Chapter 7

The effectiveness of a physical activity stimulation program for children with cerebral palsy on social participation, self-perception and quality of life: A randomized controlled trial

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Clin Rehabil 2013, Sept 18th [Epub ahead of print].
Chapter 7

Abstract

Objective
To determine the effects of a six-month physical activity stimulation programme on social participation, self-perception and quality of life in children with cerebral palsy (CP).

Design
Multi-centre randomized controlled trial with concealed allocation, blinded assessments and intention-to-treat analysis.

Setting
Paediatric physiotherapy practices, special schools for children with a disability, and the child’s own home.

Subjects
49 children with spastic CP (28 male), aged 7-13 years, able to walk with and without walking aids.

Interventions
The intervention group followed a six-month physical activity stimulation programme involving counselling through motivational interviewing, home-based physiotherapy and four months of fitness training. The control group continued regular paediatric physiotherapy.

Main measures
Outcomes included social participation in domestic life, social participation in recreation and leisure (Life-Habits Kids, and Children’s Assessment of Participation and Enjoyment questionnaires), self-perception (Harter’s Self-Perception Profile for Children), and parent-reported quality of life (CP Quality of Life questionnaire). Assessments were performed at baseline, at six months (6mo, except quality of life) and at twelve months (12mo).
Results
Intervention resulted in a positive effect on social participation in domestic life at 12mo (mean between-group difference=0.9, 95% CI=0.1 to 1.7 [1-10 scale], p=0.03), but not at 6mo. No significant effects were found for social participation in recreation and leisure, self-perception at 6mo and 12mo or for quality of life at 12mo.

Conclusions
The combination of counselling, home-based physiotherapy and fitness training was not effective in improving social participation in recreation and leisure, self-perception or quality of life, but did show a potential for improving social participation in domestic life over the longer term.
Introduction

The International Convention on the Rights of the Child has emphasized the importance of community participation for children with disabilities such as cerebral palsy.\(^1\) Compared to children developing typically, children with cerebral palsy show restricted social participation,\(^2,3\) as well as lower quality of life and self-perception mainly related to physical type domains.\(^3,4\) Children with cerebral palsy and their parents commonly indicate that they would like to see issues of social participation and quality of life addressed during treatment.\(^5\)

Cerebral palsy is a non-progressive disorder, but some children show a deterioration of activities as they grow older.\(^6\) It has been suggested that reduced levels of fitness\(^7\) and physical activity\(^8\) contribute to this deterioration, which leads to an increased risk of becoming trapped in a vicious cycle of deconditioning.\(^9\) The focus of physiotherapeutic treatment programmes has therefore shifted towards the improvement of fitness and promotion of physical activity.\(^10\) We developed a programme aimed at stimulating physical activity (the LEARN 2 MOVE 7-12 programme), which consisted of counselling by means of motivational interviewing, home-based physiotherapy to improve the carry-over of learned activities into the daily situation, and a fitness training programme.\(^11\)

In a separate analysis of this physiotherapeutic programme,\(^11\) we found that neither physical activity nor fitness were improved.\(^12\) Since this programme took a broad approach, with a particular focus on functional improvements and behavioural changes aimed at achieving a more active lifestyle, we wished to explore whether there were possibly beneficial effects on outcomes more closely related to behaviour and well-being, including social participation, self-perception and quality of life.

There is no information available on the potential of physical activity stimulation programmes to improve social participation and quality of life, since the only other study - investigating an internet-based physical activity counselling programme in adolescents with cerebral palsy - did not evaluate these outcomes.\(^13\) Nevertheless, positive short-term effects on social participation and quality of life have been demonstrated in a physiotherapeutic programme aimed at improving fitness, although no sustained
Effects were found at four months follow-up. Since the current study combines fitness training with behavioural change strategies, we hypothesized that LEARN 2 MOVE 7-12 would improve social participation, self-perception and quality of life in children with CP.

**Methods**

This multi-centre, parallel-group randomized controlled trial with concealed allocation and blinded assessments was conducted in paediatric physiotherapy practices and special schools for children with disabilities in the Netherlands between September 2009 and February 2011. Two previous publications have described the study design and programme results on physical activity, mobility capacity, fitness, self-reported fatigue and attitude towards sports. The study was approved by the Medical Ethical Board of the VU University Medical Center, Amsterdam. Parents, and children of 12 years of age and over, gave written informed consent before data collection began.

Walking children with spastic cerebral palsy, aged 7 to 13 years, were recruited via paediatric physiotherapy practices and special schools for children with disabilities. Inclusion criteria were: classification in Gross Motor Function Classification System levels I-III, understanding of the Dutch language and fulfilling at least one of the following criteria: 1) less active than the international physical activity norm (less than one hour daily at moderate or vigorous intensity [>5 Metabolic Equivalents]), 2) no regular participation in sports or a (physiotherapeutic) fitness programme (less than 3 times a week for at least 20 minutes) or 3) experience of problems related to mobility in daily life or sports. The most important exclusion criteria were: surgery in the previous six months, botulinum toxin treatment or serial casting in the previous three months (or planned), unstable seizures, and contra-indications for physical training.

Participants were randomized 1:1 to the intervention group or control group, with stratification by Gross Motor Function Classification System level I versus level II/III. Sealed envelopes were filled with a piece of paper indicating randomly generated group allocation. Envelopes were opened by LW after registration and participants were

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14. GMFCS I: Walking without limitations; GMFCS II: Walking with limitations; GMFCS III: Walking with a hand-held mobility device; GMFCS IV: Self-mobility with limitations, may use powered mobility; GMFCS V: Transported in a manual wheelchair.
informed of group allocation following baseline assessments.

The intervention group followed the physical activity stimulation programme, which involved a lifestyle intervention and fitness training (extensively described elsewhere). In short, the lifestyle intervention included counselling, which also involved the parents, to motivate and coach the child to adopt a more active lifestyle, in addition to the home-based physiotherapy. Parents and child received counselling at home provided by LW, using the motivational interviewing technique. Home-based physiotherapy, aimed at increasing the capacity for performing daily activities in a situation relevant for the child, was individually tailored based on an inventory of mobility-related problems experienced by the child and parents, and was provided by the child’s regular physiotherapist.

The fitness training programme, aimed at increasing lower-extremity muscle strength and anaerobic fitness, was based on existing training protocols for children with cerebral palsy with proven efficacy in increasing muscle strength and anaerobic capacity. Children trained for four months, in groups of 2 to 5, under supervision of their physiotherapist. During the first two months, children trained twice a week for one hour. In the following two months, training frequency was reduced to once a week, allowing children to participate in other physical activities during the intervention as indicated by counselling. Training load was progressively increased during the training period.

The control group continued regular individual paediatric physiotherapy at the physiotherapy practice. The content of the paediatric physiotherapy varied between physiotherapists and involved stretching and task-oriented physiotherapy. The control group did not receive counselling or fitness training.

Children visited the hospital on three occasions for evaluation: at baseline, after six months (end of intervention) and after twelve months. Before the visit, parents completed a questionnaire about their child’s quality of life. To reduce the burden on parents this questionnaire was only completed at baseline and 12 months. Hospital-
based interviews of children assessed self-perception and one of the parents was interviewed regarding their child’s social participation in domestic life and social participation in recreation and leisure. Additionally, parents provided information on the frequency of sports participation of all immediate family members using five categories (from 1=‘never’ to 5=‘daily’), from which a mean score was calculated. Interviews were performed by assessors blinded for group allocation.

Social participation in domestic life and social participation in recreation and leisure were assessed using the Dutch versions of the short-form of the Life-Habits for children version 1.0, and the Children’s Assessment of Participation and Enjoyment. The Life-Habits for children determines the accomplishment of social participation based on the level of difficulty and the type of assistance needed. Domains in which at least 50% of the items involved walking (‘housing’: domestic life), or sports and play (‘mobility’, and ‘recreation’: recreation and leisure) were administered. Assessment is by a ten-point ordinal scale that ranges from ‘not accomplished’ to ‘no difficulty and no assistance’, or ‘not applicable’. To account for differences in the number of applicable items, weighted average domain scores were used for analyses. The separate domains of the Life-Habits for children have good intrarater reliability (intraclass correlation coefficients > 0.91). The psychometric quality of the Dutch version has not yet been investigated. The Children’s Assessment of Participation and Enjoyment determines the frequency of social participation in recreation and leisure over the preceding four months. The domains ‘physical activities’, ‘social activities’, and ‘skill-based activities’ were administered. Frequency of social participation was determined on a seven-point ordinal scale ranging from ‘once in four months’ to ‘once a day’. The Dutch version of this questionnaire has good psychometric properties for children with cerebral palsy aged 7 to 13 years.

Self-perception was measured with a version of Harter’s Self Perception Profile for Children specifically adapted for children with cerebral palsy, using the domains ‘global self-worth’, ‘athletic competence’, and ‘motor competence’ (additional domain in the cerebral palsy version). Children indicated on a four-point scale how much they resembled the children described in two opposite statements. It has been shown that
the Dutch version of Harter’s Self Perception Profile for Children can be used in a clinical situation.21

The parents’ judgment of their child’s quality of life was assessed with the parent-proxy version of the cerebral palsy quality of life questionnaire.22 This questionnaire consists of the domains ‘social well-being’, ‘functioning’, ‘participation’, ‘emotional well-being’, and ‘impact of the disability’. Each item was scored on a nine-point ordinal scale (1:‘feeling very unhappy’ to 9:‘very happy’) and then transformed to a score from 0 to 100 (1=0, 2=12.5,..., 9=100). Validity and reliability of this questionnaire have been established for children with cerebral palsy aged 7 to 13 years.22

For all questionnaires, except for the Life Habits for children, at least 75% of the items in each domain had to be completed to be included in the analyses. For the calculation of the domain scores, we adhered to the procedures described in the questionnaires’ manuals.

The sample size calculation for social participation was based on the Life-Habits for children domain ‘housing’, with power set at 0.7 and alpha set at 0.05, using a standard deviation of the difference of 1.3 points, and an effect size of 10% (1 point).3 A sample size of 22 children per group was required. Allowing for a 10% drop-out rate, 25 children were included in each group.

To determine the intervention effect, intention-to-treat analyses were performed using linear regression analyses (p<0.05). Outcomes at 6 months and 12 months were the dependent variables, with group allocation and the measured outcome at baseline as the independent variables in the analyses. For variables with non-normally distributed residuals, a non-parametric Mann-Whitney U test was used. Age, sex, and frequency of sports participation of the immediate family were included as confounders in the analyses when they changed the intervention effect by more than 10%.

Results

The participant flow, with reasons for exclusion and drop-out, is represented in Figure 1.
Children with cerebral palsy assessed for eligibility (n=110)

Excluded (n=60)
- Not interested (n=22); 9 were too active
- Too busy to participate (n=24)
- Language or logistical problems (n=7)
- Planned botulinum toxin treatment (n=4)
- Wrong address; did not reply (n=2)
- No diagnosis of cerebral palsy (n=1)

Signed informed consent and randomised (n=50)

1 child signed informed consent but dropped out before baseline, due to unexpected botulinum toxin treatment

Baseline

Measured at least one of the outcomes of social participation, self-perception and parent-reported quality-of-life (n=49)
(n=25)                                                     (n=24)

Lost to follow-up at 6 months
- medical reasons (n=1)
- lack of motivation to continue intervention (n=1)

6 months

Measured at least one of the outcomes of social participation and self-perception (n=46)
(n=23)

Lost to follow-up at 6 months
- medical reasons (n=1)
- lack of motivation to continue intervention (n=1)

12 months

Measured at least one of the outcomes of social participation, self-perception and parent-reported quality-of-life (n=45)
(n=23)                                                     (n=22)

Lost to follow-up at 12 months
- lack of motivation (n=1)

Figure 1. Design and flow of participants through the trial.
Children were treated at 13 paediatric physiotherapy practices (n=27) and three special schools for children with disabilities (n=23). The participant characteristics are shown in Table 1. Details of the completion of the intervention have been reported previously. Briefly, families received a median of 5 counselling sessions, fourteen of the 23 families requested physiotherapy at home and children attended, on average, 21 (range: 17-24) of the 24 training sessions (91%). Training load gradually increased over the 24 training sessions (e.g. the loaded sit-to-stand increased from 5.9 kg in the fourth week to 10.6 kg in the final week).

Table 1. Participant characteristics.

<table>
<thead>
<tr>
<th></th>
<th>Started with the study</th>
<th>Lost to follow-up</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>Intervention n=25</td>
<td>Control n=24</td>
</tr>
<tr>
<td>Age (yr), mean (SD)</td>
<td>9.5 (1.5)</td>
<td>10.0 (1.8)</td>
</tr>
<tr>
<td>Sex, n males (%)</td>
<td>12 (48)</td>
<td>16 (67)</td>
</tr>
<tr>
<td>Body height (m), mean (SD)</td>
<td>1.36 (0.11)</td>
<td>1.38 (0.14)</td>
</tr>
<tr>
<td>Weight (kg), mean (SD)</td>
<td>33.4 (8.8)</td>
<td>36.4 (12.6)</td>
</tr>
<tr>
<td>Body mass index (kg/m²)</td>
<td>17.8 (2.7)</td>
<td>18.5 (3.6)</td>
</tr>
<tr>
<td>Gross Motor Function Classification System, n (%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Level I</td>
<td>15 (60)</td>
<td>13 (54)</td>
</tr>
<tr>
<td>Level II</td>
<td>6 (24)</td>
<td>6 (25)</td>
</tr>
<tr>
<td>Level III</td>
<td>4 (16)</td>
<td>5 (21)</td>
</tr>
<tr>
<td>Type CP, n (%)</td>
<td></td>
<td></td>
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<tr>
<td>Unilateral spastic</td>
<td>12 (48)</td>
<td>11 (46)</td>
</tr>
<tr>
<td>Bilateral spastic</td>
<td>13 (52)</td>
<td>13 (54)</td>
</tr>
<tr>
<td>Selective motor control*, (0 to 8)</td>
<td>5.4 (1.8)</td>
<td>4.4 (2.3)</td>
</tr>
<tr>
<td>Wheelchair long distances, n yes (%)</td>
<td>5 (20)</td>
<td>5 (21)</td>
</tr>
<tr>
<td>Orthoses, n yes (%)</td>
<td>17 (68)</td>
<td>15 (62)</td>
</tr>
<tr>
<td>School type, n (%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Regular education</td>
<td>14 (56)</td>
<td>12 (50)</td>
</tr>
<tr>
<td>Special school for children with disabilities</td>
<td>11 (44)</td>
<td>12 (50)</td>
</tr>
<tr>
<td>Family</td>
<td></td>
<td></td>
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<tr>
<td>Siblings, n yes (%)</td>
<td>19 (76)</td>
<td>20 (83)</td>
</tr>
<tr>
<td>Parental marital status, n (%)</td>
<td></td>
<td></td>
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<tr>
<td>Living together</td>
<td>22 (88)</td>
<td>21 (87)</td>
</tr>
<tr>
<td>Single parent</td>
<td>3 (12)</td>
<td>3 (13)</td>
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<tr>
<td>Highest parental educational level, n (%)</td>
<td></td>
<td></td>
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<tr>
<td>High school or intermediate vocational education (low)</td>
<td>14 (56)</td>
<td>13 (45)</td>
</tr>
<tr>
<td>College or university degree (high)</td>
<td>11 (44)</td>
<td>11 (46)</td>
</tr>
<tr>
<td>Sport frequency immediate family*, (1 to 5)</td>
<td>2.7 (1.0)</td>
<td>3.3 (0.9)*</td>
</tr>
</tbody>
</table>

* A higher score means better selective motor control, or higher sport frequency; CP=cerebral palsy; * p<0.05.
Table 2. Mean (SD) of each group at each measurement occasion, and mean (95% CI) differences between groups for social participation.

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th>Baseline</th>
<th>Month 6</th>
<th>Month 12</th>
<th>Month 6 minus Baseline</th>
<th>Month 12 minus Baseline</th>
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<tr>
<td><strong>CAPE (1 to 7)</strong></td>
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<td></td>
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<tr>
<td>Active physical</td>
<td>1.16 (0.47)</td>
<td>1.15 (0.71)</td>
<td>1.40 (0.32)</td>
<td>1.41 (0.52)</td>
<td>1.25 (0.61)</td>
<td>1.27 (0.68)</td>
<td>-0.01 (-0.23 to 0.22)</td>
<td>-0.05 (-0.40 to 0.30)</td>
<td></td>
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<tr>
<td>Social activities</td>
<td>2.92 (0.81)</td>
<td>3.05 (0.72)</td>
<td>3.00 (0.79)</td>
<td>3.37 (0.79)</td>
<td>2.95 (0.95)</td>
<td>3.30 (0.71)</td>
<td>-0.23 (-0.75 to 0.12)</td>
<td>-0.17 (-0.59 to 0.26)</td>
<td></td>
</tr>
<tr>
<td>Skill-based</td>
<td>1.18 (0.52)</td>
<td>0.97 (0.56)</td>
<td>1.03 (0.68)</td>
<td>0.90 (0.66)</td>
<td>0.95 (0.46)</td>
<td>0.94 (0.64)</td>
<td>-0.04 (-0.39 to 0.31)</td>
<td>-0.23 (-0.49 to 0.03)</td>
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<tr>
<td><strong>Life-H kids (1 to 10)</strong></td>
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<tr>
<td>Housing</td>
<td>7.90 (1.88)</td>
<td>8.76 (1.16)</td>
<td>8.15 (1.68)</td>
<td>8.33 (1.56)</td>
<td>8.70 (1.19)</td>
<td>8.23 (1.43)</td>
<td>0.38 (-0.67 to 1.43)</td>
<td><strong>0.92 (0.10 to 1.74)</strong></td>
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<tr>
<td>Mobility</td>
<td>7.58 (1.61)</td>
<td>7.66 (1.67)</td>
<td>7.59 (1.65)</td>
<td>8.09 (1.32)</td>
<td>7.56 (1.89)</td>
<td>7.99 (1.43)</td>
<td>195 (-0.17)</td>
<td>193 (-0.11)</td>
<td></td>
</tr>
<tr>
<td>Recreation</td>
<td>7.89 (2.07)</td>
<td>8.16 (1.88)</td>
<td>8.09 (2.00)</td>
<td>8.71 (1.49)</td>
<td>7.98 (2.35)</td>
<td>8.26 (1.88)</td>
<td>220 (-0.04)</td>
<td>201 (-0.04)</td>
<td></td>
</tr>
</tbody>
</table>

Int=Intervention group; Con=Control group; CAPE=Children’s Assessment of Participation and Enjoyment; Life-H kids=Life-Habits kids questionnaire; a Adjusted for baseline values and adjusted for age, sex, and sports frequency of the immediate family if necessary; b A higher score reflects higher frequency of participation; c A higher score reflects a better accomplishment of participation (less difficulty and/or less use of assistance); d The Life-H kids domain ‘recreation’ was completed for 22 children in the control group at baseline and at six months, and completed for 21 children in the control group at twelve months; Significant intervention effects are marked in bold text; †=Intervention effect in favour of the intervention group; U=Mann-Whitney U test; r=effect size (Z/√N).
Table 3. Mean (SD) of each group, and mean (95% CI) difference between groups for self-perception and quality-of-life.

<table>
<thead>
<tr>
<th>Groups</th>
<th>Baseline</th>
<th>Month 6</th>
<th>Month 12</th>
<th>Differences between groups, mean (95% CI)</th>
<th>p-value</th>
</tr>
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<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Month 6 minus baseline</td>
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<td></td>
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<td></td>
<td>Month 12 minus baseline</td>
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</table>

**SPPC (1 to 4)**

- **Athletic competence**: 2.85 (0.46) vs. 3.03 (0.51), 0.07 (-0.20——0.35) (p=0.59), 0.08 (-0.20——0.35) (p=0.57)
- **Motor competence**: 3.14 (0.51) vs. 3.18 (0.42), -0.07 (-0.31——0.16) (p=0.53), 0.01 (-0.23——0.24) (p=0.94)
- **Global self-worth**: 3.41 (0.40) vs. 3.39 (0.51), 0.07 (-0.22——0.36) (p=0.63), 0.03 (-0.23——0.30) (p=0.80)

**CP-QOL (0 to 100)**

- **Social well-being and acceptance**: 75.9 (8.4) vs. 75.4 (11.9), Na vs. Na, -3.1 (-7.9——1.7) (p=0.19)
- **Functioning**: 71.1 (8.6) vs. 71.3 (11.4), Na vs. Na, -2.5 (-7.3——2.3) (p=0.30)
- **Participation and physical health**: 65.5 (11.6) vs. 67.2 (16.5), Na vs. Na, -0.8 (-5.7——4.1) (p=0.75)
- **Emotional well-being and self-esteem**: 77.7 (8.2) vs. 79.7 (15.1), Na vs. Na, -0.3 (-5.3——4.7) (p=0.90)
- **Pain and impact of the disability**: 30.5 (16.8) vs. 32.9 (21.0), Na vs. Na, 5.0 (-5.2——15.2) (p=0.33)

Int=Intervention group; Con=Control group; SPPC=Harter’s Self-perception Profile for children (adapted for children with CP); CP-QOL=cerebral palsy quality-of-life questionnaire; a Adjusted for baseline values and adjusted for age, sex, and sports frequency of the immediate family if necessary; b A higher score reflects a higher self-perception, or a higher parent-reported quality-of-life; c A higher score reflects being bothered more by the disability; Na=Not assessed at six months.
There was a significant positive effect for social participation in domestic life at 12 months (mean between-group difference=0.9, 95% CI 0.1 to 1.7, p=0.03), but not at 6 months (p=0.47) (Table 2). There were no significant intervention effects for social participation in recreation and leisure at 6 months or at 12 months (Table 2). Social participation scores were missing for two children at 6 months and for three children at 12 months.

There were no significant intervention effects for the child’s self-perception at 6 months and 12 months or for parent-reported quality of life at 6 months (Table 3). One child did not complete the interview on self-perception at baseline and was excluded from these analyses. One other child did not complete the interview at 12 months and three parents did not complete the quality of life questionnaire at 12 months.

Discussion

To our knowledge this study is the first to evaluate the effect of a physical activity stimulation programme on social participation, self-perception, and quality of life in this population. We found that although a programme to stimulate physical activity did not improve social participation, self-perception or quality of life in general, there was a small positive long-term effect on social participation in domestic life.

The positive effect found for social participation in domestic life at 12 months indicates that the intervention group had less difficulty in performing activities in and around the home on the longer term. Although performing multiple statistical tests over the different time points increases the chance for a type-I error, the effect size of +0.9 point (+12%) seems relevant in light of the one point difference in social participation between children with cerebral palsy and children developing typically. In addition, the improvement in social participation in domestic life is in accordance with expectations, since counselling was aimed at expanding physical activity in daily life with a strong focus on activities in and around the home, and the home-based physiotherapy component of the physical activity stimulation programme involved practising activities in and around the home. Our findings therefore support the notion that a combination of counselling and home-based physiotherapy may have greater potential to improve
social participation in domestic life than regular paediatric physiotherapy, although this should be confirmed in future studies.

Although we found no evidence for an effect of the physical activity programme on improved physical activity and sports club participation, an improved accomplishment of social participation in domestic life, particularly at follow-up, is promising. Expanding activities in and around the home may be more feasible for children with cerebral palsy than expanding the frequency and intensity of physical activity and sports activities. However, whether less difficulty in performing activities in a domestic situation leads to increased physical activity in and around the home over the longer term, thus counteracting the vicious cycle of deconditioning, should be confirmed by future research.

Social participation in recreation and leisure was assessed using two questionnaires that provide different information: the Children’s Assessment of Participation and Enjoyment questionnaire measures the frequency of social participation, whereas the Life-Habits for children questionnaire assesses the accomplishment (difficulty and assistance needed) of social participation in children with cerebral palsy. We could not demonstrate an effect on social participation in recreation and leisure for both questionnaires. This might be explained by environmental barriers that are hard to modify such as absence of proper sport accommodation and transportation, limiting factors that may be difficult to change in the short term. The contrast with the clinically relevant improvement found for social participation in domestic life supports this hypothesis, since activities in and around the home may be less influenced by environmental barriers.

We were unable to find any previous studies describing the effects of physical activity stimulation on social participation. However, the positive effects on social participation in recreation and leisure reported after aerobic and anaerobic training in older children with cerebral palsy, and the lack of effect after lower-extremity strength training in school-aged children with cerebral palsy, illustrate the current lack of clarity regarding the role of fitness training in improving social participation in recreation and leisure.
That the effects of the current programme on social participation in domestic life were only seen at follow-up suggests that a longer period of counselling, with a focus on alternatives to physical activity in the community, may be needed to improve social participation in recreation and leisure. However, this should be the subject of further research.

The physical activity stimulation programme was not effective in improving the child’s self-perception and quality of life. Since it has previously been shown that parents generally rate their child’s quality of life lower than the children themselves, we used both interviews of the child’s self-perception, as well as parent-reports of the child’s quality of life. However, none of the outcomes showed any effect, despite positive trends for gross motor capacity, attitude towards sports (described previously), and an improvement in social participation in domestic life (this publication). No information was available on the effects on quality of life after a physical activity programme for adolescents with cerebral palsy. However, positive effects on child-reported and parent-reported quality of life have been reported for fitness training in children with cerebral palsy, but only in the short-term. One possibility is that our assessment of self-perception and quality of life at respectively two and eight months after finishing the fitness programme, and the lack of effect on physical activity (previously described), explains the lack of an effect on quality of life in the present study. Nevertheless, the present findings suggest that our physical activity stimulation programme did not have added value with respect to regular physiotherapy for improving self-perception and quality of life of children with cerebral palsy.

A limitation of this study was the small size and heterogeneity (Gross Motor Function Classification System level I-III) of the study sample. Nevertheless and despite the small sample size, a substantial between-group improvement was found for social participation in domestic life. Future research should examine the effects of a physical activity stimulation programme on social participation in a larger and more homogeneous sample.

A strength of this study was that it was the first to evaluate the effects of a physical activity...
programme on social participation, self-perception, and quality of life in children with cerebral palsy in a randomized controlled trial with blinded assessments. Furthermore, the home-based physiotherapy and fitness training programme were provided by the child’s regular paediatric physiotherapist, which increases the generalizability of the results.

In conclusion, the physical activity stimulation programme presented here, incorporating counselling through motivational interviewing, home-based physiotherapy, and fitness training, was not effective in improving social participation, self-perception and quality of life, but did show potential in improving social participation in domestic life over the longer term. This may indicate that expanding activities in and around the home is a more practical and feasible alternative for children with cerebral palsy than expanding activities in the community such as sports, although this conclusion needs to be confirmed by future research. In conclusion, future studies should determine whether an increased focus on alternatives to social participation in recreation and leisure, including activities in and around the home, has added value in improving physical activity.

References
8. Carlon S, Taylor N, Dodd K, Shields N. Differences in habitual physical activity levels of young people with cerebral palsy and their typically developing peers: a systematic review. Disabil Rehabil
Effects of a physical activity program for children with CP on participation and quality of life


