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

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Chapter 7
General discussion

7.1 Introduction

The present thesis reports on an evaluation of the MOVE curriculum for children with PIMD who attend a CSE. This curriculum occupies a unique position within current motor interventions for children with PIMD. In terms of both its theoretical foundations and its strong systematic approach, it is in many respects at odds with regular forms of intervention such as Neuro Development Treatment, Vojta, haptonomy and sensory stimulation (Nakken, Reynders, Vlaskamp & Procee, 1998). The basic principle of the curriculum's developers is an interesting one – namely, that motor activity is also essential for children with PIMD. This view ties in with current theoretical thinking and developments relating to our knowledge of the functioning of the nervous system and motor development, the acquisition of motor skills and parental participation in their children's training (Ketelaar, Petegem-van Beek, Vermeer & Helders, 1998; Reynders, 2000).

The MOVE curriculum has been implemented in the Netherlands since 1994 as part of the education and support of children with PIMD, and positive results have been reported on the basis of this practical experience (Homeijer, 2000; Lengkeek & Homeijer, 1994; Vink, 1998; Willemsen, 1999). However, there was little scientific basis for the curriculum, making it worthwhile to examine both the working mechanisms and the effects of the curriculum on children with PIMD. The research therefore had to produce an assessment of the value of the curriculum and how it can best be implemented within the present education of children with PIMD. The present chapter provides a summary of the study's main findings, together with theoretical considerations. It also examines the methodological aspects and makes recommendations for further scientific research. The chapter concludes by placing the results within a clinical, scientific perspective and examines the value of MOVE within the care for children with PIMD.

7.2 Major findings of the current study

The research was designed to analyze the MOVE curriculum and evaluate the psychometric quality of the different instruments it uses. The focal point of the research is the evaluation of the curriculum for children with PIMD who attend a CSE. The effects on anatomical and physiological structures and functions, and the acquisition of motor skills and whether support can be reduced during the performance of motor skills were investigated. After all, this is one of the primary features of the MOVE curriculum and tells us something about how the effects can arise. Finally, the effects on functional skills were analysed. The present section looks at the main findings in terms of these aspects.

Both the TDMMT and the PRP play a key role in the planning and evaluation of the intervention offered in the curriculum. The findings of the study in chapter two show that the psychometric properties of the TDMMT are only partially sufficient. Principal component analysis did not confirm the assumption of three underlying factors that describe the movement skills of sitting, standing and walking. The 16 movement skills that make up the TDMMT can be explained by one or two underlying factors. With regard to reliability, results showed good internal consistency among the 16 categories. However, this consistency was so high that some categories can probably be assumed to be 'redundant' (Streiner & Norman, 1995), which is consistent with the results of the principal component analysis. The test-retest reliability is satisfactory and the inter-rater reliability was strong. Scale analysis indicated a hierarchical and one-dimensional structure for the subscales of the TDMMT, which enhances construct validity and indicates the presence of a one-dimensional theoretical construct. This could be the amount of independence in performing movement skills. However, the fact that a scale can be constructed with good psychometric qualities is insufficient reason for concluding that the underlying theory is valid. Reliability of the

subscales was satisfactory and the scales can be said to be strong. The order of the items, however, differed from the TDMMT. Also, the allocation of items into levels could not be fully substantiated. The results of the TDMMT suggest that adaptations to its structure are needed for children with PIMD.
With regard to the instruments used to determine level of support when performing the motor skills of sitting, standing and walking, research was conducted on the 'dimensionality' of the charts. The results show that the items in the PRP for sitting cluster on two factors. Items A, B and C cluster on factor one, which can be defined as the amount of support 'close to the centre of the body'. Item D clusters on a second factor and is defined as the amount of support 'further from the centre of the body'. For standing and walking, all items cluster on a single factor – the number of prompts while standing and walking.

With regard to the effects of the MOVE curriculum on children with PIMD who attend a CSE, analyses were carried out in the anatomical-physiological and motor domain.
In the anatomical-physiological domain a significant change was found in passive joint motion as a whole as well as in the different components in a direction contrary to what was expected (see chapter three). The study examined various explanations for these unexpected results, such as the influence of outliers and the degree of MOVE intervention. The most plausible seems to be the large variability in joint motion measurements, particularly for spastic children (Harris, Smit & Krukowski, 1985; McDowell, Hewitt, Nurse, Weston & Baker, 2000; Stuberg, Fuchs & Miedaner, 1988). Nevertheless, this variability could provide a partial explanation although the reliability study, conducted as part of the study, yielded positive results. Furthermore, the variability does not explain the remarkable course of the passive PROM after the third measurement. Active motor function increased significantly in the nine months following implementation of the curriculum, with a large clinically relevant effect.
Results, described in chapter four, of the effects of MOVE on independence when children with PIMD perform movement skills confirm the assumption that independence increases significantly in this group if they are supported by a curriculum with a functional focus. This change can be interpreted as a relevant clinical outcome with a moderate effect size. The level of independence when performing movement skills among children with PIMD who were supported by a regular programme 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 experiment.
Findings of the study in chapter five, that investigated whether support with the acquisition of motor skills can be systematically reduced with children with PIMD using the MOVE curriculum and how this reduction of support occurs confirm the assumption. The mean degree of prompting during skills relating to sitting, standing and walking declined significantly during the intervention period, with a large intervention-related effect. Positive results were also observed at the individual level. For sitting, standing and to a lesser degree walking, most children benefited, and the amount of support decreased during the intervention period. How this reduction occurred appears to depend on both the age and the different items for which support can be reduced. For sitting, the level of support decreased in the group of young children in particular, whereas for walking and standing there was no difference in prompt reduction between the young and older children. It appears, however, that the level of support at the start of the study was higher for the group of older children than the younger. In terms of the different aspects for which support can be reduced, this was true of sitting for the items 'support to the head', 'the type or control needed in order to maintain a sitting position' and 'the prompts needed to keep the hips placed for sitting'. For standing too, reduction occurred in five of the six items, whereas for walking reduction only occurred in the item 'the number of body segments that need to be prompted'. The significant

decrease found in the analyses of the sum scores can be wholly attributed to reduction in this item. We can conclude from these results that prompts can be reduced for children with PIMD when performing the skills of sitting, standing and walking. How this proceeds seems to depend on the age of the child, the place on the body and the degree of support.
With regard to the effects of MOVE on the acquisition of functional skills, the results in chapter six show that the goals formulated for children supported by MOVE are substantively inconsistent with the basic principles of functionality outlined in the literature (Fetters, 1991; Ketelaar et al., 1998; Pellegrino, 1995; Rothstein, 1994). Although most goals had been formulated in terms of concrete skills, the goals focused primarily on the motor system. Far fewer goals were concerned with such matters as play or communication. It was precisely the acquisition of these functional skills that constituted the point of departure for MOVE's founders (Bidabe & Lollar, 1995). Many goals also covered aspects relating to care of the child without it being clear what the significance was for the child itself. Often the child was trained in having a diaper changed while standing without it being clear whether this benefited the child or the care givers. Almost half of all goals were formulated in such a way that it was not clear what benefit the child derived from accomplishing the goal. This was particularly true for goals designed to accomplish motor skills.

7.3 Methodological reflections

7.3.1 Research group and selection

The study focused on the target group 'children with PIMD'. The size of the research groups involved in the different parts of the study ranged from 20 to 66 children with PIMD attending a CSE. The number of CSEs taking part in the study ranged from three to eight. The selection of the CSEs, the groups and the children was not random.
Within the described studies, sample size seems to be rather small. Although, the samples form a substantial part of the total estimated population of children with PIMD in the Netherlands. However, it is not possible to state clearly how many children with PIMD there are in the Netherlands. According to the Dutch Health Care Inspectorate (IGZ) (2000), the Netherlands has 91 CSEs caring for a total of 3551 children, 38% of whom have PIMD (IGZ, 2000). Based on these figures, there are an estimated 1349 children with PIMD attending a CSE. In addition, some children with PIMD will be living at home and not making use of residential facilities. According to the IGZ, this involves 680 children with PIMD aged 0 to 18 years (IGZ, 2000). These figures do not reveal the true extent of the group of children with PIMD. The Netherlands has an estimated 120,000 people with an intellectual disability, 53,600 of whom have a severe intellectual disability. This group includes an estimated 6000 children aged 4-9 years and 8300 aged 10-19 years (www.rivm.nl), amounting to a total of 14,300 children with severe intellectual disabilities aged 4-19 years, and an indeterminate number aged 0-4 years. Children with PIMD constitute a further subgroup. Going by these figures, the estimated number of children with PIMD in the Netherlands will be higher than the figures provided by the Health Care Inspectorate (2000).
The following can be observed regarding the extent to which the children in the study fall within the target group of children with PIMD. The children were selected on the basis of an internationally accepted description by Nakken and Vlaskamp (2002) and are representative of the group of children with PIMD as a whole (Hogg & Sebba, 1986; Nakken & Vlaskamp, *submitted*; Vlaskamp & Nakken, 2004). Some children dropped out as a result of illness and/or moving house. Dropout and the resulting lack of data are typical of this group. However, no reasons were found for assuming that the children who dropped out constituted a separate group in terms of severity of disability, age, fragility or reactivity to the MOVE curriculum. It is assumed that dropout occurred through chance. The CSEs took part in the research on a voluntary basis and had planned to implement the MOVE curriculum before the study began. This voluntary participation

increases the response but also produces a certain bias in the sense that it may involve CSEs that have DSPs who are especially motivated. This can negatively affect the external validity of the results and reduce the generalizability to other care facilities and/or DSPs. However, the CSEs compare with others in terms of group size, educational level of staff and educational programme. The setting is also comparable to settings where MOVE is implemented in other countries such as the USA, UK and Germany (Barnes & Whinnery, 2002; Elkins, 1994; Oosten, 2002; Schomerus, 1996). However, the current study provides no insight into the extent to which the results can be extrapolated to individuals with less profound disabilities or to settings such as residential facilities or community homes for individuals with intellectual disabilities.

7.3.2 Research designs

Different designs were used in the three effect studies such as a repeated measurement design with baseline measurements, a repeated measurement design without baseline measurements and a quasi-experimental pretest-posttest with control-group design.

For the study of both MOVE's effects on the anatomical-physiological domain and prompt reduction, a repeated measurement design was used without a control group. Neither study used control groups because the research questions were not concerned with whether the passive range of motion, active muscle function and the level of support improved *compared with* a group that did not follow the MOVE curriculum. However, a control period was used in the study of effects in the anatomical-physiological domain. In retrospect, the duration of this baseline was possibly too short given the traits of the target group: perhaps these children need more time for 'change'. Ideally, the study of prompt reduction should have included one or more baseline measurements. However, the PRP and the way in which this must be used is a fixed part of the MOVE curriculum. Practically speaking, it is almost impossible to carry out the PRP measurements without implementing the MOVE curriculum.

In the study of effects in the motor domain, an experimental pretest-posttest with control-group design was used. Because the research groups were not determined at random, this constitutes a real threat to internal validity. In ethical and practical terms, however, it was impossible to determine both groups on this basis. The children in the control group were on average slightly older than those 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 therefore, the threat of the internal validity is small.

7.3.3 Instruments and analysis

The study included measurements in the anatomical-physiological, motor and functional domains. However, almost no evaluative instruments were available in any of these domains that were designed for children with PIMD and whose psychometric quality was known to be good (Sommerfeld, Fraser, Hensinger & Beresford, 1981). Normally, the quality of an instrument must to be determined anew when used with a new target group and context (Yun & Ulrich, 2002). In retrospect, it would have been better if the present study had first extensively tested the different instruments for reliability and validity. The fact that this did not happen has to do with the particular dynamic of research in practice. When the study began, the different participating CSEs had been planning to implement the MOVE curriculum in the near future, making it difficult to extend still further the already lengthy preparation time by examining the psychometric quality of all the instruments that make up an intervention. For this reason, an analysis of the psychometric quality of the various measurement instruments only occurred to a limited extent.

In the anatomical domain, passive range of motion was established by measuring the passive mobility of different joints. Prior to this, a reliability study was carried out with a small number of children, producing good results. Nevertheless, on completion of the study it was concluded that the possible variation in outcomes may have been partly responsible for the remarkable results. Active motor function was also measured. Bidabe and Lollar (1995) describe an increase in strength of the extensor muscles in particular. One way of measuring this is electromyography (EMG), or with a dynamometer (a less invasive method). Using EMG to determine muscle strength gives rise to ethical problems as dynamometers are not customary with the target group. A decision was therefore taken to 'measure' active motor function with the help of a questionnaire developed as part of the study. Several analyses were made of the questionnaire's internal consistency. Further research needs to be carried out to establish whether this too is a sufficiently reliable and valid instrument.

Some of the instruments used in the present research were developed in the MOVE curriculum itself, which may have affected the reactivity of the instruments on the items measured. Moreover, the psychometric quality of instruments such as the TDMMT and the different PRPs was unknown. For this reason, an analysis was made of the psychometric quality of the TDMMT, thus making a start on research into its reliability, validity and usefulness. It is no easy matter to examine the psychometric properties of the TDMMT with children with PIMD. Reasons include the difficulty of finding a large enough research group and the retrospective administration required by someone who knows the child well. Agreement between raters can only be properly established if the raters have equivalent knowledge, which precludes the use of unbiased, independent raters. Also, it is nearly impossible to determine intra-rater reliability because the exact same administration cannot be repeated. In addition, research into criterion-related evidence is not possible because of the lack of an instrument comparable to the TDMMT.

In the absence of an instrument that 'measures' functional skills with children with PIMD, a goal analysis was used to evaluate effects in the functional domain. The idea behind this was that goals were the point of departure for planning and selecting activities (Giangreco, Dennis, Edelman & Cloninger, 1994; Sigafoos et al. 1993). If goals focus on functional skills, we might expect the right activities to be carried out to achieve these goals and changes to be observed in the functional domain. Yet, effects could also occur with regard to the acquisition of functional skills that were not formulated in the MOVE goals.

Different statistical analyses were carried out at the group level. On the basis of these results, no assertions can be made about the effects of the MOVE curriculum at the individual level. The reverse is also true: results observed at the individual level do not always hold for the group of children as a whole. Together with the problem of generalizability, certain statistical analyses could not be carried because of the relatively small groups, the high drop-out rate of children and the quantity of incomplete data. For instance, it was not possible to conduct a multi-level analysis despite the "nesting" of the data.

7.3.4 Reliability and validity

In addition to the threats already described to the internal validity of the research designs, a further threat is a possible test effect. In other words, the children may have progressed not as a result of the intervention but because they did the test better the second time round. This may have been the case for the examination of passive range of motion and muscle function. However, given the traits of the target group (children with PIMD), this does not seem very likely. In addition, the measurements for passive range of motion were carried out by an independent evaluator, which would appear to safeguard objectivity. This did not apply to the DSPs. They may have expected

the children to have progressed, which would have affected the scores for active motor function, for instance. The same applies to the scores for the different PRPs and the TDMMT.

Another threat to the internal validity may be in the area of instrumentation (Cook & Campbell, 1979). Where the TDMMT was used in the study, the mean scores of the participating children was low. In the study of prompt reduction, the children scored on average very highly and the opportunities for improvement were slight.

7.4 Theoretical reflections on the major findings

The founders of MOVE assumed that the movement-oriented activities in the MOVE curriculum had various effects on those who followed it (Bidabe & Lollar, 1995). Alongside these effects, the founders emphasized the physical burden and motivational aspects of DSPs, and interaction between DSPs and the people they supervised. The present research only looked at effects that may occur with the children who are supervised with the MOVE curriculum. Possible effects on the DSPs fall outside the scope of this study.

In the anatomical-physiological domain, Bidabe and Lollar (1995) describe positive effects on for example bone health, joint health, muscle function, fitness and alertness. In the motor domain, they claim an increase in independence when performing motor skills relating to sitting, standing and walking. In addition, Bidabe and Lollar (1995) claim that the amount of support needed when performing motor skills declined as a result of the MOVE activities. In the functional domain, the participating children showed improvements in a range of skills like eating and drinking, self-management and hand function.

However, it is not clear from the various descriptions by Bidabe and Lollar (1995) whether these effects did in fact occur, how they were achieved and what the relationship was between the different activities and the effects. Nor did the descriptions always make it clear what precisely was meant by the different terms. In addition, the founders of MOVE make a single reference to research that substantiates their claims. Because of the lack of a standardized research design and structure, however, no single conclusion can be drawn on the basis of these data. Nevertheless, we can generally assume that the authors are referring to the effects of physical activity on children with PIMD. Earlier research mentioned in the introduction to this thesis also provides scant confirmation of the assumed effects of MOVE for children with PIMD.

The following sections look at which of Bidabe and Lollar's claims (1995) can be substantiated. Naturally, only those aspects are described which were the focus of the present research.

7.4.1 Anatomical-physiological domain

In the anatomical-physiological domain, Bidabe and Lollar (1995) describe effects on joints, bone structure and muscle function. They claim that joint deformities can be reduced or prevented as a result of MOVE activities. According to them, the traditional 'passive movement' of the various joints to prevent contractures is no longer necessary if children are supported by MOVE. They also claim that movement-oriented activities have a positive effect on bone quality, and that muscle function of the extensor muscles in particular improves by practising the skills of sitting, standing and walking.

The described effects on joint structures, by the founders of MOVE, could be supported by other studies that show a prevalence of lower bone mineral density in individuals with mild to severe mental retardation (Center, Beange & McElduff, 1998, Foster, Walkley & Temple, 2001) and children with spastic quadriplegia (Henderson, 1997), the positive effects of weight bearing physical activity on peak bone mass for people both with and without disabilities (Jones & Dwyer, 1998; Kotaniemi, Savolainen, Kröger, Kautiainen & Isomäki, 1999; McKay et al., 2000), and the

negative aspects of immobilization on the development of bone change (Takahashi, Nagao & Matsuda, 1995).
Paleg (1996) endorses the claims of Bidabe and Lollar with regard to joint mobility in a description of two case studies. Because this is not standardized research, however, it is uncertain how much value can be attached to the findings. None of the earlier studies of the MOVE curriculum make reference to this (Barnes & Whinnery, 2002; Elkins, 1994; Schomerus, 1996). In general, studies of the effect of movement on joint range of motion for people with severe mental disabilities and cerebral palsy show no effects (Bower & McLellan, 1992; Sommerfeld et al., 1981).
With regard to the claims about muscle function, it may generally be assumed that children with PIMD have less muscle strength or function than children without disabilities, although to our knowledge there is no scientific evidence to substantiate this. We do know that people with an intellectual disability and, for example, Down's syndrome have less muscle strength (Cioni et al., 1994; Horvat, Croce, Pitetti & Fernhall, 1999), as have cerebral palsy sufferers (Engsberg, Ross, Olree & Park, 2000). Research also supports the idea that physical activity in general has a positive effect on muscle strength and/or function among healthy children (Salminen, Oksanen, Mäki, Pentti & Kujala, 1993) and children and adults with cerebral palsy (van den Berg- Emons, van Baak, Speth, & Saris, 1998; MacPhail & Kramer, 1995).
To our knowledge, no earlier research has been conducted on the effect of movement on joint structures and muscle function among children with PIMD. Research involving participants with less severe or no disabilities only partly supports Bidabe and Lollar's claims. The question remains: to what extent can we extrapolate these findings to children with PIMD? These children differ markedly from children with cerebral palsy, for instance.
Results of the present research only partially confirm the claims of Bidabe and Lollar (1995). No effect was found on passive joint motion and only a very small effect on active motor function as a result of MOVE. The research provides no answer to the question about the clinical significance of these findings, namely whether this also produces effects at a functional level such as improved communication.

7.4.2 Motor domain

In the motor domain, Bidabe and Lollar (1995) claimed increased independence and a reduced level of prompting when performing motor skills relating to sitting, standing and walking as a result of the MOVE activities.
The idea behind the claim that motor activity has positive effects on the acquisition of motor skills is supported by various studies (Bower & McLellan, 1992; Brown, Effgen & Palisano, 1998; Trahan & Malouin, 2002; Schindl, Forstner, Kern & Hesse, 2000; Ulrich, Ulrich, Angulo-Kinzler & Yun, 2001). However, these studies were conducted with different target groups and with different types of movement intervention.
Studies outside the Netherlands that evaluated the MOVE curriculum show a positive tendency with regard to sitting, standing and walking skills (Barnes & Whinnery, 2002; Elkins, 1994; Schomerus, 1996). However, these studies were conducted with small research groups and not all results reveal a significant difference. For this reason it is not certain whether the differences can actually be attributed to MOVE and which components of the curriculum produced the effects. What does emerge from these studies, however, is that children with PIMD are in a position to learn skills like sitting, standing and walking and that MOVE offers more benefits in this respect than traditional interventions (Elkins, 1994).
The present research confirms some of the claims made by Bidabe and Lollar (1995) in the domain of motor skills acquisition. The study found a difference in the level of independence between the

experimental and the control group. It is interesting to observe that although the experimental group scored lower in the first measurement of independence than the control group, it ended higher. The MOVE curriculum appears to have minor value compared with a regular intervention. One explanation is the possible minor difference between the two interventions. Children in the regular programme were also given physiotherapy, which may approximate the activities of the MOVE curriculum. Present-day physiotherapy increasingly focuses on training functional skills (Ketelaar et al., 1998). Perhaps in the late 1980s, when the MOVE curriculum was developed, the need for such an approach was greater than it is now. Some of the effects may have been caused by the way in which the curriculum is applied in practice. How activities are carried out and the choice of activity type largely determine the effectiveness of an intervention. Also substantiated by the research is the assumption that, despite their limitations, children with PIMD do have abilities and can benefit from the movement-oriented activities in a curriculum like MOVE in terms of prompt reduction when performing motor skills. Group analyses show that the average amount of support during skills relating to sitting, standing and walking declines significantly during the 12-month MOVE intervention, with a large intervention-related effect.

7.4.3 Effects on the acquisition of functional skills

With regard to functional skills, Bidabe and Lollar claimed effects such as improvements in skills like eating and drinking, communication, interaction with the environment and self-reliance and independence.

These claims are supported by various studies (Belfiore, Browder & Mace, 1993; Jones et al., 1999; Sowers & Power, 1995). As with studies describing the acquisition of motor skills and the effect on anatomical and physiological structures and functions, here too the studies involved other target groups than children with PIMD.

A study by Schomerus (1996) of the effects of the MOVE curriculum on the functional domain shows nevertheless that there is greater activity among children supervised with MOVE. The same phenomenon is reported among the non-participating children who share a class with children following the MOVE curriculum. Schomerus (1996) states that alongside effects in the motor domain the curriculum also raises the level of the activities, the self-esteem and self-awareness of the children. In addition, MOVE changes the way in which teachers and therapists work (Schomerus, 1996). What the study does not clarify, however, is the extent to which the research questions that were asked arose out of an accurate analysis or whether they were the consequence of the way in which the researcher viewed the MOVE curriculum.

Only to a very limited degree does the present research support the claims of Bidabe and Lollar regarding the acquisition of functional skills. The goals formulated in MOVE do not satisfy the theoretical principles of the curriculum and, in terms of their content, the majority of the goals concern the acquisition of motor skills without it being clear where this leads in functional terms. For example, the child must be able to walk, yet the goals do not specify the purpose or the context. Few goals deal substantively with aspects like eating and drinking, and communication. This may be due to the way in which the goals are formulated and how the curriculum is structured. After all, the content of the goals was partly determined with the help of a questionnaire which addressed not just the child's needs but also the convenience of the caregivers. In addition, a large part of the curriculum targets motor skills. The MOVE activities are aimed primarily at the motor system and to a lesser extent functional skills like play or communication. Not unless goals relate to functional skills can we expect the right activities to be carried out to accomplish those goals. Changes will then be observed in the functional domain. If functionality is absent from the goals, it is unclear whether effects can and do arise in the

functional domain. In addition, the instruments used in the curriculum such as the TDMMT and the PRP aim primarily at motor skills.

7.4.4 Conclusion

It must be concluded that the effect and the application of MOVE on children with PIMD does not match the claims made by Bidabe and Lollar (1995). The effects were observed primarily in the motor domain. This seems to be caused by inconsistencies in the theoretical foundations of the curriculum, and perhaps by the way in which the curriculum is structured. A further cause is the implementation of the curriculum in practice. There is no clear implementation strategy for the curriculum. In addition to a sound theoretical basis, an innovative intervention like the MOVE curriculum requires adequate professional support (in the longer term as well), a general coordination point, sufficient personnel and sufficient familiarity with those involved if it is to be implemented effectively (Ravensbergen, Jong & Splunteren, 1999; Wiefferink & Dukkers van Emden, 1996; Zijlstra, 2003). The curriculum content and the accompanying instruments also focus primarily on motor skills.

7.5 Scientific and clinical implications

We have little understanding in the different domains when it comes to children with PIMD. This applies for instance to knowledge about communication and sensory impairments, which are vitally important in the education and support of these children (IGZ, 2000). In the motor domain too, there is a lack of knowledge about how motor development occurs among children with PIMD. It is unclear whether it proceeds in a similar fashion to children without disabilities, whether major motor milestones are only reached with some delay, or whether motor skills development among children with PIMD differs fundamentally and bears no resemblance to the overall pattern in the normal course of development. It can be assumed that the intellectual, motor and sensory disabilities of children with PIMD interfere to such an extent that the developmental process and acquisition of motor skills deviates substantially from the normal process (Engelbert & Lauteslager, 2000). Also important for the right selection of the right care and intervention is an understanding of how children learn motor skills and of the factors affecting motor abilities. After all, if critical developmental periods do exist but are missed, we run the risk that key development opportunities are not being utilized. De Groot (1998) states that a child's developmental stage is a key consideration when deciding which therapeutic approach can best be employed.

In different respects, the findings of the studies described here do provide evidence for the assumption that children with PIMD develop differently. They also give some indication as to when MOVE can best be implemented for these children.

The analysis of the TDMMT, for instance, indicates that children with PIMD do indeed master skills differently from how the founders of MOVE had assumed. Interestingly, both the sequence and the items in the different scales of the TDMMT match those in regular motor development. Analyses in the present research reveal, however, that the acquisition sequence of the items in various scales of the TDMMT is different among children with PIMD. In other words, these children can perform certain items without being able to perform others that are supposed to be 'easier'. Although these results must be interpreted with the necessary caution, it does indicate a different 'development profile' for children with PIMD. This acquisition of skills in a different sequence has major implications for both planning and the evaluation of the intervention. Together with this practical implication, the study of the TDMMT has also helped develop an instrument to chart the motor functioning of children with profound multiple disabilities. Specifically, this is an instrument designed to establish motor functioning from a functional perspective, something

which has not previously been tested for this group. Even without the MOVE curriculum, the TDMMT can be used to evaluate movement interventions and effects in the functional domain.
In addition, the findings of the present research show clearly that, despite their disabilities, children with PIMD are also able to 'learn' and to master skills. Skill acquisition does appear to depend, however, on both the age of the child to whom the intervention is offered and the duration or degree of intervention before a result is observed. For example, the study of prompt reduction shows that reduction of support during sitting is greatest for children younger than seven. If children are older than seven at the start of intervention, the reduction is considerably less. In practice, this is an argument for beginning with movement training aimed at prompt reduction when children are young. It also appears that support can be reduced from the start of the intervention but that reduction occurs less rapidly after an average of six to eight months' intervention. The situation is different for standing, however. Here it appears that older children required more support at the start of the study than children younger than seven. If training had begun earlier, less support may have been needed. Moreover, reduction only occurred after an average of four months' intervention, stabilizing at about ten months after the start of the intervention. Although these findings and conclusions should also be interpreted with the requisite caution, they do provide clues for practice. For any results to appear, training aimed at reducing prompts during standing-related activities must be carried out over a long period; also, the gain from that training diminishes after about six months. However, reduction in support must always be seen in the light of what this means for the child thus must be accompanied by an increase in the independence of the child. The aim of a maximum reduction in support must not be at the cost of the abilities of the child to be independent. Findings for active motor function suggest that a substantial positive change does not take place until nine months after the start of the movement-oriented intervention. This would perhaps suggest that in the anatomical-physiological domain as well the intervention has to be applied to a particular extent over a particular period in order to produce a substantial effect.
Finally, when implementing the intervention it is possible to take into account the child's level of functioning. 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 most from a functional curriculum. If this can be confirmed, it would have practical implications for establishing which children can best benefit from MOVE, and perhaps their optimum age.

7.5.1 Application of the MOVE curriculum

On the basis of the studies described here, the effects of the movement-oriented activities in the MOVE curriculum on children with PIMD appear small. However, 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 attending a CSE. The general conclusion is that a functional movement curriculum such as MOVE may have value for children with PIMD in acquiring independence when performing movement skills and that such a curriculum 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 these children. In concrete terms, this means the possible integration of functional activities into the full-day programme, performed by all the child's DSPs and directed towards specific measurable goals set within a multidisciplinary framework. Despite the apparently limited abilities of this group of children, the interventions offered should aim to increase the child's independence, however minimal this may appear to be. For example, enabling a child to move small distances by itself with only the support of a walking frame gives that child a greater say over where, when and who it wants to be with, and whether it wishes to participate in an activity. Thus a limited increase in

independence, possibly achieved through a programme such as MOVE, has a great effect on a child when directed at the acquisition of autonomy and control over its own life.
A vital question is of course the value of the MOVE curriculum for children with PIMD. On the one hand, given the effects observed in the studies described here, the value of MOVE for children with PIMD is small. MOVE requires a huge investment in terms of time and the cost of the necessary equipment and licences, and the ultimate effects achieved appear rather small to justify such an investment. On the orher hand, MOVE has a clear value when it comes to the perspective on educating and supporting children with PIMD. In the curriculum, children with PIMD are perceived as children who are able to learn, and who, just like other children, need to be activated. The MOVE curriculum proceeds from what the child can do and, with that as a starting point, the child is expected to do what it can. The curriculum also emphasizes functionality. Only those skills are trained from which the person derives some immediate benefit, with practice occurring in the right environment. In addition, the curriculum pays attention to the issue and role of parents of children with PIMD. Goals are formulated in the curriculum in consultation with the parents and some of the activities are ultimately designed with them in mind. In addition, MOVE offers a strong system which, if applied properly, can lead to the right planning and evaluation.
If MOVE is used for children with PIMD it needs to be deployed as part of an adapted curriculum. First, a clear implementation strategy is required, and the way in which goals are formulated needs to change to reflect a more functional viewpoint. In addition, it must rest on a clearly formulated pedagogical and theoretical basis, with the underlying principles explicitly incorporated into the procedures. The present description is inadequate as it does not properly lead to the drafting and implementation of functional goals. The MOVE curriculum emphasizes the acquisition of motor skills. The ultimate goal, increasing a child's self-reliance and independence, remains as it were behind the scenes. If MOVE is integrated in a context where activities are pedagogically driven, this facilitates the transfer of purely motor activities to functional ones. One way of doing this would be to integrate MOVE in the right way into the 'Educational programme' developed by Vlaskamp, van Wijck and Nakken (1993). This programme guides the care and supervision of children with PIMD with an emphasis on cooperation among the different professionals from the same educational perspective. They set priorities within the programme, and establish how the goals are to be achieved and what resources are required. This process is divided into small steps by defining long term goals (main goal) and short term goals. Furthermore, evaluation takes place at a regular basis with use of Goal Attaimant Scale. In this way the programme leads to a situation in which, in a systematic, goal-oriented and assessable fashion, people with PIMD can determine what happens to them and how. Taking as its starting point the child and/or the parents as primary educators, the programme determines what is needed and which resources should be deployed (Vlaskamp, van Wijck & Nakken, 1993; Vlaskamp, 1999). One such resource could be the MOVE curriculum. Utilizing MOVE in the educational programme in the right way can provide direction for the motor skills of sitting, standing and walking in the sense of a formulated perspective and a primary goal. For example, MOVE could be deployed to teach a child how to walk in a gait trainer. This is not a goal in itself, however. The purpose is to enable the child to explore its environment in a more independent fashion. This last point is made explicit if the educational programme is used. In this case, MOVE becomes a tool to enable the child to explore its environment independently. This gives explicit content to the above implicit end goal of the MOVE curriculum. Figure 1 presents in diagrammatic form the place MOVE could occupy within the educational programme.

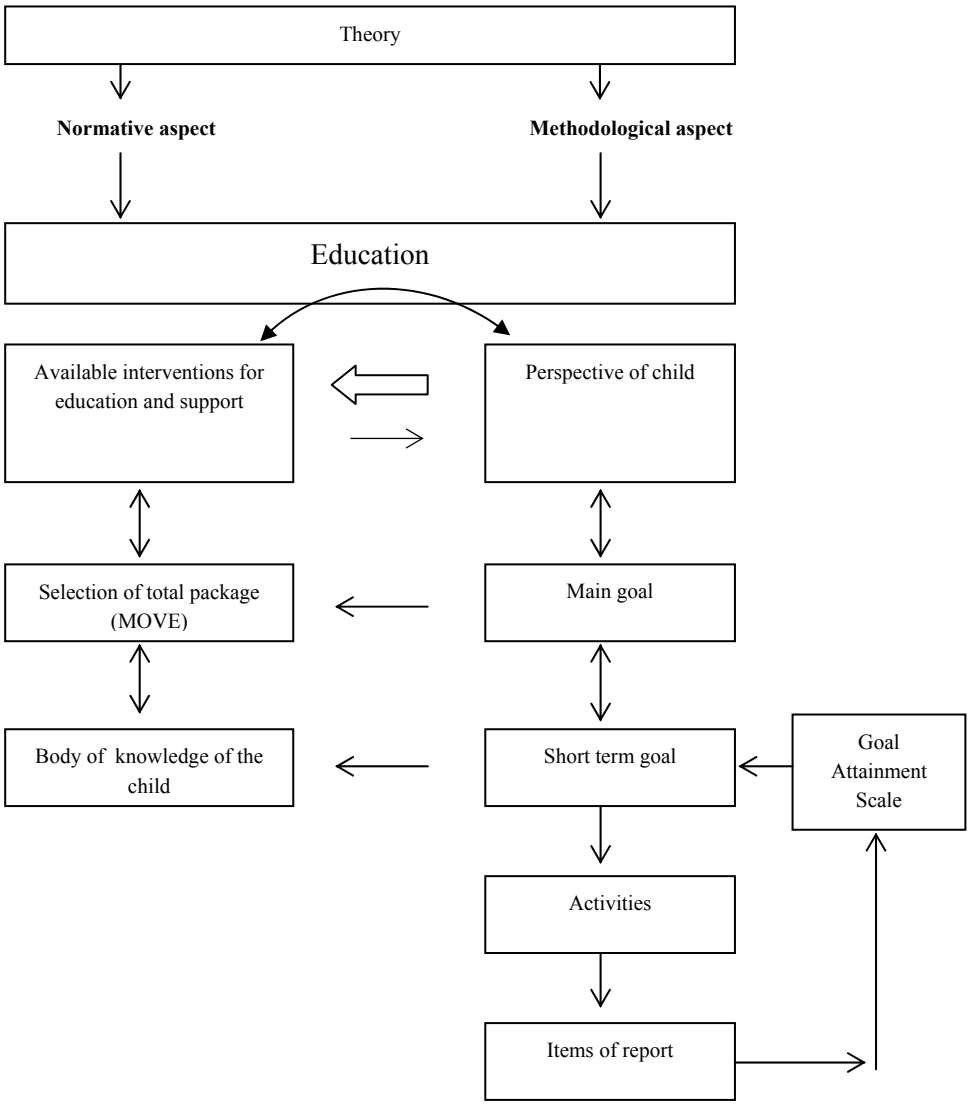

Figure 1 MOVE and the Educational programme

7.6 Further research

Further research is needed on the value of MOVE if the curriculum is to be implemented within a framework like the educational programme. More research is also needed into the curriculum itself and the way in which it is implemented in practice. The results to date may be caused by a lack of functionality or purposefulness of the activities offered. However, no analysis was made of the type of activity offered to the children or of the relationship between the activities and the goals. Furthermore, the relationship between implementation of the activities and the children's abilities was not the subject of the study, although it could be a factor behind the lack of results. Further research must be conducted to discover whether all or part of the theoretical underpinnings of the MOVE curriculum should be refined or whether the curriculum failed in its implementation.

Further research needs to be conducted into the TDMMT and the MOVE curriculum before the results can be generalized to other settings, such as residential facilities, and to other groups, such as adults with PIMD. Nevertheless, agreement among therapists, support staff and parents can be

an appropriate strategy for providing more evidence about the reliability of the TDMMT (Burton & Miller, 1998). Research could also look at content-related evidence, with a panel of judges evaluating the TDMMT on the basis of specific criteria relating to relevance and accuracy (Yun & Ulrich, 2002). Further research into aspects such as intensity, kind of activity and focus, as well as possible discrepancies between the planned and performed activities should provide more insight into precisely which part of the curriculum is most effective. This can then be used as a basis for further developing MOVE and determining how it should be implemented within the educational 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 disability and/or abilities of the children when acquiring independence while performing movement skills.

7.7 Concluding remarks

The present thesis reported on a study of the MOVE curriculum for children with PIMD. The research was carried out at the request of the Ipse Foundation, which provides support for people with intellectual or multiple disabilities. In 1994, the MOVE curriculum was added to the total support package of interventions offered to the target group. With the implementation of MOVE, Ipse also wished to research the value of the curriculum. They were interested not just in the effectiveness of MOVE but the question of how the curriculum could best be deployed to maximize this effectiveness. Thus the research was not especially aimed at the question of whether or not the curriculum worked; it also investigated the questions as to why, how and when MOVE was most effective for children with PIMD. For this reason research techniques were selected that analysed not only the external validation, but also the theoretical foundations of the curriculum and its application in practice. By conducting research in this way the emphasis was on renewing and improving an intervention and the effects that can be achieved with a certain target group in a specific context. The present research has produced a specific understanding of the possible effects of MOVE on children with PIMD, how these effects can be achieved and how the curriculum can best be implemented within the present context.

Although the ascertained effects of the movement-oriented activities within the MOVE curriculum lie primarily in the acquisition of motor skills, the main value of the curriculum is the idea that the support and supervision of children with PIMD must be directed towards increasing the independence of the children. Independence means that the children are able to exercise more control over their own life, their environment, and the way they are addressed. Within MOVE, this is achieved by teaching the children skills so that, for example, they are able to move independently and participate in activities. The MOVE curriculum thus meshes perfectly with current ideas on the supervision of children with PIMD. Within this vision and the resultant policy, the recognition of a person's abilities also takes central place and supervision and support are directed towards increasing independence, self-sufficiency and autonomy (van Gennep & Ruigrok, 2002). In addition, the starting points of MOVE also dovetail with recent shifts towards 'functionality' within movement interventions and changing theoretical insights in child-rearing and education, among other things (Reynders, 2000).

The results of the research described in this thesis make clear that children with PIMD can profit from movement-oriented activities. The idea to activate children with profound disabilities and the positive effects associated with this is interesting because only a limited number of activities are offered within the regular care context and they are partially dependent on the abilities of the person with the intellectual disability (Hatton, Emerson, Robertson, Henderson & Cooper, 1996). Further, the activities on offer are characterised by passivity and are 'body related', for example lying on a waterbed or listening to music (Wiersma, Beumer, Koedoot & Vlaskamp,

2002). Based on the results of the current research, the content of the care on offer for children with PIMD should be supporting activation in the widest sense of the word.

Finally, it should be noted that although results have been found by this scientific research into MOVE, they appear to be minor. However, even minor changes, progress or even prevention of deterioration in the acquisition of skills can be of great importance for a child with PIMD. For example, by training the children and offering them the possibility to move independently in whatever way they can, with or without aids, enables the children to choose whether or not they want to join their friends, which contributes to their self control and increasing their independence.

The results of this research have produced more insight into the functioning and effects of the MOVE curriculum for children with PIMD. The results of this scientific research have thus led to new insights which can be used by organisations that offer care to children with PIMD. The current research may also provide the necessary input for the maintenance or (re)implementation of the MOVE curriculum within the total care package for children with PIMD.