From policy to practice
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Document Version
Publisher's PDF, also known as Version of record

Publication date:
2007

Link to publication in University of Groningen/UMCG research database

Citation for published version (APA):

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Chapter 6

General discussion
6.1 Introduction

One of the implications of the new educational law, which was introduced in 2003, was that all children, including those with the most profound disabilities, would be able to attend school. As these children usually attended CSEs, the authorities recognized the need for new methods of assessing these children and the educational programme required by each of them. At that time no such methods were available in schools.

The present thesis reports on the development and use of an instrument describing child characteristics and reports on the implementation of a curriculum for children with profound and multiple disabilities (PIMD) that was developed specifically for them. The introduction of the new law was not expected to lead to a situation in which all children with PIMD would make a switch from a CSE to a school instantly. Therefore, the thesis also reports on the implementation of the new educational policy.

6.2 Major findings of the study

The focus of the research is threefold: development, implementation and evaluation. With regard to the development of an instrument for use in the education of children with PIMD we can conclude that we have succeeded in developing a reliable instrument. Both inter-observer reliability and internal consistency appeared to be high. In addition, factor analysis revealed factors that experts found to be highly interpretable. The checklist of child characteristics can be used as a tool to design an Individual Educational Programme (IEP). It provides information on the strengths and weaknesses of the child, gives an indication of the level of participation in class, and reveals details of the support that a child requires. The combination of qualitative and quantitative data looks promising for the education of children with PIMD.

The research on the implementation of the curriculum within three schools reveals that although they received the same training, each school applied the programme differently. The 'evaluation of goals' and 'working on short-term goals' are elements that were difficult to achieve. Teachers found it hard to estimate what a child could learn within a set period. The three schools obtained different results with regard to the number and percentage of goals that were achieved during the research period, with the deviation from the original programme being larger in two schools than in the third. Some factors seemed to contribute to more positive results, for example, working together and supporting each other within the team, which seemed to be crucial for good results. Teachers in one school had most positive opinions about the elements of the programme, its usefulness, and the collaboration involved. This school also achieved the best results.

With regard to the new educational policy, we found that there are indeed differences in the characteristics of children with PIMD in schools and children who remain in CSEs. The profiles of children in schools differ from the profiles of
children in CSEs, with children in CSEs appearing on average to have fewer functional abilities and less communicative and task-oriented skills. However, the two groups of children do not necessarily differ with respect to their ability to participate in class. Results indicated that children with profound motor disabilities and additional problems such as epilepsy and feeding problems are more likely to stay in a CSE. As yet, the policy of educating children with severe and profound intellectual and multiple disabilities seem to have failed, at least for a specific group of children. Although there are no formal boundaries left, many implicit boundaries seem to remain.

6.3 Methodological reflections

6.3.1 Research methods

Explorative methods were used in all studies. As previous chapters have already explained, a factor analysis was conducted with regard to the checklist of child characteristics. Eleven factors that were highly interpretable according to several experts were revealed. However, to be more certain that the factors are not based on coincidence but have meaning and contain the right items, factor analysis should be repeated with another sample.

Cluster analysis, which was used to compare children in schools and children in CSEs, is also an explorative method that is known to be sensitive to outliers. With a small dataset, the initial grouping will determine the clusters significantly. The cross-validation check that was conducted, revealing high kappa scores, gave the clusters more body. We only used the Checklist of Child Characteristics (CCC) to compare children in a CSE with those in school. As the CCC does not account for all variance, the use of other instruments may reveal more or additional information that gives even better insight into the differences.

In further research, more instruments could be used and more children should also be in the sample in order to obtain firmer results.

In the case studies, information was collected on different levels: teachers, classes and children were involved. Multilevel analysis would have been preferable, as it would have taken all of these levels into account (nested data). However, the sample size was too small, as sample sizes less than twenty will give very restricted information and less than ten should be regarded with suspicion (Snijders, 2003). It is recommended that further research should undertake such analyses.

6.3.2 Sample

The sample size differed from one study to another, based on the purpose of the study as well as the finances available. None of the samples was chosen at random. In the studies using the CCC, schools and CSEs were asked to fill in the checklist of child characteristics for one or more children. There was little control over which children were or were not selected by teachers and direct support persons (DSP). This may have influenced the representativeness of the samples, although there was much variation in the samples. The
representativeness of the samples is also threatened by the small number of children with PIMD in schools and by the unfamiliarity of schools with the actual population of children with PIMD. Because teachers are not familiar with the target group, their frame of reference may differ from that of DSP in CSEs. Teachers may label a child as having PIMD, even if the child has a higher estimated developmental age or no additional disabilities. Retrospective checks have therefore been conducted by the researchers in order to eliminate children who did not fall within the criteria that were set.

The number of schools and CSEs that were involved in the studies range from one CSE and two schools (in the case studies) to 24 CSEs and 35 schools when comparing the population in schools and CSEs. The three schools in the implementation study are not representative of all schools and CSEs in the Netherlands. As the children that were involved in this study had relatively high developmental levels and little additional impairments, this may threaten the representativeness of the results for other children with lower developmental levels or more severe additional impairments. Prudence is called for in the generalization of these results. However, results indicate a series of difficulties that can occur when implementing the curriculum. These are relevant for other schools that are planning to implement the curriculum as well, and can be used as guidelines.

6.3.3 Reliability and validity

Although the CCC was subjected to reliability and internal validity checks, it needs further consideration. As we have already discussed in Chapter 2, a small sample was used to estimate the inter-observer reliability. The method that was used in order to estimate the inter-observer reliability did not account for coincidence, thus reliability values may be overestimated. The internal consistency of the CCC was high, but that can also be the result of a long test with low inter-item correlations (Drenth & Sijtsma, 1990). The validity research that was conducted showed positive results but was rather small as only content validity was taken into account. Due to the lack of instruments with which to compare the checklist, no research with regard to concurrent validity could be conducted.

As has already been mentioned in Chapter 4, external and internal validity are of concern with regard to the case studies that were conducted. As the children were not chosen at random, this could threaten the internal validity of our research. The ability to generalize beyond the small sample is limited. It is not clear if the same results would have occurred if other schools were involved. Neither can the results be generalized to the whole population of children with PIMD. Children in the case studies had few additional problems compared to many other children with PIMD. It is not clear whether good results could be achieved with a population of children with the most profound disabilities. Furthermore, no control groups were used. Therefore, little can be said about whether the curriculum contributes more or less to the development of children than any other programme used in education. There is a danger of a test effect as well, for example, teachers may have set more goals, or worked more in
accordance with the programme as they knew this was to be checked by the researchers.

6.3.4 Other considerations

More research is needed in the area of the curriculum. The study that is described in Chapter 4 accounted for a period of one school year. Due to a late start by the schools, approximately eight months were available to conduct the research. Schools should be followed for several years in order to establish the long-term effects on the children. This would also provide more information on the developmental pattern of these children over the years, which is a very important area of research in which little is known (Zijlstra & Penning, 2005). Also, following the schools for a longer period would provide information on the sustained use of the programme. A very successful implementation does not necessarily lead to the sustained use of a programme, as Woodward (1993) has already shown.

In the study that we conducted, we only checked the implementation fidelity. The effectiveness should be examined more carefully and gaps within the curriculum need to be filled. Furthermore, the use of the curriculum should be evaluated once again in schools that also teach children with the most profound disabilities, and not just children who have relatively high levels of functioning.

6.4 Reflections on practical relevance

The most important issue in our study, of course, is the significance of the findings for cluster 3 schools, especially the actual contribution of the findings to the provision of education for children with PIMD and, related to this, an estimation of what is still missing and what needs further consideration.

6.4.1 Assessment

It is crucial to get to know the child before designing an Individual Educational Programme (IEP). A broad idea of the ability of the child is important, as disabilities and additional deficits affect all areas of development (Nelson, Van Dijk, McDonnell & Thomson, 2002). As was already argued in the introductory chapter, in order to teach children with PIMD, information is necessary with regard to the kind of disabilities, functional abilities and level of communication, as well as knowledge of the kind of activities that can be offered and information on how and when activities should be offered.

The development of the CCC is a great improvement, as there were no instruments available for use in the education of children with PIMD in Dutch schools. At present there is a reliable and valid instrument that can be used to design an IEP. The CCC attempts to provide information on several important areas: functional abilities, performance of activities and participation. Nevertheless, the CCC can be criticized on several points. One disadvantage may be that the CCC asks for the opinion of the teacher and is therefore subject to his/her subjective view of the child. The ideas of teachers reflected in the CCC
may not be congruent with the actual abilities of the child. Data from other sources such as observational data and parents’ questionnaires may help to provide a congruent and complete idea of the child’s requirements (Voelker, Shore, Lee & Szuszkiewicz, 2000; Downing, 2001). Another problem is that the CCC does not explain all the variance between children. Although the CCC collects information on several important areas, other factors that also contribute to differences between children must be taken into account. These factors should be allowed for, as they may contribute to the focus of the IEP. Based on our research, it is unclear what other factors are important in providing a suitable IEP. Yet, several areas have been noted as requiring our attention.

As described in Chapter 1, alertness plays a prominent role in this context, as being responsive to the environment is necessary in order to select and respond to stimuli (Potenski, 1993). Being responsive is an important condition for being able to learn. Knowing when a child is alert can lead to better fine-tuning of activities and learning activities of a child. Extra attention should therefore be paid to the child’s state of alertness (biobehavioral state). Children with PIMD have very short periods of alertness (Guess, Roberts & Rues, 2002; Guess et al., 1993), and alertness patterns are very much individually determined (Petitiaux, Elsinga, Cuppen-Fonteine & Vlaskamp, 2006). Being aware of the moment a child is alert can be very helpful in planning activities. It is also important to know how to raise the level of alertness. More variation in activities can be helpful, as offering the same stimulus for a long time may decrease the level of alertness (Nelson et al., 2002). Alternatively, offering too many stimuli at the same time, as occurs, for example, in the multi-sensory approach (Blaha, Shafer, Smith & Moss, 1996), may lead to overstimulation (Fonteine, Vlaskamp & Tadema, 2005). The introduction of an instrument that assesses levels of alertness (Vlaskamp, Fonteine & Tadema, 2005; Petitiaux et al., 2006) may contribute to the knowledge of individual patterns of alertness.

The preferences of children are not taken into account within the CCC. More attention should be paid to the preferences of children with PIMD as they exhibit more interaction with materials chosen by themselves (Realon, Favell & Lowerre, 1990), and social interaction also increases (Kennedy & Haring, 1993). Opportunities for choice making may also improve the behaviour of the child (Stafford, 2005). In preference assessment, it is shown that assessing the preferences of children by offering them objects gives a better indication of their preferences than asking their teacher or DSP to predict the preferences of the children (Green et al., 1988; Green, Gardner & Reid, 1997; Lohrmann-O’Rourke & Browder, 1998; Piazza, Fisher, Hagopian, Bowman & Toole, 1996). Preference assessment is a good instrument for seeking materials that suit the child and assist in increasing learning opportunities.

Although the CCC briefly questions the medical problems that children have, medical needs require extra attention. Kerr et al. (2003) showed that fully trained nursing staff easily overlooked the medical needs of their clients. For teachers who have not followed a nursing course, the risk of overlooking these needs is even greater. Without an adequate idea of the medical needs of a child it is difficult to develop a realistic programme for them (Zijlstra & Vlaskamp,
Careful reassessment of medical needs by appropriate specialists is recommended.

Finally, although communication skills are taken into account within the CCC, they require extra attention. The interpretation of the behaviour of children with PIMD is difficult and complicated by the different meanings that a sound, movement or facial expression, for example, may have in different situations. If the CCC reflects the fact that a child has little communicative skills or a limited ability to respond to their environment, this may indicate a lack in the teachers’ ability to adequately interpret the behaviour of the child, rather than a lack in the skills and abilities of the child. Training the teachers to become more aware of the non-verbal communicative attempts made by children (Payne & Ogletree, 1995, Golden & Reese, 1996) may in such a case be more effective than focusing on teaching new skills to the child.

Within our research, attempts have been made to overcome the limitations of the CCC by developing two other instruments, the first concerned with health, communication and the social network of children (Vlaskamp & Tadema, 2005), and the second concerned with preferences and the sensory system (Tadema, Hiemstra, Wiersma & Vlaskamp, 2005). However, these instruments have not yet been subject to extensive research.

6.4.2 Curriculum

Prior to 2005, schools did not have any tool to rely on for determining their teaching activities. Now they can use a curriculum that is specifically designed for the education of children with PIMD. The curriculum has been subject to evaluation, and results are promising. The development of the curriculum is therefore a great improvement compared to the situation prior to 2005. Nevertheless, the curriculum can be criticized on several points.

First of all, the development of the curriculum was characterized by duality, as two different products were developed. In our research, a framework was developed that was based on the Educational Programme (Vlaskamp, 1999; Vlaskamp, Poppes & Zijlstra, 2005). The framework was chosen because children with PIMD do not develop according to normal developmental patterns (Carpenter, 1992; Lacey & Ouvry, 1998; Vlaskamp & Nakken, 2004; Van der Putten, 2005). Moving from one developmental milestone to another is not a feasible approach with regard to the acquisition of skills (Carpenter, 1992; Goodman & Bond, 1993).

The focus group concerned with curriculum development decided to list developmental goals in five areas, despite knowledge of the fact that children with PIMD do not develop according to normal standards. In the summer of 2005, all cluster 3 schools received both the framework and the package with developmental goals. Applying two products with very different assumptions and procedures carries a great risk. Providing schools with a package that has its goals derived from normal development standards suggests that children with PIMD also develop according to normal developmental patterns, and that developmental milestones should be taught to these children. Although it was made clear that the developmental goals should be used as a source book to
provide inspiration for the kind of activities that teachers can offer to a child, it is possible that schools might merely pick out several developmental milestones and use these to develop an IEP for a child. The risk of ‘teaching to the test’ without considering the functionality and relevance of the skill that has been taught (Downing & Perino, 1992) is thus present. The impact on progress measurement is also great, as progress should not only be seen in terms of developing new skills, but also in terms of extending existing skills, accepting reduced support in completing a task, increased engagement, or retaining skills in the case of regression that may be caused by progressive disease (Marvin, 1998; Male, 1998).

The use of a framework, although advised, asks for more effort from the teachers. They must be able to fill in this framework for each child, again based on the specific information gathered for that child. This is more demanding for the teacher, and may be especially difficult if a teacher is not experienced in teaching children with PIMD. Implementation of the curriculum is indeed difficult, as can be seen from the case studies which show, for example, that teachers have difficulty in setting proper goals. Despite the extra effort that is expected from the teacher, a framework is preferable to a curriculum containing developmental sequences only. Obviously, improvements are necessary, especially with regard to providing teachers with more knowledge and skills. For example, attention should be paid to setting short-term goals as well as the evaluation of these goals. Although criteria with regard to setting goals became apparent during the training programme, a more extensive training course specifically directed towards setting goals may give better results (Poppes, Vlaskamp, De Geeter & Nakken, 2002).

6.5 Reflections on the educational policy

The intention of the ‘backpack policy’ was that all children, no matter what their level of disability, should be able to make use of educational facilities. Nevertheless, several years after the introduction of the new law, many children with PIMD are still looked after by a CSE. The educational policy itself may have complicated a successful transfer. In order to provide education for children with PIMD, a clear and coherent strategy from the authorities is needed (Ware, Julian & McGee, 2005). The Dutch authorities have failed to provide such a strategy.

Firstly, they did not make a clear decision on the best place for taking care of children with PIMD. On the one hand, the new educational law clearly removes the lower limit for PIMD children to follow education in schools. On the other hand, cluster 3 schools for children with intellectual disabilities (ID) can avoid the legislation by not applying for broadened admission criteria. In 2006, 98 of the 116 schools for children with ID (ZML schools) participated in a survey in which 45% of these schools indicated that they had not applied for broadened admission criteria (Landelijke Vereniging Cluster 3 Scholen, 2007). Children with PIMD are still unable to attend these schools despite the change in legislation. Implicitly, a new lower limit for obtaining education has thus been created.
The failure of the authorities to make a clear and univocal choice with regard to the best place in which children with PIMD can be cared for is also shown in the conflicting policies concerning CSEs. Criticized for their segregated nature, educational policy aims to transfer children from CSEs to schools. However, in contrast, the policy of the Ministry of Health, which is responsible for the CSEs, aims to develop them into ‘Expertise Centres’ concerned with the support and coaching of children with PIMD. CSEs can apply for funding in order to help them develop into such Expertise Centres (Fonteine et al., 2005). This is a curious development, which seems inconsistent with the attempt of the authorities to transfer children with PIMD to schools.

Although the cooperation of schools and CSEs was initially seen as being very important in the move towards education for all, the collaboration projects that were funded by the authorities were discontinued after several years. Since, the expertise that is available in CSEs can less easily be applied within schools. This is an undesirable development, certainly given the importance of specific knowledge and expertise that is required to provide care for and education to these children.

The Dutch authorities initially defined four domains that were expected to contribute to an increase in knowledge and expertise in the education of children with PIMD: the development of an instrument to describe child characteristics, the development of a curriculum, promotion of expertise, and a description of preconditions. Two of these domains (assessment and curriculum development) were studied in our research. The domains ‘promotion of expertise’ and ‘description of preconditions’ remained the responsibility of the focus groups, which provided information on these topics (Wegbereiders, 2003). The authorities took responsibility for the distribution of the information and products, but did not force schools to meet any requirements with regard to the manner in which they should use and apply this information and these products. Furthermore, the authorities did not financially support any improvements that might result from the information that became available. The research on the implementation of the curriculum shows that despite training, schools still found it difficult to implement such a curriculum. Training in working with the curriculum thus seems a minimal requirement. Without training the quality of education does not seem to be sufficiently guaranteed. It should be a task of the authorities to supervise and guarantee the quality of education, including that of children with PIMD.

Formalizing the promotion of expertise in specialist training would contribute to such a guarantee of quality. Such training should, as well as working with the curriculum and the CCC, also pay attention to other areas that are known to be relevant in teaching children with PIMD, for example, procedures for providing medical care, knowledge of how medical problems can affect educational performance, knowledge of broad assessment strategies, instructional styles, use of the curricular framework, and cooperating with therapists and parents (Giangreco, 1996; Thuppall & Sobsey, 2004; Wolff Heller, 2004).

With regard to the preconditions, the authorities should also set requirements for schools so that they are able to educate these children. As long
as schools remain inaccessible to children with severe physical disabilities who at present often remain in CSEs, the number of children with severe physical disabilities will not increase within schools. Schools should be forced to meet several requirements, including the accessibility of the school building, classroom equipment (including hoists, standing frames and augmentative communication devices), and the provision of extra spaces, such as changing rooms and sensory rooms. In addition, all classes should be accessible to children with PIMD, as going to school should comprise more than being in a special class within a special school. Special PIMD classes should be avoided, as this will inevitably restrict the children’s range of experiences despite the possibly well-resourced nature of special classes (Ouvry, 1987). Such classes amount to merely relocating the CSEs (Cuppen-Fonteine & Vlaskamp, submitted).

Specific attention should be paid to the child-teacher ratio. The size of a group is important (Argyle, 1991; Conroy, 1992) as children with PIMD depend on staff to recognize their communicative signals. In a larger group, there is less attention to those signals and a slower reaction by staff. Groups smaller than five are considered best (Tossebro, 1995). Financial resources should be available to schools in order to expand their facilities and to create smaller groups.

Alongside the organizational problems which have been mentioned, remarks concerning the content of the curriculum and assessment are also noted. The largest problem is probably the curriculum that has been developed, because it is based upon two opposing assumptions that are difficult to combine. The dangers of using developmental sequences have already been described. It is important that the authorities oppose this approach in order to prevent a situation in which educating children with PIMD becomes a matter of following developmental sequences without taking into account the individual needs and abilities of the child. In current developments in educational policy, however, the focus is increasingly directed towards a subject-based approach. Cluster 3 schools are obliged to also make use of this approach for children with PIMD. Given experiences in the UK (Ware, 1994), for example, this focus seems not to contribute to an improvement in the quality of education for children with PIMD.

6.6 Concluding remarks

The inclusion of children with PIMD in schools is a commendable initiative that is in accordance with international policies. Yet, the results of this research show that inclusion has not come within the reach of many children with PIMD. Furthermore, the quality of care that is needed for children with PIMD should not be forgotten. Irrespective of the place where children with PIMD are taken care of, whether at school or a CSE, specific care and support is required.

Common practices in CSEs, such as assessing children on a wide range of aspects, are as important in schools as they are in CSEs. Children with PIMD in schools still develop atypically and need a curriculum that takes account of this developmental pattern and acknowledges the individuality of these children. The availability of the facilities that are necessary to offer these children all the
medical, developmental and educational care and stimulation that is needed should be guaranteed in schools as well as in CSEs. Children with PIMD in schools also have the right to be educated by qualified teachers and teaching assistants who have all the knowledge and skills required in order to do so. Finally, children should be able to learn from and interact with children who are less disabled, meaning they should be given the opportunity to learn in a heterogeneous environment.

As long as schools do not meet all these provisions, there is little added value in attending a school. If schools are not able to meet the needs of children with PIMD, then children may still be better off in CSEs given the expertise that is available and the high level of care provided. It is the task of the authorities to take all necessary measures in order to provide opportunities for real inclusion for all children.
References


