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

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Chapter 1
General introduction
1.1 Introduction
The research project ‘Evaluating the MOVE curriculum with children with profound intellectual and multiple disabilities’ was launched in October 1998 as part of a collaboration between the Institute of Human Movement Sciences and the Department of Educational Psychology at the University of Groningen (RUG). The aim of the research was to evaluate both the effects and the working mechanisms of the movement-oriented American curriculum ‘Mobility Opportunities Via Education’ (MOVE)™ (Bidabe & Lollar, 1995) on children with profound intellectual and multiple disabilities (PIMD) who attend a centre for special education (CSE). The research was conducted at the request of the Ipse Foundation, which ‘offers custodial care to people with an intellectual or multiple disability’. Ipse approached the above departments at the RUG to conduct the research because of their considerable expertise in the field of evaluating mobility programmes and care for people with intellectual and multiple disabilities.

Since 1994, children with profound or severe multiple disabilities in the Netherlands have been taught in accordance with the MOVE curriculum within a limited number of settings such as rehabilitation facilities, centres for individuals with intellectual disabilities and CSEs. At ‘De Zonnehof’, a CSE in Naaldwijk that is specifically geared toward children with PIMD, the movement-oriented curriculum MOVE was implemented on the initiative of a physiotherapist and an occupational therapist. Both felt that the principles of MOVE were so attractive for this target group that the curriculum should be incorporated into the care package offered by the CSE. When positive results were subsequently observed in practice, the Ipse Foundation, of which ‘De Zonnehof’ is a part, decided in 1997 to become a licensee for MOVE. As licensee, the Ipse Foundation wished to expand the use of the curriculum within the Netherlands and Dutch-speaking Belgium. But first they needed a greater understanding of MOVE’s effectiveness with children with PIMD. By effectiveness, Ipse was thinking not only of the external validation of the curriculum; it was also concerned with an understanding of the possible value of MOVE and the question of how to best implement the curriculum within the total care package. Thus the research focus was not simply the question of whether or not MOVE worked, but also why, how and when it was most effective for children with PIMD.

1.2 ‘Mobility Opportunities Via Education’
The Mobility Opportunities Via Education™ curriculum (MOVE) consists of movement-oriented activities for children and adults with profound multiple disabilities. The curriculum was developed in the USA by Bidabe and Lollar at a time when discussions were held about how to educate and activate children and young people with profound multiple disabilities (Elkins, 1994). These discussions arose out of changes made in some US states to existing laws and regulations relating to what constituted specialist medical care and rehabilitation and what form special education and adapted mobility training should take. The MOVE curriculum was initially developed to assist special-needs teachers by improving both the form and substance of their care and training of children with multiple disabilities. Later the curriculum was implemented in various European and Asian countries, not just within special education, but also in rehabilitation facilities and centres for people with intellectual and other disabilities (Barnes & Whinnery, 2002). In the Netherlands, MOVE has primarily been used since 1994 in caring for people with profound multiple disabilities. The MOVE curriculum is based on the acquisition of functional skills so that participants can live as independently as possible. The ultimate objective, as stated by Bidabe and Lollar, is ‘to improve the quality of life for these very special children, their parents or care providers’ (Bidabe & Lollar, 1995).
1.3 Origins of the MOVE curriculum

The curriculum was developed by Linda Bidabe, a special education teacher, and Jack Lollar, a physiotherapist. They wondered why children with profound multiple disabilities showed barely any improvement in the acquisition of movement skills and other skills despite receiving physiotherapy and other interventions. Bidabe and Lollar observed that children with multiple disabilities are heavily reliant on others because of their limited ability to move about independently. This limits the children’s options, thereby reducing their degree of control over their lives (Bidabe & Lollar, 1995). In addition, the founders of MOVE found that over time children with profound multiple disabilities lose the skills they have acquired, thus further increasing their dependency on other people and on equipment. Bidabe gives four explanations for this decline in the number of skills. It is these ‘explanations’ that served as the starting point for the curriculum. According to Bidabe and Lollar (1995):

1. Children with profound multiple disabilities require more practice to acquire a new skill than children without disabilities. The rate of learning (the number of repetitions required to learn a new skill) is so slow in this group of children that the training of less relevant skills such as crawling and rolling requires too much time and effort.
2. The children’s passivity increases as they grow older. As the children become larger and heavier, it is more difficult for parents and caregivers to manage them. There is an increased need for aids, which in turn further increases the children’s passivity.
3. The ability to generalize: children with profound multiple disabilities are much less able to transfer a skill learned in one situation to another than children without disabilities.
4. Because caring for the children takes so much time, there is little time left each day for the acquisition and practice of skills.

Using these ideas as their starting point, Bidabe and Lollar developed a curriculum for children aged seven and above who had ceased to show any improvement in acquiring the skills of sitting independently, bearing their body weight on their feet, or taking reciprocal steps. After analyzing the existing work situation, Bidabe came to the conclusion that most children sat in a wheelchair as a substitute for what it was felt they could not do, namely move. Bidabe drew the following conclusion: ‘We worked from the premise that all people learn. Our people weren’t learning, so the fault had to lie in our teaching’ (Bidabe & Lollar, 1995, p2). Bidabe began by developing materials so that the children could learn to move. The MOVE curriculum is set out in a curriculum guide (Bidabe & Lollar, 1995).

1.4 Description of the MOVE curriculum

The starting point for developing the MOVE curriculum was to determine the basic skills necessary for leading as independent a life as possible. From the basic, everyday skills such as eating and drinking, self-management, communication and play, an analysis was made of the motor skills relating to sitting, standing and walking that are needed to accomplish them. The MOVE curriculum focuses on training and improving these motor skills, and on the degree of assistance required to perform them. Where possible, the aim is to reduce the level of support, with the independent functioning of the child as the ultimate objective. Practice proceeds from the skills that the child already possesses, and skills are extended from this level as part of the ‘top-down’ approach described in the curriculum. The commonly held view that the acquisition of movement skills should follow the lines of normal development is thus abandoned. MOVE emphasises the importance of making the most of opportunities for systematic practice in situations that recur daily. In this way there is an emphasis on the child itself regularly changing position, with considerable importance attached to the feeling of contact with the floor (e.g. by placing the child in a low chair so that its feet reach the floor). This attention to active transfer – the changing of
position or posture – no longer occurs unexpectedly; the child itself plays an active role. The MOVE curriculum is built up systematically as follows:

1.4.1 Testing
First, the child is tested to see which movement skills have already been mastered. This is done using the Top-Down Motor Milestone Test (TDMMT™), a criterion-referenced instrument developed as part of the MOVE curriculum for instructional planning and progress evaluation (Burton & Miller, 1998). The TDMMT is made up of various movement skills organized into 16 categories. All movement skills relate to ‘sitting’, ‘standing’ and ‘walking’ and the transitions between them such as the transition ‘from sitting to standing’, ‘from standing to sitting’, ‘from standing to walking’ and ‘from walking to standing’. The original skill selection was based on the relationship to functional activities; for instance, ‘maintaining a sitting position’ facilitates communication with the environment, according to the developers (Bidabe & Lollar, 1995). Each mobility skill or category consists of three to eleven items, referred to as ‘motor milestones’ (Elkins, 1994) that form a hierarchical scale. The items are described in quantitative terms with parameters such as the amount of support needed to perform the skill and/or the time or distance that needs to be covered. The parameters are based on the ‘functional use of the skill’. In total, the TDMMT consists of 74 items. The format is dichotomous, i.e. the items can be scored either negatively or positively. A positive score is given once the child has mastered the particular item. The items within each category form an ordinal scale with the most difficult item at the top. The items are ranked in four levels, which reflect the degree of independence (Bidabe & Lollar, 1995). The TDMMT is administered orally among the direct support professionals (DSPs) such as parents, therapist(s), caregivers etc. If there is any doubt as to whether a particular item has been mastered, the child itself is tested.

1.4.2 Formulating goals and task analysis
Following testing, one or more goals are formulated, in consultation with the DSP and where possible the child itself. The objectives may relate to a range of matters such as activities of daily life (ADL), communication and play. They are formulated within the curriculum using a questionnaire developed by MOVE’s founders. A task analysis is then carried out for each objective to establish the motor skills that need to be trained in order to achieve that objective.

1.4.3 Measurement and the reduction of support
In the next step of the MOVE curriculum, it is determined how much support the child needs in the skills mastered at the time that the TDMMT was administered. The degree of support is set out in the ‘Prompt Reduction Plan™, developed as part of the curriculum (Bidabe & Lollar, 1995). There are separate charts for both sitting, and for standing and walking, which show where the child needs what type of prompt. Based on the objective and the level of support, it is then decided how the prompts should be reduced over time to achieve the ultimate objective. The end result and the intermediary steps with regard to support are set out in a chart to be made as clear as possible for the various DSPs.

1.4.4 Practising the skills
The actual skill acquisition occurs in the last step of the curriculum. Practice is subdivided into four ‘stages of learning’ (Bidabe & Lollar, 1995). The child learns a new skill in the ‘acquisition
stage’. This skill is learnt in the ‘therapy situation’ because of the considerable effort required. In the ‘fluency stage’, the child takes a more active role. The child knows what is expected, and it is now important to functionally apply the skills acquired. In the ‘maintenance stage’ the skill becomes part of everyday life. A start can now be made on introducing a new skill. The emphasis in the final stage, the ‘generalization stage’, is on applying the skill in different situations.

When practising and performing the skills, use can be made of special equipment developed as part of the curriculum: a mobile stander, a gait trainer and a special ‘MOVE chair’. This equipment provide maximum assistance, which can gradually be reduced to a minimum. Activity and functionality characterize training in the MOVE curriculum. Training is dynamic, encouraging children to be as active as possible and to participate to their fullest potential (Barnes & Whinnery, 2002). Functionality means that only those skills are trained from which children will derive some direct benefit in their natural environment; the normal developmental sequence for motor skills is not followed. Attention is paid to improving the skill itself, as well as to the amount of support needed to perform the skill. The child is given the degree of support (mechanical or physical) it requires. All activities are integrated into daily routines. In this way, the child is given frequent and immediate opportunities to practise the skills in its natural environment. The activities are supported by all the child’s DSPs. In practice, this means that when the child enters the CSE, it is encouraged to walk to the class independently (with or without a walking aid). Or the child sits in a special MOVE chair during play activities, with only the support the child needs. Practice and execution of the skills occurs during daily activities and are integrated into the child’s daily programme.

1.5 Target group of the MOVE curriculum

MOVE was initially developed for ‘students over the age of seven who had not developed the physical skills necessary to sit independently, bear weight on their feet, or take reciprocal steps’ (Bidabe & Lollar, 1995). Later, following the success of the curriculum in the USA, it was expanded to include younger children with profound multiple disabilities, people with orthopaedic disabilities only and the elderly (Brach, Jekosch, Dierbach & Heck, 2000). In addition to this broad application, contra-indications are also given. These are: a head that is too large to be supported by the neck, respiratory problems and circulatory disease which prevent a person from being placed in a vertical position, brittle bones, muscle contractures, deformations of the spine, hip dislocation, foot and ankle abnormalities, and pain or discomfort.

1.6 Claimed effects

Bidabe and Lollar (1995) describe a number of claimed effects of the MOVE curriculum. These can be divided into effects on anatomical-physiological structures and functions, on the acquisition of motor skills and on the acquisition of functional skills. Bidabe and Lollar (1995) also describe effects on DSPs. If both the motor and functional skills of a child improve, this reduces both the time for support and the time and energy for custodial care. The current study looked only at the curriculum’s effects on children with profound multiple disabilities; it did not cover possible effects on DSPs. Sections 1.6.1, 1.6.2 and 1.6.3 describe the anticipated effects on children with profound multiple disabilities who followed the MOVE curriculum.

1.6.1 Effects on anatomical-physiological structures and functions

In the anatomical-physiological domain, effects are described of the MOVE curriculum on joints and bone structure, muscle function and on the functioning of internal organs. Bidabe and Lollar
(1995) state that joint deformities can be reduced or prevented using the curriculum. They claim that the traditional ‘passive movement’ of the different joints to prevent contractures is no longer necessary if children and adults use MOVE. In addition, Bidabe and Lollar state that the movement-oriented activities have a positive effect on bone quality. A further anatomical-physiological benefit, according to the authors of MOVE, is that muscle function improves in the extensor muscles in particular and muscle tension is normalized as a result of practicing skills like sitting, standing and walking. Being more physically active and adopting a more vertical position leads to an improved functioning of different internal organs such as intestines, heart and lungs, which according to Bidabe and Lollar (1995) improves the child’s fitness and stamina.

1.6.2 Effects on the acquisition of motor skills
In the motor skills domain, the founders of MOVE claim that the curriculum leads to improvements in the motor skills that are trained. MOVE focuses specifically on sitting, standing and walking, which are regarded as the basic skills for the acquisition of functional skills like communication. The motor skills are improved on the one hand by increasing the number of subskills, and on the other hand by reducing the level of support. Improving motor skills in turn affects the anatomical and physiological domain and leads to an improvement in functional skills such as language use (expressive language), work (work opportunities) and ADL activities (bathing, toileting), according to Bidabe and Lollar (1995).

1.6.3 Effects on the acquisition of functional skills
At the functional level, improvements are claimed in the basic skills of eating and drinking, communication, self-management, interaction with the environment, play and language development. For children who follow the MOVE curriculum, the movement-oriented activities ultimately lead to greater independence and to an improved quality of life. Because children learn to move independently, they are also more aware of their environment and this environment expands for them. They can also communicate better with their environment and can better explore the space around them (Elkins, 1994). Improved sitting, standing and walking skills, and the increased independence these bring, reduce the physical burden on the DSPs caring for the children. The child participates as it were in the support and requires less help. This also affects the time required for custodial care and support for children with a multiple disability (Bidabe & Lollar, 1995; Elkins, 1994). Bidabe mentions the effect of the children’s vertical posture on those around them. She says: ‘…it is my experience that more is expected of the child if it adopts a vertical, or more normal position. The child feels better and the people around it feel more at ease in their interaction with the child’ (Elkins, 1994). The emphasis here is on a more active posture. If a child sits up straight, it can chew and swallow better and is better able to focus on the environment. This position provides the child with more opportunities to develop such skills as hand function (Bidabe & Lollar, 1995).

1.7 Research into the MOVE curriculum
To our knowledge, four studies have been conducted into the effects of the MOVE curriculum. Barnes and Whinney (2002) posed the following research questions: ‘Do functional mobility skills in students with physical disabilities improve as a result of direct training using the MOVE curriculum and will these skills be maintained over time?’ The researchers looked mainly at the skills of ‘walking forward’ and ‘standing in place’. Five children, aged 3-9 years, with severe multiple disabilities took part in the study. For each child, there is a brief description of the
diagnosis, level of intellectual functioning and potential in the area of motor skills. A multiple-baseline, single-subject design was used. Repeated measures were taken during baseline, the intervention phase (one school year) and the maintenance phase (next school year). Results show that four out of five children showed advances in walking skills from baseline to intervention. At the start of the study, none of the children were able to carry out functional walking skills, with or without support, while at the end of the intervention period three children were able to walk with support and to participate more fully in the activities selected for them. One child was able to walk small distances completely independently. During the maintenance phase, three of the four participants maintained skills and made further gains (Barnes & Whinnery, 2002).

Bidabe and Lollar (1995) substantiate the claimed success of the MOVE curriculum with data obtained in a three-year study (from 1986 to 1989), which looked at a single group of children who followed the MOVE curriculum. The research group comprised 15 individuals with multiple disabilities, aged 6 to 16 years. The researchers do not provide precise details for the children. Only children whose developmental age was regressing were selected. In 1986 and again in 1989, children were tested to determine how many achieved a positive score on eight items described in analogous terms to the TDMMT (see table 1). The founders of MOVE conclude that the data support the success of the curriculum, with sitting, standing and walking improving during this period (Bidabe & Lollar, 1995). Table 1 presents an overview of the items and data as presented in the MOVE curriculum guide (Bidabe & Lollar, 1995).

Table 1  Overview of the items and data as presented by Bidabe & Lollar (1995)

<table>
<thead>
<tr>
<th>Item</th>
<th>1986 n</th>
<th>1989 n</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Sits on a classroom chair for 30 minutes.</td>
<td>9</td>
<td>14</td>
</tr>
<tr>
<td>(this is the average length of time for any classroom activity and for most meals)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Sits on a stool for five minutes.</td>
<td>9</td>
<td>12</td>
</tr>
<tr>
<td>(if a person can sit this long without support, the caregiver has ample time to get the person off the bed, the edge of the bathtub, etc.)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Bears full weight on feet for one minute.</td>
<td>6</td>
<td>13</td>
</tr>
<tr>
<td>(in one minute, a person’s diaper can be removed or clothing adjusted and the person can be placed on the toilet. The person can also stand to have a diaper reapplied).</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Pulls to a standing position with an aid.</td>
<td>3</td>
<td>12</td>
</tr>
<tr>
<td>(A person who can assist in getting to a standing position does not have to be lifted).</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Maintains standing balance for one minute when stabilized at the knees.</td>
<td>0</td>
<td>10</td>
</tr>
<tr>
<td>(A person who can maintain hip, trunk, and head balance while leaning against a table or counter has free arm movement for brushing teeth, washing hands etc.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Walks 5 ft using reciprocal steps when balance is provided by walker or person.</td>
<td>5</td>
<td>14</td>
</tr>
<tr>
<td>(the ability to walk a minimum of five feet gives access to almost any toilet or small space inaccessible to a wheelchair).</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. Gets up from a chair, walks 20 feet, seats self in a chair without assistance.</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>(a person who has achieved these skills will have independence within the home environment).</td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. Some functional use of upper extremities.</td>
<td>6</td>
<td>13</td>
</tr>
<tr>
<td>(Functional use is defined as self-feeding, wheelchair movement, or purposeful grasp and hold).</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

n = number of children who master the item

Elkins (1994) conducted a comparative study over a seven-month period with children with profound multiple disabilities. The central research question was whether there was a difference in the acquisition of sitting, standing and walking skills between an experimental group, to whom the principles of MOVE were applied, and a control group who followed a ‘traditional’ programme. Elkins also looked at whether the age of the children affected the acquisition of skills; for this purpose, both groups were broken down into ‘young’ children (3 to 7 years) and ‘older’ children (8 to 22 years). The experimental group contained 41 children (25 young and 16 older children)
and the control group 25 (11 young and 14 older children). Elkins describes the groups as being comparable in terms of the nature and severity of the disabilities and the age of the children (Elkins, 1994). She describes in detail the features of MOVE and of traditional programmes. MOVE’s principal feature was the functional and dynamic nature of its activities. The children used standard school furniture and took part in all group activities. They were encouraged to move independently and practised by using aids such as mobile standers. The key principle of traditional programmes was that they followed the steps of normal motor development. Elkins (1994) describes those traditional programmes as passive, with children seated mainly in wheelchairs or beanbags in the classroom. At school the children mainly worked individually or with the teacher’s help. To move around the classroom, children were carried and/or static aids were used. Both before and after the experiment, the TDMMT was used to determine the level of functioning. Results show that in general MOVE achieved greater effects than the traditional programmes with regard to sitting, standing and walking. Not all the results are significant, however. With regard to sitting, the older children derived more benefit from the MOVE curriculum. No difference was observed for the younger children between the two interventions in this respect. The opposite was the case for learning to stand: MOVE worked better for young children, with older children obtaining the same result in both interventions. For learning to walk, MOVE was more effective than traditional programmes, for both young and older children. Elkins (1994) concludes on the basis of these results that a child’s age has no effect on the acquisition of the skills with the MOVE curriculum.

Schomerus (1996) carried out a qualitative study into MOVE. Three case studies were described, with a focus on the following aspects: the participating and non-participating child, teachers, therapists, the class as a whole and the teaching team, and the MOVE curriculum itself. Results show that the implementation of the MOVE curriculum did not lead to any problems for the three participating children. They made large advances in sitting, standing and walking compared with the children who did not take part. They also made progress in terms of their sense of self-worth and self-awareness, and there was greater activity than with the non-participating children. This latter group displayed interest in the former, and as a result, they joined in more actively with the ‘experiment children’. The teachers observed a change in the overall approach in the classroom because of the different demands made on teachers by the MOVE curriculum. Breaking old routines and changing procedures led to changes in the classroom to which the children responded positively. However, the teachers had initial difficulties in accepting MOVE and changing their method of working and basic assumptions. The switch from a deterministic, hierarchical intervention to a more adaptive one led to insecurity among the therapists. The usual classroom planning also changed considerably as a result of the curriculum. The teachers in the study said that that this was also their wish, as they had reached a dead end in their work with the children. The objectives, design, sample, intervention, variables and key results of the four studies are presented in appendix 1.

1.8 Problem definition, objective and research question

The general conclusion is that it is not clear whether the anticipated effects as outlined in the MOVE curriculum are actually achieved and whether, insofar as effects do exist, they are in fact caused by the movement-oriented activities in the curriculum. In addition, research into the curriculum does not reveal any unequivocal effects and provides no insights into achievement of the effects. Although the presented studies do show positive results, they are based on too small a sample and standardization to be reliable.

In practice then it is not clear whether MOVE has a value in interventions with the specific group of children with PIMD and, if this value does exist, how the curriculum should be implemented as
part of regular care for children with PIMD. Finally, it is not known which effects can be achieved with the MOVE curriculum and how any possible effects come about for children and adults with profound multiple disabilities. The general objective of the research into the MOVE curriculum is formulated as follows: ‘Evaluation of the “Mobility Opportunities Via Education” curriculum with children with PIMD who attend a CSE’. The central research question is: What are the effects and what are the working mechanisms of the MOVE curriculum for children with PIMD who attend a CSE?

1.9 Target group and setting of the present research

1.9.1 Target group

The category of children with PIMD is a group that is difficult to define (Vlaskamp, 2002). Often different terms are used in the literature to describe these children e.g. ‘children with profound multiple disabilities’ or ‘children with complex multiple handicaps’ etc. However, the reverse is also the case, with the same terms being used to refer to different groups (Nakken & Vlaskamp, 2002). Children with PIMD are characterized by the presence of profound intellectual and profound or severe motor disabilities. In addition to these key traits, there are others such as profound sensory impairments and general medical problems (Hogg & Sebba, 1986; Nakken & Vlaskamp, submitted). The most recent definition of people with PIMD is as follows (Nakken & Vlaskamp, submitted):

**Individuals with Profound Multiple Disabilities**

The group consists of individuals with such profound learning disabilities that no existing standardized tests are applicable for a valid estimation of their level of intellectual capacity, and who possess profound neuromotor dysfunctions like spastic tetraplegia. These individuals have little or no apparent understanding of verbal language, no apparent symbolic interactions with objects, and nearly no ability for self support.

In addition to profound intellectual and physical disabilities, sensory impairments are also frequently experienced, and especially the prevalence of a Cerebral Visual Impairment is high. Individuals with profound multiple disabilities also have an overall risk of developing medical complications, and almost all require regularly administered medication (e.g. anti-convulsion drugs, sleep medication, medication to prevent reflux and drugs with a sedative effect). A number of individuals have gastrointestinal feeding tubes or suffer from physical difficulties with food ingestion. Individuals with profound multiple disabilities form a physically very vulnerable group of persons with a heavy or total dependence on personal assistance for everyday tasks.

This definition demonstrates that profound intellectual disabilities often go hand in hand with profound or severe motor disabilities. Vlaskamp and Nakken (2004) suggest that we visualize this as a two-dimensional spectrum although they concede that the various types of disability can also be viewed more in terms of an axial model. Because of the lack of a diagnostic tool for determining intellectual functioning, there is often uncertainty as to its precise level. In general it is assumed that children with PIMD have an estimated intelligence quotient of less than 25 points (Vlaskamp, 2002). Motor disabilities may consist of profound spasticity, athetosis, ataxia or combinations of these, so that arms and/or legs cannot be used or only to a very limited extent. Alongside the profound intellectual and severe or profound motor disabilities, sensory impairments also occur very frequently in the target group. These may consist of visual impairments or blindness, hearing impairments or deafness, and/or problems with touch such as...
hypersensitivity or low susceptibility (Janicki & Dalton, 1998), and problems relating to smell and taste (Bromely, 2000). In addition to intellectual, motor and sensory disabilities, most children with PIMD also have general disorders such as epilepsy, stomach and/or intestinal problems, cardiac abnormalities, sleeping problems, and problems relating to general fitness and feeding/drinking (Didden & Sigafoos, 2001; IGZ, 2000; Nakken & Vlaskamp, 2002; Richdale, Francis, Gavidia-Payne & Cotton, 2000). There is no clarity about the prevalence of these disorders among children with PIMD (Vlaskamp, 2002). For example, the occurrence of auditory disabilities ranges from 1% to 33% and visual disabilities from 3% to 81% (Evenhuis, Theunissen, Denkers, Verschuure & Kemme, 2001; IGZ, 2000; Zijlstra & Vlaskamp, in press). This uncertainty stems from the small number of CSEs that conduct a periodic screening for sensory disabilities (IGZ, 2000; Zijlstra & Vlaskamp, in press). Splunder, Stilma and Evenhuis (2003) make a more radical claim, stating that all children with PIMD may have a visual impairment unless proven otherwise. Zijlstra and Vlaskamp (in press) have recently conducted research into the prevention of general disorders among children with PIMD and found that 85% suffered from epilepsy, 54% had other sensory disabilities (e.g. tactile disorders), 67% suffered from stomach or intestinal problems, 38% suffered from pulmonary problems, 31% experienced sleeping problems, 48% had feeding/drinking problems, 6% suffered from dental problems, and 50% had behavioural problems (e.g. screaming, rumination, eye-poking, apathy) (Zijlstra & Vlaskamp, in press). It is also known that of the children with PIMD who attend a CSE, 15% are fully or partially fed by tube, of whom 89% are tube-fed on a permanent basis. Here too it may be a question of substantial underdiagnosis and it is assumed that perhaps 75% of the severely multiple disabled suffer from easily treatable reflux disease (IGZ, 2000).

Because of these disorders and disabilities, children with PIMD have few opportunities to use any form of language (speech, gestures or symbols). They communicate mainly through body language e.g. movements involving differences in frequency, intensity and direction, sounds with varying intonation, tempo or pitch, or by displaying physiological reactions such as changes in breathing rate, muscle tension, or pupil dilation. Facial expressions like raising eyebrows or making eye contact are also a means of communication. Some children can show what they want by pointing, grasping and reaching, but others are unable to do so. Therefore, although children with PIMD do have communication options, the signals are often so subtle that they are difficult to recognise and comprehend, thus requiring immense powers of observation, effort and knowledge on the part of the DSP to notice and to interpret them correctly. Matters are further complicated by the fact that it may take considerable time before a child reacts to something and that the same signals often have different meanings in different situations. Many children experience difficulty taking part in group activities because they cannot observe what other children are doing or because they have no concept of ‘waiting your turn’. This affects how they function in social situations (Vlaskamp, 2002; Vlaskamp, 2005).

The common characteristic of this group of children is that they are completely, or almost completely, dependent on others throughout the day and in all areas of daily life (Nakken, 1997). Many of them must also rely on various aids such as wheelchairs, braces, orthoses, standers and hoists. (IGZ, 2000).

1.9.2 Centres for Special Education

The children with PIMD in the current study attend a CSE during the day. CSE are centres that are specially designed for children with intellectual or multiple disabilities (Willems, 1997). The children live at home (or in a family-like setting) and attend the CSE during the day. There is a total of 91 CSEs in the Netherlands that receive this target group. The age of the children ranges
from 0 to 18 years, although most are between 5 and 11 years old. The majority of the children (80%) visit the centre 7 to 10 mornings/afternoons per week (IGZ, 2000). At the CSE, there are different groups who are classified by age, and by type and severity of disability. Although the number of children within each group and the number of DSPs varies, most groups consist of 7 to 10 children and the ratio of children to full-time staff equivalents is about 2.5: 1 (IGZ, 2000). The CSE staff are DSP’s, one third of whom have medical care training and two-thirds socio-cultural training. In addition, almost all CSEs employ a doctor, a remedial educationalist/psychologist and several paramedics (IGZ, 2000). The children receive different developmental activities such as play activities, Snoezelen, swimming and other therapies such as physical therapy, occupational therapy and speech therapy (Willems, 1997). Considerable use is made of paramedical care. Eighty-nine percent of the children with PIMD who attend a CSE receive physiotherapy, 63% receive speech therapy and 48% occupational therapy. In addition, 27% are given play and/or music therapy (IGZ, 2000).

1.10 Thesis outline

The MOVE curriculum was initially developed for children of seven years and above with profound multiple disabilities. The target group was later expanded to include younger children (Bidabe & Lollar, 1995). The present research has evaluated the MOVE curriculum with a specific subgroup of the initial target group, namely ‘children with profound intellectual and multiple disabilities’. The research focused on the following three aspects:

- analysis of the psychometric quality of the TDMMT, a criterion-referenced assessment developed as part of the MOVE curriculum,
- evaluation of the effects of the MOVE curriculum on children with PIMD in different domains inherent in the claims outlined by Bidabe and Lollar (1995),
- evaluation of the working mechanism of the MOVE curriculum with a specific analysis of prompt reduction, according to the developers of MOVE one of the key components of the skill acquisition process.

With regard to the psychometric quality of the TDMMT, research was conducted into the validity, reliability and usefulness of this instrument for children with PIMD. The methods, results and conclusion of this psychometric analysis are described in chapter two. With regard to the anticipated effects of the MOVE curriculum as described by its founders in sections 1.6.1, 1.6.2 and 1.6.3, research was conducted into the effect of MOVE in the domains described. Chapter three of the thesis describes a study designed to determine the effects of the movement-oriented activities in MOVE on the anatomical-physiological domain. The study looks specifically at the effect of MOVE on the passive range of motion and active muscle function for children with PIMD. Chapter four describes the research into the effects of the MOVE curriculum in the motor domain, paying specific attention to the question of whether MOVE has a positive effect on independence while performing motor skills. Chapter five discusses the working mechanism of the MOVE curriculum with children with PIMD. The developers of MOVE claim that the level of support can be reduced during the performance of motor skills with children with PIMD. In the study described in chapter five, we see whether this is in fact possible and just how prompt reduction occurs. Chapter six looks at research into effects in the functional domain, in the form of a goal analysis. Finally, the results of the different studies are brought together and discussed in chapter seven.
References


Nakken, H & Vlaskamp, C. Classification and assessment of persons with profound and multiple disabilities. *Submitted for publication*. 

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Appendix 1  Objectives, design, sample, intervention, variables and key results of the four studies of MOVE

<table>
<thead>
<tr>
<th>Author(s) year</th>
<th>Objective of the study</th>
<th>Design</th>
<th>Subjects</th>
<th>Intervention</th>
<th>Variables/ Instruments</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Barnes &amp; Whinnery (2002)</td>
<td>Do functional mobility skills improve in students with physical disabilities as a result of training using MOVE? If so, are these effects maintained?</td>
<td>Multiple baseline across subject design. Single subject design. 6 selection criteria including severe multiple disability e.g. a physical impairment and a medical release to be in upright, weight-bearing positions.</td>
<td>5</td>
<td>3-9</td>
<td>Severe multiple disabilities. Brief description of characteristics of the children such as age, diagnosis, mobility skills, and communication skills.</td>
<td>MOVE curriculum: duration and frequency? The text seems to suggest that the research period was one year. Maintenance phase: after 2 years.</td>
</tr>
<tr>
<td>Bidabe &amp; Lollar (1995)</td>
<td>No specific research objective</td>
<td>One research group. Pre- and post-test. Selection by regression on developmental scale.</td>
<td>15</td>
<td>6-16</td>
<td>Severe multiple disabilities Cerebral Palsy (n=12) Deformities (n=10) Hypertonia (n=5) Most children (n=?) developmental age &lt;6 months, max. 18 months.</td>
<td>MOVE intervention over three years. No further specification of the intervention. ‘Functional skills’ (e.g.: “pulls to a standing position with an aid”, “gets up from a chair, walks 20 feet”) with use of checklist.</td>
</tr>
<tr>
<td>Elkins (1994)</td>
<td>Does MOVE result in higher achievement levels than a ‘traditional’ programme? Is there an effect of age?</td>
<td>Quasi-experimental non-randomized control group pretest-posttest design. Exp. group (n=41); Control group (n=25). Sub-division into groups by age. Selection by medical history and functional status.</td>
<td>66</td>
<td>3-22</td>
<td>Children with severe multiple disabilities. Brief description of the characteristics of the subjects.</td>
<td>Intervention over 7 months. Experimental group: MOVE 5 x per wk, 30 minutes per session. Control group: traditional therapy and school programme 2 x per wk, 30 minutes per session.</td>
</tr>
</tbody>
</table>