Chapter 4

Children with Profound Intellectual and Multiple Disabilities: the effects of functional movement activities.

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Abstract

**Objective**
To determine the effect of functional movement activities within the MOVE (Mobility Opportunities Via Education) curriculum on the independence of children with profound intellectual and multiple disabilities (PIMD).

**Subjects**
44 children with PIMD.

**Setting**
Centres for special education (CSE).

**Design**
A quasi-experimental pretest-posttest with control-group design.

**Intervention**
The children in the control group (n=12) were supported by the regular programme at the CSE. The children within the experimental group (n=32) were additionally supported by the MOVE curriculum.

**Method**
Both group comparisons and individual analyses were conducted.

**Results**
The level of independence of the experimental group increased significantly in performing movement skills; the control group did not increase significantly. At an individual level, 20 children (63%) of the experimental group improved in comparison with the control group, in which 4 children (33%) improved.

**Conclusion**
Results showed that the children receiving functionally focused activities achieved the greatest improvements in independence when performing movement activities. For children with PIMD, even a slight improvement in this independence can have enormous impact on participation and control over their own existence.

**Keywords**
Profound Intellectual and Multiple Disabilities; functional movement activities; Mobility Opportunities Via Education (MOVE)
Introduction

Children with profound intellectual and multiple disabilities (PIMD) have a wide variety of severe and profound disabilities that are related to each other in a range of complex ways. The extent and nature of these disabilities means that these children are heavily dependent on their direct support persons (DSP), i.e. parents, teachers and support staff, for all aspects of their daily existence. Despite their disabilities and the high degree of dependency of these children, it is nevertheless assumed that it is possible to influence their independence in certain fields to a certain degree. Independence for this specific group of children means providing them with the opportunity to exercise more control over their own existence, over their environment and over the things that happen to each individual child. For example, by providing a child with more ways to communicate through a mechanical means of communication will enable that child to better indicate whether or not he or she wants to participate in an activity. This can be achieved by training an arm or hand to function in such a way that the child can operate the means of communication, thus promoting the child’s participation. These changes towards the teaching of functions and skills supposed to lead to changes in the policy and actions of DSP in practice and thus to improved participation of the children. Consequently, the interventions offered to children with PIMD must focus on and be evaluated in terms of functional outcome and independence.

The starting points of the American curriculum ‘Mobility Opportunities Via Education’ (MOVE) appear to fit in well with current developments in how children with PIMD are being supported. This curriculum aims to enhance the independence and participation of the child by training functional movement skills. Enabling a child to move independently, whether or not with the help of apparatus, means that the child can choose where it wants to go, thus enhancing participation and independence in the sense of ‘more control over the own life’. What is unusual about MOVE is the idea that children with PIMD, just like children with no disabilities, can and must be activated, and that the children can thus benefit from the positive effects generated. The idea that independence and participation can be influenced by the motor system is supported by recent research that reveals that people with PIMD are able to master skills and, for example, to communicate and to move by means of a range of technical devices. In addition, MOVE starts with the skills a child already has and the training is integrated into the daily routine where the child is supported by all the DSP. These starting points contradict interventions that mainly emphasize a child’s limitations and focus on the recovery of function for a child with PIMD. In this ‘medical model’, the therapy services provided are separated from educational goals and treatment is theoretically based on a developmental model in which the therapist attempts to correct deficits and remediate underlying processes of movement to promote normalization. The shift in services towards a model of ‘support’ or educational viewpoint, as with the MOVE curriculum, results in the integration of therapy and educational services and emphasizes functional outcomes. We assume that the independence in performing movement skills in children with PIMD supported by a functionally focused curriculum increases in contrast to children with PIMD supported with a curriculum based on the ‘traditional medical model’.

In spite of extensive implementation of the MOVE curriculum in a large number of schools for special education, rehabilitation facilities and centres for individuals with disabilities across the USA as well as throughout Asia and Europe, little research has been conducted into the effectiveness of the MOVE curriculum especially where children with PIMD are concerned. Although the studies that have been conducted yield some clear positive results, they do have significant shortcomings, including small sample size, relatively short intervention phases and the
lack of control groups. In addition, the studies focus on individuals who are mildly or severely disabled. Information on the effectiveness of the MOVE curriculum derived from these research projects cannot therefore be generalized to a group of children with profound intellectual and multiple disabilities.

Because of its interesting starting points and expected positive effects, the MOVE curriculum has been implemented in centres for special education (CSE) and institutions for individuals with intellectual disabilities across the Netherlands. In a previous research project, we examined the effectiveness of the MOVE curriculum for children with PIMD from different perspectives. In particular, we used a research design that involved groups of children rather than analyses of single cases. This research only partly supported the assumption that MOVE has a positive effect on the anatomical-physiological domain in children with PIMD. It is unclear whether the functionally focused activities also result in positive effects on the motor domain in children with PIMD. Therefore, the current study asked the following question: does independence in performing movement skills in children with PIMD improve as a result of the functional movement activities of the MOVE curriculum.

**Method**

**Participants**

A total of 44 children (23 boys and 21 girls) aged between 2 and 16 years (mean: 9.3; SD: 3.8) participated in this study. All participants are children with PIMD. The children have an estimated intelligence quotient of 25 points or less, are nonambulant and either cannot use their arms and hands or only to a limited extent. Besides the profound intellectual and severe or profound motor disabilities, these children also suffer from additional problems, such as sensory disorders, seizure disorders and medical problems such as reflux, recurrent respiratory infections, etc. The children live at home and attend a CSE during the day.

The participants were recruited from seven CSEs throughout the Netherlands. Before the study started, five of these CSE were planning to implement the MOVE curriculum as part of their services. Children who met the following criteria were selected from these CSEs to serve as the experimental group: 1. diagnosed as PIMD, and 2. eligible to participate in the MOVE curriculum. In total, the experimental group consisted of 32 children with PIMD (17 girls, 15 boys; mean age 8.8 years). Children diagnosed as PIMD were selected to serve as the control group from the two CSEs where the MOVE curriculum was not part of the regular services. This control group consisted of 12 children with PIMD (4 girls, 8 boys; mean age 10.6 years). The two research groups were clinically comparable in terms of the functions and/or skills the children already had. However, due to the variety and combination and type of disabilities, each child has his own functions and limitations. This makes the group of children with PIMD a heterogeneous one. The setting, the CSE, was comparable for both research groups. Written informed consent was obtained from the parents for all selected children to participate in the study.

**Design**

A quasi experimental pretest-posttest with control group design was used. In the experimental and control group, the independence in performing movement skills was measured twice with a 12-month interval between the measurements. In the experimental group, independence when performing movement skills was measured before the implementation of the MOVE intervention and 12 months after the implementation of MOVE. In the control group, independence when performing movement skills was measured twice with a 12-month interval.
Instrument

The amount of independence when performing movement skills was determined by the ‘Top Down Motor Milestone Test’ (TDMMT). The TDMMT consists of 16 movement skills derived from the skills sitting, standing and walking, organized into 16 categories. Each movement skill consists of several items or motor milestones. Mastering the motor milestones corresponds with a level of ‘independent mobility’. The amount of independent mobility is expressed by four levels (grad level, level I, level II and level III). Recent research showed that each of the 16 movement skills (categories) consists of items that form a unidimensional hierarchical scale. The movement skills can be explained by a single underlying factor that expresses the amount of independence in performing movement skills. The inter-rater reliability as well as the test-retest reliability of the TDMMT is satisfactory.

Procedure

In the experimental situation, the MOVE curriculum was implemented at the CSE by means of a structured protocol. All DSP were trained by an internationally qualified MOVE trainer. During implementation of the MOVE curriculum, the TDMMT was scored by a team consisting of the child’s DSP. When it was not certain whether a child could master a particular item, the child’s therapist double-checked it. Twelve months after the MOVE activities started, the TDMMT was scored again by the same team. In the control group, the TDMMT was scored identically twice with a 12-month interval.

Intervention

The children in the control group received the regular educational program carried out at the CSE. This programme consists of various learning and play activities that take place in a group context. In addition, the children received individual therapies such as physical therapy. All but one of the children in the control group received physical therapy twice a week. The treatment approach provided tended to be specifically based on a developmental model e.g. Neurodevelopment Treatment (NDT) and Vojta. The activities were supported by a physical therapist and primarily performed in a therapy room during special therapy hours. Each session took 30 minutes. The therapy aims were described in general terms such as ‘prevent or reduce contractures and deformities’, ‘normalization of tonus and or relaxation’, ‘increase or maintain skills such as walking a few steps or maintaining a sitting position’, ‘facilitate symmetry’, ‘normalization of sensory stimuli processing’ and ’to offer different positions’.

The MOVE curriculum for the children in the experimental group was added to the regular program at the CSE and implemented by an internationally recognized MOVE trainer by means of a protocol. Goals were set for each child in close consultation with the DSP. Existing therapy goals were integrated into the MOVE goals. The MOVE goals were formulated in concrete terms and were concerned with increasing functional or movement skills such as ‘Kevin can move independently with the help of a gait trainer, both inside and outside’ and ‘social functioning’ such as communication, interaction with contemporaries and playing. For example, ‘Within a year, Emma was able to pull herself up into a standing position to see what was on a low table, and with support for torso and lower arms is able to stand for three minutes so that she can play a game’. For each goal, decisions were made concerning the type, frequency and duration of the MOVE activities to be performed in order to reach this goal. All activities focussed on sitting down/being seated, standing up/standing or walking. Only those skills that the child could use immediately in his natural environment were trained. The ‘MOVE activities’ were integrated into the daily routine of the child and supported by all the child’s DSP. During each activity, the children were
encouraged to be as active as possible and to function at their highest potential. For instance, when a child arrives at the CSE, the DSP supports the child when walking (with or without a walking aid) and gives only the support the child needs. Or during play activities the child sits in a special MOVE chair with only the support he needs while playing. In addition, therapy sessions continued with the same duration and frequency; however, the therapist(s) now continued to support the child when performing the MOVE activities in the child’s daily environment.

Analysis
The analysis of the TDMMT scores has taken the adaptations suggested by Van der Putten and colleagues into account. This has resulted in a changed order for some items within the TDMMT categories, and an adapted organization of the items within the four levels. The TDMMT scores have been determined as follows. First, for each of the 16 movement skills it was determined which ‘motor milestone’ (item) was scored positively. Second, this ‘motor milestone’ was related to the corresponding level of independence whereby ‘level III’ corresponds to a score of ‘1’ and ‘grad level’ with a score of ‘4’. A score of ‘0’ was given if the child did not master one of the items of the movement skills. Finally, a composite score was calculated from the 16 level scores. Theoretically, this score can range between 0 (none of the items were scored positively) and 64 (the highest level was scored within every category). This final score expresses the level of independence in performing movement skills. A higher score thus expresses a greater independence.

Two kinds of analyses were conducted: group comparisons and individual analysis. In the group analysis, a Mann-Whitney test was used to determine a significant difference in independence when performing movement skills between both groups at the first measurement. A Wilcoxon signed ranks test was used for both groups to determine whether the independence had changed significantly between the measurements. Effect was said to be significant if the probability level of a type I error was .05 or less. Mean differences were standardized to quantify an intervention’s effect in units of standard deviation, and thus allow comparison of the different outcomes of a intervention, independently of the measuring units. The resulting statistical measure is called the effect size index (ES). The ES was calculated in cases where significant changes were detected. Corrections were made for the correlation between the combined observations. An ES <. 20 was judged as ‘trivial’, an ES ≥ .20 < .50 as ‘small’, an ES ≥ .50 < .80 as ‘moderate’, and an ES ≥ .80 as ‘large’. Because of the heterogeneity and small size of both groups, individual analyses were also performed. The individual changes from pretest to post-test were examined for each child.

Results
Group comparison
Table 1 presents the level of independence in performing movement skills at the first and second measurements (mean and standard deviation (SD)) for the experimental and the control group. A higher score expresses more independent functioning.
Table 1  Level of independence when performing movement skills at the two measurements for the experimental and the control group

<table>
<thead>
<tr>
<th>Group</th>
<th>Measurement 1</th>
<th>Measurement 2</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Min</td>
<td>Max</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Experimental</td>
<td>8.0</td>
<td>50.0</td>
</tr>
<tr>
<td>$n=32$</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Control</td>
<td>8.0</td>
<td>58.0</td>
</tr>
<tr>
<td>$n=12$</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Min: minimum  
Max: maximum  
SD: standard deviation

At the pretest, the level of independence of the experimental group was slightly below the level of independence of the control group. This difference between the two groups was not statistically significant ($Z=-.29$, $p=.77$). In the experimental group, the level of independence in performing movement skills increased after twelve months MOVE intervention ($Z=-3.48$, $p=.001$). This effect can be called ‘moderate’ (ES=.69). In the control group, the level of independence when performing movement skills also increased but this change was not statistically significant ($Z=-.93$, $p=.351$). In both groups, additional analyses were conducted into the effects of extreme scores. In both groups, the independence when performing movement skills increased unexpectedly highly for two children. Analysis omitting these children yielded the same results. Figure 1 illustrates the level of independence when performing movement skills for both groups.

Figure 1  Level of independence when performing movement skills for the experimental and the control group at both measurements

Individual analysis

Figure 2 shows the difference in the TDMMT scores between the pretest and the posttest for the experimental group. Each column gives the difference score for one child. An increase in the level of independence when performing movement skills is presented as a bar above the x-axis, a decrease appears as a bar underneath this axis. Figure 3 presents the same information for the children in the control group.
In the experimental group, the level of independence when performing movement skills increased for 20 children (63%). In the control group, the level of independence when performing movement skills increased for four children (33%). Furthermore, the independence of four (13%) children involved in the MOVE curriculum decreased in contrast with the children in the control group. In the control group, the independence when performing movement skills decreased for three children (25%). In the experimental and control groups, respectively eight (25%) and five (42%) children did not change their level of independence.

Figure 2  Individual scores of the children in the experimental group

Figure 3  Individual scores of the children in the control group
Discussions

The objective of this study was to examine the effects of a functionally focussed curriculum (MOVE) on the independence when performing movement skills of children with PIMD. The assumption that independence increases significantly in a group of children with PIMD supported by a functionally focused curriculum is confirmed. This change can be interpreted as a relevant clinical outcome with a moderate effect size. The level of independence when performing movement skills of children with PIMD who were supported by a regular program at the CSE did not change significantly over time. In addition to positive effects at group level, the movement activities within MOVE have also resulted in positive results on an individual level. Over half of the children supported by the functional curriculum improved their independence when performing movement skills during the 12-month experiment.

Within the research, the children were not divided over the two research groups at random, which could threaten the internal validity. However, both groups were clinically comparable in terms of their functions, the ability to perform activities and in terms of participation and independence. Any differences there were between the two groups were assumed not to have any significant influence on the results. After all, heterogeneity in terms of functions and skills is characteristic of a group of children with PIMD. Furthermore, the participants may be considered to be representative of the total group of approximately 1350 children with PIMD who attend a CSE. The CSE are also comparable with respect to group size, educational level of staff and educational programs. The setting for the research is also comparable with settings in other countries where MOVE is employed, such as the USA, the UK and Germany. However, the current study provides no insight into how far the results can also be generalized to individuals with less profound disabilities or in settings such as residential facilities or community homes for individuals with intellectual disabilities. With regard to age, the children in the control group were on average slightly older than the children in the experimental group. This is a possible selection bias, and the difference found between the two groups may be explained by the fact that younger children can ‘develop’ more than older ones. However, the age difference between the two groups is not statistically significant. Another threat to the internal validity may be in the area of instrumentation. Both groups of children had average scores on the TDMMT that were very low; the average in the pretest was about 20 points for both groups and the median within both groups was 13 points. More detailed analyses revealed that of those children who scored under the 50th percentile at the first measurement, those who followed the MOVE curriculum increased their independence when performing movement skills whereas those who were in the control group decreased. This difference is not present in children who scored above the 50th percentile. Although these results need to be interpreted with care due to the small size of the research groups, they do offer valuable starting points for both practical and academic research.

The results of the current study show that the children within the MOVE group increased their independence when performing movement skills more than a group of children following a regular programme. However, this does not yet provide insight into precisely which part of the MOVE curriculum is the most effective (‘critical component’). The MOVE group may be undergoing more intensive training than the control group, which may play a role in the results. Thus far, however, it is still unclear whether intensity is a parameter for the effect to be achieved. The differences in type of activity, ‘functional’ versus ‘non-functional’, between the two research groups may be the cause of the results. Research by Ketelaar has shown that children with CP who follow a functional curriculum show more advances in the acquisition of functional skills than children who follow a traditional curriculum. Elkins has also found an effect from functional activities in the form of the MOVE curriculum when compared with a traditional programme for children with severe multiple disabilities.
Within the current study, the children who were supported by the ‘functional’ MOVE curriculum improved more than children who were supported by the regular programme and regular physiotherapy. That the demonstrated difference between the two groups is small. Current physiotherapy already concentrates more on achieving ‘functional’ effects than in the time when the MOVE curriculum was developed. Finally, ‘specific measurable goals’ were established within the experimental group in consultation with the DSP of the child. This focus in the sense of how goals are formulated is regarded as an important parameter when acquiring skills or movement skills. This is different from drawing up more ‘generalized aims’, which happened within the control group. Further research into aspects such as intensity, kind of activity and focus as well as the possible discrepancy between the planned and performed activities should provide more insight into precisely which part of MOVE is ‘the most effective’. This will then provide starting points for further developing the curriculum and the way that MOVE should be implemented within the care process for children with PIMD. In addition, follow-up research with larger groups of children should reveal the role played by age and level of independence or the level of disability and/or abilities of the children when acquiring independence when performing movement skills. The results of this research suggest, for example, that it is mainly the children who scored very low at the start of the study, who benefit the most from a functional curriculum. If this can be confirmed, it would have practical consequences on which children, and possibly at which ages, MOVE can best be implemented in the support of these children.

The results of this study provide insight into the effects of a functional movement curriculum when compared with a regular programme offered to children with PIMD who attend a CSE. The general conclusion is that a functional movement curriculum such as MOVE may possibly have added value for children with PIMD in acquiring independence when performing movement skills and that a curriculum such as MOVE could form part of the total package of activities and interventions within a CSE. This has clear implications for practice with regard to both the content and organizational aspects of care for children with PIMD. In concrete terms, this means the possible integration of functional activities within the entire day programme, performed by all the child’s DSP and directed towards specific measurable goals set within a multidisciplinary framework. Despite the apparently limited possibilities of this group of children, the interventions offered should be directed towards increasing the independence of the child, although this may appear minimal. For example, by enabling a child to move small distances himself with only the support of a walking frame gives him a great deal of say over where, when and with whom he wants to be, and whether he wants to participate in a group activity. Thus a limited increase in independence, possibly achieved through a programme such as MOVE, has a great effect on a child when directed towards the acquisition of autonomy and control over his own life.

Clinical messages

- Children with PIMD, despite their limited possibilities, can increase their independence when performing movement activities.
- Small improvements in their independence can have large effects on the life of children with PIMD.
- A functional curriculum such as MOVE should form part of the total care package for children with PIMD.
References


