From policy to practice
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Abstract

The research reported in this doctoral thesis derives from a new education policy aiming at ‘education for all’. This policy resulted in a new educational law, called ‘the backpack’. The implications of this new law for children with profound intellectual and multiple disabilities are central in this thesis.

In Chapter 1 the background and purpose of the research is explained. Prior to the introduction of the new educational law, most special schools maintained a lower limit for their students, claiming that a developmental age of at least 24–30 months was the minimum for receiving education. Children with PIMD, who have an estimated developmental age below 24 months, were usually exempted from education and went to centres for special education (CSEs) instead. The intention of the ‘backpack policy’ was that all children, no matter their level of disability, should be able to join (special) education. Children with PIMD will most likely be placed in cluster 3 schools (that is ‘ZML’ and ‘mytyl/tytyschools’). However part of these schools (ZML-schools) need to apply for broadened admission criteria before being required to accept children with additional disabilities.

Given the new situation, extensive knowledge, skills and facilities became necessary in schools as they would now be expected to be able to educate children with PIMD. Gaining the required knowledge and skills is complicated by the fact that teachers cannot rely on specific instruments that can help them to gain knowledge of the child. Nor can the teachers rely on a specific curriculum that can help them to develop their teaching activities.

In order to facilitate the introduction of the new law, the government has supported several developments aimed at the successful implementation of this law. Four focus groups were initiated to do pioneering work that would contribute to the enhancement of knowledge and experience in four related domains defined by the government. These domains were:

- To develop an instrument to categorize the characteristics of children with PIMD
- To develop a suitable curriculum for children with PIMD
- To map the expertise that is necessary for educating children with PIMD
- To map the preconditions necessary to optimally educate children with PIMD

The authorities decided that it was also important to scientifically follow and underpin the developments with regard to the new educational law. Therefore, the University of Groningen (RuG) Department of Special Education was asked to contribute to the new developments as well. The focus of the research project started by the RuG was threefold: the development of a reliable and useful instrument to categorize the characteristics of children with PIMD, the development and implementation of a specific curriculum and the evaluation of the characteristics of children with PIMD in schools and CSEs.
Although there was consultation with the focus groups, the RuG had an independent position, and the activities of the two ‘focus groups’ and the RuG did not correspond exactly. The development of the curriculum for example, was characterized by a duality as the focus group developed another ‘product’ than did the RuG.

Chapters 2 and 3 describe the development of an instrument called ‘the checklist of child characteristics’. The aim of this instrument is to prepare a support profile, showing clearly what forms of support (both educational and care) are necessary for the particular pupil and allow the instrument’s use in programme planning. The content is based on the International Classification of Functioning, Health and Disability (ICF) in which various categories are distinguished: functions and body structures, activities and participation.

The developments of the content of the checklist as well as its psychometric properties are described in Chapter 2. Firstly, a draft checklist was developed. Nine professionals completed the draft versions of the checklist and gave their comments. Based on their comments the checklist was adjusted. Next, the checklist was filled in for 123 children. The checklist has then been subjected to reliability trials. Estimates of the internal consistency as well as the interobserver reliability were sufficiently high. Exploratory analysis (principle component analysis) followed by a varimax rotation was used to obtain factors consisting of related items. Eleven factors were revealed (four in the category of functions, three in the category of activities, and four with regard to participation). All factors were given a short description by the researchers. Fifteen professionals were then consulted regarding the suitability of this description for the items forming part of the same factor. A short questionnaire was used for this purpose in which the professionals’ opinion was sought. Based on their comments several changes were made in the descriptions.

Chapter 3 reflects upon the validation process as well as the use of the instrument. It firstly demonstrates how the scores on the checklist can be transformed into support profiles. Then it discusses the results of a validity assessment conducted on support profiles that were compiled for 32 children. An expert panel of teachers and direct support persons (DSP) was composed for this purpose. In interviews the members of this panel are asked to judge the content of the support profiles. They appeared generally satisfied with the support profiles. They were able to recognize the child from the description.

Research with regard to the implementation of an educational programme (curriculum) for children with PIMD was conducted in three schools. The results are presented in Chapter 4. A specific curriculum has been developed, but no knowledge has been gained regarding the implementation of this curriculum. Therefore, case studies, involving five children per school have been conducted in order to explore the implementation process in three schools after they had completed a training programme in working with the curriculum. The implementation fidelity, number of positively evaluated goals, as well as the opinions of teachers have been taken into account. Results show that the
implementation of the new curriculum is difficult and can be accompanied by many problems. Following the programme and setting clear goals is found to be difficult. However, the more precise the guidelines of the curriculum are followed, the better the results are. The cooperation within the team and a positive attitude towards working with the curriculum are seen as contributively towards more success in working with the curriculum.

Chapter 5 examines the implementation of the new education law with respect to the transfer from CSEs to schools. The objective of the study described in this chapter is to determine if there are differences in the school population and CSE population of children with PIMD. K means cluster analysis was used to group the children according to their scores on the checklist of child characteristics. 198 checklists were collected for this purpose. It is found that students with specific problems, such as epilepsy, feeding problems and severe motor disabilities are more likely to stay behind in CSEs.

In Chapter 6 the general conclusions that can be drawn from this study are presented and subjected to further discussion. Methodological and practical limitations of the study are taken into account. Results indicate that a reliable checklist has been developed that results in an adequate support profile for each child. Furthermore, teachers are able to work with the curriculum if steps are followed precisely. Nevertheless, comments can be made with regard to both checklist and curriculum. The checklist, for instance, does not take into account several aspects, such as preferences, state of alertness, and health conditions, although these aspects are relevant to the education and care of children with PIMD. Attempts have been made to overcome these limitations by developing two other instruments, but these instruments have not yet been subject to extensive research.

The effectiveness of the curriculum should be taken into account more extensively, with a larger group of children and for a longer period of time. Too, the development of the curriculum was characterized by duality, as two different products were developed. Next to the framework developed by the RuG, the focus group on curriculum development decided to list developmental goals in five areas. The Ministry of Education sent both products to all cluster 3 schools, pretending they belonged together. However, applying two products with very different assumptions and procedures carries a great risk, as it is possible that schools might merely pick out several developmental milestones and use these to develop an IEP for a child, despite the fact that children with PIMD do not develop according to normal standards.

The intention of the 'backpack policy' was that all children, no matter their level of disability, should be able to go to school. 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. The authorities took responsibility for the development and distribution of a curriculum and checklist, but did not force schools to meet any requirements.
with regard to the use of these products, to extra training of personnel, or to the acquisition of essential facilities.

Many organisational and content changes are necessary with regard to quality of education, as well as surplus value that going to school should offer compared to going to a CSE. It is the task of the authorities to take all necessary measures in order to provide opportunities for real inclusion for all children.