Moving towards independence? Evaluation of the 'Mobility Opportunities Via Education' curriculum with children with profound intellectual and multiple disabilities
van der Putten, Annette

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Chapter 6
A functionally focussed curriculum for children with profound multiple disabilities.
A goal analysis

Annette van der Putten¹, Koop Reynders¹, Carla Vlaskamp² & Han Nakken²
¹Institute of Human Movement Sciences, University of Groningen, the Netherlands
²Department of Educational Psychology, University of Groningen, the Netherlands

**Abstract**

**Background**
This study analysed goals formulated in a functionally focussed curriculum called Mobility Opportunities Via Education™ (MOVE).

**Method**
The subjects were 49 children with profound multiple disabilities (PMD) who attended a centre for special education where the MOVE curriculum was implemented. Each goal was analysed to see whether or not it was formulated in terms of concrete skills. Furthermore, each goal was analysed for its objective and it was decided whether or not the goal focused on the child’s interests. The three aspects were analysed separately, so the percentages cannot be added up.

**Results**
96% of the goals were formulated in terms of concrete skills. With regard to the objectives, 53% of the goals dealt with mobility skills and 23% were related to social functioning. Only 14% of the goals dealt with aspects related to care. In 52% of the analysed goals it was made clear what the interest of the child was.

**Conclusions**
Goals formulated for children with PMD by a curriculum that is based on functionality did not completely satisfy theoretical principles. This can be partially explained because the concept of functionality is a broad and unspecific notion that can be implemented in various ways.

**Keywords**
functionality, goal analysis, MOVE curriculum, profound multiple disabilities
Introduction
Professionals in the field of education of children with disabilities increasingly concentrate on the assessment and training of functional skills rather than on isolated impairments (Haley 1992; Barnes & Whinnery 2002). This ‘functional approach’ focuses on the performance of meaningful functional activities whereby explicit attention is given to the physical and social environment in which the functional task is to be performed (Ketelaar et al. 1998). Although, functionality is a broad and general notion, which differs by patient group, the basic theoretical principles are the same.

In the slipstream of the development towards a ‘functional approach’, a functionally oriented curriculum for children with (profound) multiple disabilities was developed by Bidabe & Lollar (1995). In this curriculum, Mobility Opportunities Via Education™ (MOVE), movement and activity play a crucial role. The purpose of the MOVE curriculum is to improve functional skills such as expressive language, play and eating and drinking in order to increase independence (Bidabe & Lollar 1995; Barnes & Whinnery 2002). The MOVE curriculum focuses on the basic minimal motor skills of sitting, standing and walking and the functional activities derived from these skills (Bidabe & Lollar 1995; Burton & Miller 1998). Attention is paid to the improvement of skills as well as to the amount of support needed to carry out skills. Quality of movement is given less priority and no attention is paid to the sequence of normal infant development where the acquisition of skills is concerned. Only those skills are trained that are appropriate for the individual and which are necessary in everyday life.

Since the 90s, the MOVE curriculum has spread to a great number of schools for special education, rehabilitation facilities and centres for individuals with disabilities across the United States as well as throughout Asia and Europe (Barnes & Whinnery 2002). In Europe, for instance, the MOVE curriculum is used in England, Germany, Spain, Switzerland, Italy, Denmark, Scotland and The Netherlands. In The Netherlands, the MOVE curriculum is mainly implemented in centres for special education (CSE) and institutions for individuals with intellectual disabilities.

The MOVE curriculum is strongly goal-oriented, whereby goals are formulated in interaction with the parents and the direct support persons (DSP) of the child. In general, goals are considered to be an essential component of an Individual Education Plan. Goals express vision about the future and guide the provision of instruction (Sigafoos et al. 1993; Giangreco et al. 1994). Goals stated in a functional framework should also be formulated in terms which are in accordance with the principle of functionality (Rothstein 1994). If goals include functionality in their content, the classroom activities for children with PMD will have a functional character. As a consequence, changes can be expected to occur in the ‘functional domain’ because goals can be seen as learning outcomes (Giangreco et al. 1994).

The central research questions in the current study are: What is the content of goals defined for children with PMD who participate in a functionally focused educational curriculum, and is this content consistent with the theoretical basis of the curriculum? It is expected that ‘MOVE goals’ are formulated in concrete skills, the objective aims at the improvement of functional skills and that the goals focus on the child’s interests.

Method
Subjects and setting
In this study, 49 children with PMD (25 females and 24 males) participated (mean age 8.1 years, SD 3.9 years). The children were recruited from 17 groups of six CSE throughout the Netherlands. Before the study started, all CSE were planning to implement the MOVE curriculum as part of their services. All children from the six CSE who met the following criteria were selected:
• Diagnosed as ‘profound multiple disabled’; having such profound intellectual disabilities that no standardised tests are applicable to test the intellectual level and having profound motor disabilities (Nakken & Vlaskamp 2002).
• Eligible for participating in the MOVE curriculum (Bidabe & Lollar 1995).
• Written informed consent obtained by the parent(s).
All selected children were non-ambulant and required extensive assistance to accomplish everyday tasks. Besides the intellectual and motor disabilities they also have sensory impairments and/or suffer from other common disorders. The predominant diagnosis and disorders, as recorded in the medical files of the children are presented in Table 1.

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cerebral palsy</td>
<td>20</td>
</tr>
<tr>
<td>Syndrome like Angleman’s syndrome, Rett’s syndrome etc.</td>
<td>16</td>
</tr>
<tr>
<td>Microcephaly</td>
<td>4</td>
</tr>
<tr>
<td>Chromosome malformations</td>
<td>2</td>
</tr>
<tr>
<td>Other</td>
<td>3</td>
</tr>
<tr>
<td>Unknown</td>
<td>4</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Disorders</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Profound spasticity</td>
<td>22</td>
</tr>
<tr>
<td>Hypotonia</td>
<td>12</td>
</tr>
<tr>
<td>Visual disorders</td>
<td>18</td>
</tr>
<tr>
<td>Auditory disorders</td>
<td>3</td>
</tr>
<tr>
<td>Seizure disorders</td>
<td>35</td>
</tr>
<tr>
<td>Intestinal disorders</td>
<td>8</td>
</tr>
<tr>
<td>Chronic lung problems</td>
<td>7</td>
</tr>
<tr>
<td>Problems with food ingestion</td>
<td>7</td>
</tr>
<tr>
<td>Behaviour problems</td>
<td>5</td>
</tr>
</tbody>
</table>

During the day, the children attended a class in a CSE. CSE are exclusively intended for children with intellectual disabilities. The children get an educational programme including learning activities and different kinds of therapies like physical therapy and occupational therapy (Willems 1997). Each group had an average ratio of two teachers for seven students.

**Procedure**

At the CSE, the MOVE curriculum was implemented with use of a structured protocol by a qualified international MOVE trainer. For each child, ‘MOVE goals’ were formulated in interaction with the parents and DSP of the child. The content of the goals was defined with use of a questionnaire developed by Bidabe & Lollar (1995; see Table 2). The researchers collected the goal descriptions by studying the children’s files.
Table 2  Questionnaire used in the goal-setting procedure for the MOVE curriculum (Bidabe & Lollar 1995)

<table>
<thead>
<tr>
<th>Questionnaire</th>
</tr>
</thead>
<tbody>
<tr>
<td>The following questions will be asked during a meeting in which the goals will be defined.</td>
</tr>
</tbody>
</table>

To the participant or the parents of the participant:
What do you, as parents, think your child wants to learn or be able to do?

To the parents of the participant:
As parents, what do you wish your child could do?
Which activity is difficult for you when physically helping your child, what makes life easier for you?

To the DSP of the participant:
What does the teacher think the child wants to learn?

Looking at the future, what does the therapist think is important for the child to learn?

Analysis
Firstly, it was tested whether the goals were defined in terms of concrete skills rather than body functions or structures. Consequently, whether formulated in concrete skills or not, each goal was analysed for its objective. Each goal was categorised into the domains distinguished within the Paediatric Evaluation of Disability Inventory by Haley et al. (1992): ‘Self care’, ‘Mobility’ and ‘the Social domain’. The domain of ‘self care’ includes skills such as eating and dressing. The ‘mobility domain’ describes ‘basic transfer skills’ such as getting in a chair and ‘body transfer activities’ such as locomotion indoors. The ‘social domain’ is concerned with skills such as communication, peer interaction and play (Haley et al. 1992). Finally, it was determined for each goal, regardless of its formulation and objective, if the goal had any relationship with the individual interests of the child.

Two independent evaluators evaluated all goals. Both evaluators underwent training, which included discussion about functionality, and evaluation of ‘MOVE goals’. The training was completed when 80% correspondence was scored three times in succession. When evaluating the goals, no distinction was made between goals that were formulated in terms of outcome and goals that were described in terms of activities or conditions. The evaluators did score the goals twice with 2 weeks in between the measurements. Cohen’s Kappa was calculated as a measure of inter and intra-rater reliability (see Table 3). There was a high level of agreement on goal evaluation where the formulation in concrete skills was concerned, and a reasonable to high level of agreement on goal evaluation where objective were concerned. At the first measurement, there was only little agreement between the two evaluators on the evaluation of goals concerning the child’s interests (de Vocht 2000). A qualitative evaluation showed that this was caused by the formulation of the goals. Goals that did not show a relationship between the described activity and the actual goal were generally evaluated differently. The goal: ‘Sarah will stand on her own for one minute within one year’, for example, fails to mention why Sarah should stand on her own. The evaluators consequently made different interpretations and different scores. Following a discussion again, the statement was made that absence of an explanation of the reasons why a certain skill must be mastered makes the goal ‘unclear or not stated if the goal is in the child’s interests’. After this training, the evaluators reached a high level of agreement on goal evaluation (de Vocht 2000; see Table 3).
Table 3  Intra-rater reliability and inter-rater reliability scores (Cohen’s Kappa) of goal evaluation

<table>
<thead>
<tr>
<th></th>
<th>Intra-rater reliability</th>
<th>Inter-rater reliability</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Rater one</td>
<td>Rater two</td>
</tr>
<tr>
<td>Concrete skills</td>
<td>1.00</td>
<td>.85</td>
</tr>
<tr>
<td>Objective</td>
<td>.77</td>
<td>.91</td>
</tr>
<tr>
<td>Child’s interest</td>
<td>.42</td>
<td>.92</td>
</tr>
</tbody>
</table>

Results

A total of 101 goals were analysed. The number of goals per child varied from one to nine goals, with a mean of 2.1 goals per child (SD= 1.4). Table 4 shows the distribution of goals into formulation in concrete skills, objectives and child’s interest. Because the three aspects were analysed separately, the percentages cannot be added up.

Table 4  Classification of the goals, in actual numbers and percentages (given in parenthesis)

<table>
<thead>
<tr>
<th>Aspect</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Formulation in terms of concrete skills</td>
<td>97 (96)</td>
</tr>
<tr>
<td>Objective</td>
<td></td>
</tr>
<tr>
<td>Self-care</td>
<td>14 (14)</td>
</tr>
<tr>
<td>Mobility</td>
<td>54 (53)</td>
</tr>
<tr>
<td>Social functioning</td>
<td>23 (23)</td>
</tr>
<tr>
<td>Child’s interest</td>
<td>52 (52)</td>
</tr>
</tbody>
</table>

Formulation

The results show that all but four of the analysed goals (96%) were formulated in terms of concrete skills. An example of a goal formulated in terms of concrete skills is: ‘Nick will be able to walk and stand up on his own in order to move around freely using the MOVE chair and gait trainer’.

An example of a goal not formulated in concrete skills is: ‘Bob will be able to balance for 20 minutes by means of a high table and supported at his legs and torso’.

The objective of the goals

Fourteen of the 101 goals (14%) were concerned with activities related to (self) care. Goals were included that concerned care aspects which are taught to the child, as well as goals which concerned (self) care given to the child by the DSP, but for which it remained unclear whether they were actual examples of self care. E.g.: Maria is able to sit with support on the shower bed in order to be washed.

In total, 54 goals (53%) referred to mobility skills. An example of a goal having mobility as its objective is: ‘Michel is able to move around with the gait trainer, inside as well as outside the house’.

Twenty-three (23%) of the goals were concerned with aspects relating to social functioning, e.g. ‘Within one year, Naomi will pull herself up into a standing position at a low table so she can see what is on it, and will remain standing for 3 minutes with support of her torso and lower arms, enabling herself to play with the toy’.

Ten goals (10%) were classified as ‘other’ because it was unclear into which category they should be placed.
The child’s interest
For 52 of the 101 goals (52%), a link existed with the interests of the child. An example of a goal for which this is the case is: ‘Pete is able to walk 10 metres within the playroom with the gait trainer and with torso and arm supports, in order to point at something he wants’.

Discussion
This study analysed goals formulated for children with PMD who participated in a curriculum that is theoretically based on functionality. Results showed that the goals did not completely satisfy the principles of functionality. The analysed goals were predominantly formulated in concrete skills instead of body functions, which corresponded with the principles highlighted by various authors (Fetters 1991; Rothstein 1994; Pellegrino 1995; Ketelaar et al. 1998). Most goals include mobility skills in their objective. However, these goals often failed to explain the actual aim of the mobility skill. Fewer goals were formulated in topics such as play and communication. Furthermore, it was remarkable that a substantial number of goals were more or less concerned with care for the child, indicating that care efficiency is one of the (hidden) goals of the treatment regime. In 52% of the MOVE goals, the child’s interest in the achievement of the goal was made explicit. However, in 48% of the goals the relationship between the formulated goals and the child’s interest was not clear. Further analysis showed that all goals that included social functioning in their content were scored as ‘aimed at the child’s interest’. In contrast, only 17 of the 54 goals concerning mobility skills (31%) turned out to be clearly aimed at the child’s interest.

These results clearly reveal that the availability of a functionally oriented curriculum does not automatically lead to functionally oriented goals. Functionality, however, seems to be a broad and general notion, hardly definable and with implications which may differ across disciplines, target groups and individuals. Barnes & Whinnery (2002), for instance, focused on the effects of the MOVE curriculum on the functional skills of children with severe multiple disabilities. The authors refer to skills like ‘walking forward’ as functional skills. On the other hand, Haley et al. (1992) drew the concept of functionality more broadly and focused on aspects such as ‘self-care’, ‘mobility’ and ‘social functioning’. Functionality is thus shaped in different ways.

The way the goals were set may also explain the results of this study. The content of the goals was defined with use of a questionnaire, with questions also aiming at the DSP’s comfort and not only clarifying the child’s interest (see Table 2: third question). Furthermore, the MOVE curriculum mainly aims at the mobility skills ‘to sit’, ‘to stand’ and ‘to move’, without explaining the actual aims of these skills in terms of functionality. Bidabe & Lollar (1995) state that activities for children with PMD should be aimed at the acquisition of skills such as communication, play, interaction, etc. The authors do not, however, describe how the transfer from these mobility skills to the described functional skills should be made.

The participating children were selected with an internationally accepted description concerning individuals with profound and multiple disabilities (Nakken & Vlaskamp 2002). Hence, the subjects of this study can be considered to be representative for the specified group of children with PMD. Also the settings in which the MOVE curriculum was implemented are comparable to those in other countries like America, England and Germany (Elkins 1994; Schomerus 1996; Barnes & Whinnery 2002; Oosten 2002). Further research has to show if the results can also be generalised to individuals with less severe disabilities. However, the way the MOVE curriculum will be implemented and the way the goals will be defined do not change.

It thus turns out to be rather difficult to determine functional goals for children with PMD. This can be achieved by means of appropriate theoretical principles, as well as by describing the ways in which the activities are to be implemented. Both the theoretical concept and the implementation strategy, including teacher training, guide the correct substantive choices.
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