; Rantanen et al., 1999).

Moreover, the weakness of Quadriceps is a predictor of mortality (Newman, Kupelian, & Visser, 2006) as they are one of the first muscles that degenerates due to inactivity (Boonyarom & Inui, 2006).

Persons with intellectual disabilities have less muscle strength particularly in the Quadriceps muscles (Horvat, Croce, Pitetti, & Fernhall, 1999) compared to their peers without ID (Carmeli, Imam, & Merrick, 2012). This may be related to a sedentary lifestyle (Borji, Zghal, Zarrourk, Sahl, & Rebai, 2014; Hall & Thomas, 2008) as well as a central nervous system failure to activate motor units and to some abnormal intrinsic muscle properties (Borji et al., 2014). It has previously been shown that persons with ID and visual impairment are physically weaker compared to those with ID (Hilgenkamp, 2016).
2 | METHODS

2.1 | Design

A multiple case study was conducted to examine the feasibility and effect of PRT of the Quadriceps muscles in persons with intellectual disabilities and visual impairment. Participants took part in a PRT programme two or three times per week that was intended to increase Quadriceps strength over a ten-week training period. A physiotherapist annex researcher and a gymnastics instructor supervised the implementation of the PRT programme. Quadriceps strength was measured in Week 1, Week 5 and Week 10 and participants’ personal goals in Week 1 and Week 10.

2.2 | Participants

Participants were recruited from a residential facility in the Netherlands. Inclusion criteria consisted of having a moderate to severe ID according to the ICD-10 (World Health Organization (WHO), 2016), having visual impairments (“mild-severe visual impairment to blindness,” WHO, 2016) and being categorized at Level 1 on the Gross Motor Function Classification System (GMFCS; Gorter, 2001; Palisano et al., 2000). The GMFCS (Gorter, 2001; Palisano et al., 2000) is a five-level system that is utilized to classify the severity of motor disabilities of persons with intellectual and physical disabilities. Those classified at Level 1 are generally capable of walking without restrictions but tend to have limitations in advanced motor skills (Gorter, 2001; Palisano et al., 2000).

2.3 | Procedure

After explaining the intervention and its purpose, each participant was asked about the individual’s willingness to be involved in the PRT programme. Depending on the degree of intellectual impairment, permission was obtained either directly from either the participant’s representative or from the participant and their representative. When written consent was obtained, participants were screened regarding support for participation from a physician specialized in ID in collaboration with a healthcare psychologist. Written consent was received from the representatives of eight participants to take part twice (n = 3) or trice per week (n = 5).

Participants’ characteristics in terms of gender, age, level of ID (estimated IQ), level of GMFCS, visual impairment, presence of a hearing impairment, weight, height and Body Mass Index (BMI) were retrieved from the medical records in order to describe the sample. Data regarding visual impairment were categorized as mild visual impairment, moderate visual impairment, severe visual impairment or blindness (Table 1). These characteristics were determined and categorized by a physician specialized in ID in collaboration with a healthcare psychologist.

In this study, participants were excluded if they exhibited any of the following exclusion criteria shortly prior to the PRT programme or at the time of the trainings sessions/measurements: mental or
physical health issues that prevented the participant from taking part such as psychoses, depression or other severe psychological problems such as behavioural and prolonged stress; somatic diseases defined as chronic diseases and/or diseases that are not resolved in a short period of time such as osteoarthritis, osteoporosis, pneumonia and general illness or fever; taking antibiotics; worsening of asthma or epilepsy as signified with recent insult or epileptic fits; fresh wound(s)/bruise(s); or other factors causing pain during movement; and, finally, stress as evidenced by a participant’s behaviour, for example, unrestful behaviour, distracted behaviour or signs of unhappiness. The participants’ caregivers, representatives and the gymnastics instructor evaluated if the level of this behaviour was such that exclusion was warranted. In the end, this decision was made in consultation between professionals and representatives. Participants with profound ID were excluded due to the duration and intensity of this study.

2.4 | Ethical statement

This study was performed in accordance with the guidelines of the Helsinki Declaration (World Medical Association (WMA), 2008). Permission was obtained from the legal Medical Ethics Committee (2017/361), University Medical Center Groningen, the Netherlands. Consistent distress or unhappiness was interpreted as a sign of a lack of consent, and further participation in the study was reconsidered. Participation in the PRT was voluntary and without any compulsion at all times.

2.5 | Intervention

The participants were scheduled group wise at fixed timed intervals of 45 min, two or three times a week with at least 48 hr of resting time in between. The gymnastics instructor was familiar with the mental and physical limitations of the participants which facilitated the accuracy of the performance during testing (Hale, Bray, & Littmann, 2007).

2.5.1 | PRT programme

The structure and intensity of the PRT programme were determined according to the standards of the American College of Sports and Medicine (ACSM, 2009). After warming up, the participants trained their Quadriceps strength on the leg extension equipment (Calders et al., 2011) according to the leg extension protocol in which attention was given to well-executed movements without compensation and to breathing through or blowing out during force. During each PRT session, participants were positively stimulated and encouraged. It was continuously checked whether participants trained to the level of fatigue of the Quadriceps muscles by verifying the possibility of increasing the number of kilograms during the PRT or performing more repetitions all without compensation. At the beginning of the PRT programme, participants trained at 50% of their measured one repetition maximum (1RM) to ultimately 80% in Weeks 9 and 10 as summarized in Table S1.

2.6 | Measurement instruments

2.6.1 | Feasibility

The number of absences per training session as well as reasons for these was recorded. The percentage of attendance was computed as the number of times present was divided by the total number of training sessions. Sufficient compliance was determined as the percentage of participants that managed to train up to the final 80% of their baseline 1RM. The programme was monitored to determine whether it needed to be adapted to the participants’ capabilities, specifically when or if it was too difficult/heavy to perform due to their cognitive or physical abilities.

2.7 | Quadriceps strength—leg extension test (1RM)

The participant sat on appropriate fitness equipment to perform maximum leg extension with two legs at the same time. Before performing the test, the maximum achievable extension (range of motion) was recorded. After practicing the leg extension, the participant was requested to fully extend the legs against the maximum achievable resistance.

In past research, persons with (severe) ID and visual impairment required a learning period of four to five times for adequately performing the leg extension test in an appropriate/reliable manner (Dijkhuizen et al., 2018). In this study, we determined whether a participant could properly perform the leg extension test in Week 1, that is, by performing the 1RM up to the maximum without any compensation. If participants achieved this, then the 1RM was measured at the beginning of the PRT programme. If a learning period was required to perform the leg extension test in an appropriate/reliable

<table>
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<th>Total</th>
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<td>N = 8</td>
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| Age, Mean, ±SD | 29.6 ± 5.9 |
| Height in cm, Mean, ±SD | 169.8 ± 11.2 |
| Weight in kg, Mean, ±SD | 70.4 ± 12.2 |
| BMI, Mean, ±SD | 24.4 ± 3.2 |
| Intellectual disability, N |
| Moderate (IQ 36–69 points) | 4 |
| Severe (IQ 20–35 points) | 4 |
| Visual impairment, N |
| Mild visual impairment | 1 |
| Severe visual impairment | 5 |
| Blindness | 2 |
| Auditory Impairment, N |
| Normal hearing | 5 |
| Hearing loss | 2 |
| Deaf | 1 |
way, the 1RM was measured later in the first week of the PRT programme. The leg extension test has shown to be a feasible and reliable instrument for measuring Quadriceps strength in persons with moderate and severe ID with visual impairment (Dijkhuizen et al., 2018).

### 2.7.1 | Personal goals—goal attainment scaling

In GAS, labels are formulated in such a way that the extent to which the goal is achieved is taken as a measure of the effectiveness of treatment: The baseline level is expressed as −2, a decrease compared to this initial baseline situation as −3, progress without fully achieving the goal as −1, a goal fully achieved as 0, a progress beyond the set goal as +1 and a progress far beyond the set goal as +2.

All six levels are formulated as specific, measurable, acceptable, relevant and time-related (SMART) (Dekkers, Viet, Eilander, & Steenbeek, 2011). The participants’ individual goals were explicitly formulated in consultation/agreement with them and their representatives since this increases the likelihood of actually achieving the goals that are established (Ekström-Ahl et al., 2005). If this was not possible due to the intellectual disability, these goals were determined after intensive consultation with the participants’ representatives in cooperation with their parents or day care. Individual changes in Goal Attainment scores were examined at the multiple case level subdivided into varying types of goals, specifically, on body composition (BMI/waist circumference), physical fitness (cycling and walking) and physical activity (ambulatory activities).

Goal Attainment Scaling has shown to be a reliable and validated method for scoring achievements of goal sets that are especially aimed at activities and participation (Bouwens, Heugten, & Verhey, 2008; Donnelly & Carswell, 2002; Ertzgaard, Ward, Wissel, & Borg, 2011; King, McDougall, Palisano, Gritzan, & Tucker, 1999; Schlosser, 2004; Steenbeek, Ketelaar, Lindeman, Galama, & Gorter, 2010; Turner-Stokes et al., 2009). In various rehabilitation teams, it has also proved to be reliable (Bouwens et al., 2008; Donnelly & Carswell, 2002; Schlosser, 2004; Steenbeek et al., 2010), and its sensitivity to changes in scores/outcomes has shown to be better than that of common standardized functional measures of abilities and participation (Steenbeek et al., 2007). To formulate Goal Attainment scales, standardization of this scale based on pre-determined agreements is needed (Dekkers et al., 2011) and influences its reliability (Bovend’eerdt, Dawes, Izadi, & Wade, 2011; Steenbeek et al., 2010). As it takes time to learn to use this method in an appropriate way and to gain experience, we elaborated the GAS scores in cooperation with their representatives.

### Table 2 | Individual characteristics, percentages of attendance, 1RM in Weeks 1, 5 and 10, percentage of progress of 1RM (as percentage of T1/Week 1 level) and achieved Goal Attainment—levels in Week 10

<table>
<thead>
<tr>
<th>Pt No</th>
<th>Age</th>
<th>Gender</th>
<th>Height cm</th>
<th>Weight kg</th>
<th>BMI</th>
<th>ID Level</th>
<th>Aud. Imp Level</th>
<th>Attend. %</th>
<th>GAS Level wk 10</th>
<th>1RM wk 1</th>
<th>Δ 5 %</th>
<th>Δ 10 %</th>
</tr>
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<tbody>
<tr>
<td>1</td>
<td>40</td>
<td>F</td>
<td>152.0</td>
<td>59.0</td>
<td>25.5</td>
<td>Severe</td>
<td>Blindness</td>
<td>89.7%</td>
<td>+1: More</td>
<td>27 kg</td>
<td>36 kg</td>
<td>39 kg</td>
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<td></td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>3xpw</td>
<td>+1: More</td>
<td></td>
<td></td>
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<tr>
<td>2</td>
<td>31</td>
<td>F</td>
<td>170.0</td>
<td>74.0</td>
<td>25.6</td>
<td>Moderate</td>
<td>Severe</td>
<td>100%</td>
<td>+2: Much more</td>
<td>39 kg</td>
<td>58 kg</td>
<td>77 kg</td>
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<td></td>
<td></td>
<td></td>
<td>2xpw</td>
<td>+2: Much more</td>
<td></td>
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<tr>
<td>3</td>
<td>28</td>
<td>F</td>
<td>170.0</td>
<td>81.7</td>
<td>28.3</td>
<td>Moderate</td>
<td>Mild</td>
<td>89.7%</td>
<td>0: Expected</td>
<td>40 kg</td>
<td>51 kg</td>
<td>80 kg</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td>3xpw</td>
<td>+2: Much more</td>
<td></td>
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<tr>
<td>4</td>
<td>30</td>
<td>M</td>
<td>169.0</td>
<td>75.5</td>
<td>26.4</td>
<td>Moderate</td>
<td>Severe</td>
<td>93.1%</td>
<td>+1: More</td>
<td>47 kg</td>
<td>55 kg</td>
<td>67 kg</td>
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<td></td>
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<td>3xpw</td>
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<tr>
<td>5</td>
<td>23</td>
<td>M</td>
<td>184.0</td>
<td>71.7</td>
<td>21.2</td>
<td>Severe</td>
<td>Blindness</td>
<td>100%</td>
<td>0: Expected</td>
<td>40 kg</td>
<td>44 kg</td>
<td>55 kg</td>
</tr>
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<td></td>
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<td>3xpw</td>
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</tr>
<tr>
<td>6</td>
<td>22</td>
<td>M</td>
<td>156.0</td>
<td>46.0</td>
<td>18.9</td>
<td>Moderate</td>
<td>Severe</td>
<td>100%</td>
<td>+2: Much more</td>
<td>30 kg</td>
<td>37 kg</td>
<td>47 kg</td>
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<td></td>
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<td></td>
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<td>2xpw</td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>35</td>
<td>M</td>
<td>181.0</td>
<td>73.0</td>
<td>22.3</td>
<td>Severe</td>
<td>Severe</td>
<td>95%</td>
<td>+2: Much more</td>
<td>25 kg</td>
<td>45 kg</td>
<td>67 kg</td>
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<tr>
<td></td>
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<td></td>
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<td>2xpw</td>
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<td></td>
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<td></td>
</tr>
<tr>
<td>8</td>
<td>28</td>
<td>M</td>
<td>176.0</td>
<td>82.5</td>
<td>26.6</td>
<td>Severe</td>
<td>Severe</td>
<td>34.5%</td>
<td>+3: Decline</td>
<td>53 kg</td>
<td>–</td>
<td>–</td>
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<td></td>
<td></td>
<td></td>
<td></td>
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<td>3xpw</td>
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Abbreviations: 1 RM week: one repetition maximum Week 1, Week 5 and Week 10. 1 RM in kg; Age: years; Height: in cm; Attend: attendance in percentages (%) and per week (pw); Aud. Imp: auditory impairment (level); GAS: Goal Attainment Scaling (level); Gender: M = male, F = female; Height: in cm; ID: intellectual disability (level); Pt: participant (no: number); pw: per week; Vis. Imp.: visual impairment (level); Weight: in kg; wk: Week; Δ: Percentages improvement in Week 5 and Week 10.
with an instructor of the GAS course in the Netherlands. In this study, participants’ personal goals, such as reducing waist circumference, did not meet the classification in activities and participation according to ICF. Though, to gain unity and overview in the evaluation of achievement of participants’ personal goals, GAS was used.

### 3 | DATA ANALYSES

The statistical analyses were performed using the Statistical Package for Social Studies (SPSS) version 22 for Windows with respect to descriptive statistics, and the statistical programming language R version 3.4.0 (R Development Core Team, 2017) for the mixed models and bootstrap estimation of a confidence interval.

Quadriceps strength was measured in Week 1, Week 5 and Week 10, and participants’ personal goals were evaluated in Week 1 and Week 10. Quadriceps strength was analysed using a linear mixed model estimation (Pinheiro & Bates, 2000) with Quadriceps strength as the outcome variable and a random intercept and slope for each participant.

If a participant had multiple personal goals, then the goal with the lowest score was used as the Goal Attainment score for statistical testing. The median Goal Attainment score after PRT was analysed by the median and the normalized bootstrap to compute its 95 per cent confidence interval (Davison & Hinkley, 1997). This approach statistically tests the null-hypothesis of group median −2, which corresponds to whether the group attained improvement compared to the baseline level of Week 1.

### 4 | RESULTS

The sample consisted of five males and three females with ages ranging from 22 to 40 years. One participant ended participating from the fifth week due to surgery. Further characteristics of the participants are depicted in Table 1.

#### 4.1 | Feasibility

The percentage of successful training attendance was 87.8%, including the participant who could no longer participate from Week 5.

This particular participant attended 34.5%, with 58.6% absence due to surgery. Other reasons for the absence of the participants in this study included health problems (9.2%), a special occasion (1.5%) and vacation (2.9%).

Seven participants that completed the whole ten-week PRT programme trained up to the final 80% of their 1RM, indicating sufficient compliance.

#### 4.2 | Effects PRT

##### 4.2.1 | Quadriceps strength—leg extension test (1RM)

The results of Quadriceps strength measured over time are shown for each participant in Figure 1. It can be observed that participants differ in strength at baseline; however, all of the participants increased in strength during each measurement with varying elevation. This suggests a random intercept as well as a random slope (steepness of line) for each of the participants. Improvement of Quadriceps strength (fixed effect) was estimated as the contrast (difference) with time point 1 as a reference.

The mean Quadriceps strength in Week 1 ($n = 8$) was 37.6 kg ($SD = 9.8$). With linear mixed model estimation, a significant time effect on Quadriceps strength was determined between Week 1 and Week 5 ($b^* 10.9$, $SE 2.8$, $t (9.4) = 3.8$, $p = 0.0037$). This indicates that, after 5 weeks of PRT, a significant increase of 10.9 kg was achieved, which amounts to an increase of 29%. Between Week 1 and Week 10, a significant time effect on Quadriceps strength was observed ($b^* 26.0$, $SE 5.0$, $t (6.0) = 5.2$, $p = 0.0020$) which indicates that, after 10 weeks of PRT, a significant increase of 26.0 kg was achieved with respect to Week 1, which amounts to an increase of 69%. Individual characteristics, percentages of attendance, 1RM in Weeks 1, 5 and 10 and percentage of progress of 1RM are shown in Tables 2.

#### 4.3 | Personal goals—goal attainment scaling

Three participants formulated two goals instead of one (see Table 2). Four participants selected their personal goals in the category body composition varying from a decrease in BMI ($n = 1$), waist circumference...
(n = 4) and buttock circumference (n = 1). Regarding physical fitness (cycling test and walking test), two participants had selected their goals in this category, whereof one selected two goals, and two participants had designated their goals within the activity category (climbing stairs independently, partly due to his visual impairment and improving confidence while walking outside). The participants’ achieved goal sets displayed in Goal Attainment—levels are shown in Table 3.

In Week 10, the median of the Goal Attainment scores was 1.0 with 95% CI −0.29, 2.35, calculated with the normalized bootstrap (Davison & Hinkley, 1997), this implies that the median value in Week 10 significantly increased compared to the value −2 in Week 1.

5 | DISCUSSION

Our results indicate that the PRT was feasible for persons with ID and visual impairment who were categorized in GMFCS Level 1. After PRT, Quadriceps strength increased, and the participants’ personal goals were generally achieved.

The percentage of attendance in this study (87.8%) is in accordance with the results of studies with participants with Down syndrome (Shields & Taylor, 2010; Shields et al., 2008). Significant attention was paid to informing and stimulating the participants’ caregivers and representatives in order to obtain and retain their cooperation to enable participants to engage in the programme for 10 weeks. This intensive contact and coordination appear to be important in this context because caregivers and representatives have a role in guiding participants to and from the gym. This attention may have positively affected the percentage of attendance. The pre-determined training programme proved to be feasible as participants were able to train up to 80% of their 1RM.

We ascertained significant increasing effects on Quadriceps strength after PRT; however, at baseline, participants differed in strength. All of the participants increased in Quadriceps strength during each measurement, though with varying elevation. Participants also differed in levels of ID and additional limitations. To be certain if the pre-determined baseline 1RM was correct, it was continuously checked whether participants trained to the fatigue limit of the Quadriceps muscles in order to prevent them from training below their level due to a possibly underestimated 1RM as a starting point. This only occurred with one participant in Week 8 after which the weight was further increased.

The mean increase of Quadriceps strength found in our study is in accordance with results of a similar study in persons with Down syndrome (Carmeli et al., 2011). The average percentage increase in muscle strength in our study was higher (69%) compared to comparable studies (39%–43% Rimmer, Heller, Wang, & Valerio, 2004; 42% Shields & Taylor, 2010). It is not clear why this percentage in our study is so much higher than those of these comparable studies. Possibly, the physical starting levels of the participants in the different studies were different and of influence. However, it was not possible to compare those levels as, in the other studies, the leg press was used to measure the strength of the lower limbs (sum of Quadriceps and Hamstrings), and we used the leg extension to measure isolated Quadriceps strength.

In general, the training programmes in the comparable studies were similar to ours except that, in our study, participants’ personal goals were used as a measuring instrument in addition to muscle strength. Perhaps this could have been an influence on achieving goals through strength training. It is possible to attribute the significant increase in Quadriceps strength in our study to the participants’ learning effects, increased locomotor experiences, learning how to train, pushing boundaries, increasing self-confidence and being venturesome. However, this is less likely as, in that case, we would expect the strongest increase during the first weeks of the PRT while our results showed that the increase in strength was actually higher during the last 5 weeks. It appears as though the increasing weight of the PRT could possibly be an important reason for this strong increase of Quadriceps strength.

In our study, the personal goals in the category body composition have been achieved more than achieved after PRT. From literature, a slight but significant reduction in BMI of adults with Down syndrome was determined (Rimmer et al., 2004). However, an increase in BMI has also been found with an unchanged waist size (Calders et al., 2011) which demonstrates that the effects of PRT on BMI are not yet clear. The findings in our study on physical fitness goal sets are in accordance with the results of Rimmer and colleagues who found a significant improvement in cardiovascular fitness for adults with Down syndrome who performed cardiovascular and strength training (Rimmer et al., 2004). The effects on participants’ activity goal sets correspond to findings from Bassey and colleagues who determined that muscle strength of lower limbs is important for ambulatory activities (Bassey et al., 1992) and that improvement in muscle strength is associated with positive changes in functional activities in adults with Down syndrome (Carmeli et al., 2002; Cowley et al., 2011). According to Steenbeek and colleagues, a significant improvement of at least two points between the median of Week 1 and the median of Week 10 would indicate a clinically relevant effect (Steenbeek, Meester-Delver, Becher, & Lankhorst, 2005). In our study, the median significantly increased and all participants increased their Goal Attainment value by at least 2 points except the participant who quited the PRT programme in Week 5.

6 | ANECDOTAL NOTE

Changes in participants’ behaviour or functioning that may have occurred during the PRT programme were monitored by the
gymnastics instructors and the participants’ representatives. Examples of reported side effects were increased walking speed, increased self-confidence in exercise and in daily life, positive behavioural changes, increase in initiative and daring to push boundaries. All of the participants experienced pleasure performing the PRT programme and expressed a desire to continue the training sessions after the end of the programme. This may have partly contributed to the percentage of attendance.

7 | STRENGTHS AND LIMITATIONS

Limitations of this study are the limited number of participants and the lack of a control group. This PRT programme is intensive for persons with severe ID and visual impairment; therefore, a multiple case study was selected to investigate whether PRT is feasible for persons who are categorized in GMFCS Level 1. In this way, the groundwork for a more comprehensive study with a comparison group and a follow-up measurement was established. In a randomized controlled trial, it may also be important to investigate side effects such as changes in the participants’ structure, behaviour and functioning. It is also recommended to repeat a comparable study with a group of persons with more severe ID or motor impairments.

In addition, this research was only focused on PRT of the Quadriceps muscles; however, according to the American College of Sports Medicine (ACSM), all major muscle groups should be trained intensively (total body workout) whereby the more intensive the strength training is, the greater the potential health benefits (ACSM, 2013).

In conclusion, PRT is a feasible and potentially effective method for increasing Quadriceps strength as well as achieving personal goals set by persons with ID and visual impairment who are categorized in GMFCS Level 1. This study can be the basis for a larger study with a control group in order to gain insight into the effects of PRT in persons with ID and visual impairment.

ACKNOWLEDGMENTS

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CONFLICT OF INTEREST

The content of this study has not been published before and is not under consideration for publication elsewhere. All the listed authors have participated sufficiently in the conception and design of this manuscript as well as in the analysis of the data and interpretation of the results. The listed authors have no conflict of interest to declare.

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REFERENCES


SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section at the end of the article.