From policy to practice
Tadema, Annemarie Catholijn

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Chapter 3

The validity of support profiles for children with profound multiple learning difficulties¹

Abstract

As a result of a new law passed in 2002, in the Netherlands an increasing number of children with profound and multiple learning difficulties will attend school. The complexity of the target group requires appropriate assessment that is focused on programme planning. A new instrument, the Checklist of Child Characteristics, has been developed for this purpose. This article demonstrates how the scores on the checklist can be transformed into support profiles. It then discusses the results of a validity assessment conducted on support profiles that were compiled for thirty-two pupils. These results suggest that the instrument is valid.

Introduction

Assessment is a process of gathering information in order to make evaluative decisions much related to the need of establishing progress or development (Meisels, 1994; McLean, 1996; Appl, 2000). In instructional settings, assessment usually involves gathering valid information about pupil performance (Lewis, 2001) and is used for programme planning and progress monitoring (Worely & Haring, 1994; Carpenter, 1995; Appl, 2000). Assessment that focuses on programme planning is extremely important to the development of Individual Educational Plans (IEP’s) for pupils with disabilities (Carpenter, 1995). However, the more severe the disabilities are, the more difficult it is to develop appropriate IEP’s that are based on the results of assessment that has been conducted (Downing, 2002). The problems of conducting appropriate, valid and reliable assessment for pupils with profound multiple learning difficulties (PMLD) are acknowledged. Knowing and understanding the abilities and needs of these pupils is complex (Nelson et al., 2002). Pupils with PMLD fall at the extreme lower end of the continuum of students with profound mental retardation, and exhibit severe physical disabilities combined with sensory, health and alertness impairments. They have little or no control over their movements, limited interaction with their environment, inconsistent responses to stimuli, sensory impairments, limited progress in learning new skills, lack of symbolic communication, and total dependence on carers for all aspects of daily living (Ferguson et al., 1996; Vlaskamp, 1999; Logan et al., 2001).

Given their limited range of response capabilities, assessing children with PMLD is particularly challenging (Voelkers et al., 2000) for both monitoring progress and programme planning. Concerning the concept of progress it is important to keep in mind that there is no clear sequence of what a student with PMLD should learn (Ferguson et al., 1996). Not only they develop slowly, their developmental sequence also differs from children without these severe disabilities (Orelove & Sobsey, 1996). Therefore progress should not only be seen in terms of developing new skills, but also in extending existing skills, accepting reduced support in completing a task, increased engagement, or retaining skills in case of regression that may be caused by progressive disease (Marvin, 1998).

With regard to programme planning isolated instruction has little if any practical value for the child. As these students have difficulty generalizing skills to the real activities where the skills are needed, a switch to developing student’s strengths within activities is critical (Downing & Bailey, 1990).

Instruments should be evaluated to the extent that they enable us to do this, and suggest ways in which we can help the individual more in the desired direction. To ensure appropriate interpretation, assessments should also fulfil a number of requirements, including the use of reliable and valid instruments that have been standardized for their target groups.

Several types of assessment can be found frequently in education for programme planning and to monitor progress, however criticism can be applied to all types with regard to children with PMLD. Existing norm-referenced
instruments for example are often minimally useful for such pupils, as they fail to provide enough information for programme planning and they are not ‘sensitive’ enough to measure progress (Downing & Perino, 1992; Ware & Healey, 1994; Appl, 2000). In addition, the validity of instruments is rarely evaluated for specific target groups, such as pupils with PMLD (Appl, 2000). Information from standardized assessment procedures is often inaccurate and biased, especially when used with young children with PMLD (Nelson et al., 2002). Criticism can also be applied to criterion-referenced tests that assess the student’s ability to perform sequentially listed skills according to a specified criterion. Individual needs or motivation to perform in specific environments is often not taken into account. Skills that the child is not able to perform, may serve as a guideline for setting educational goals. The risk of ‘teaching to the test’ without considering if the given skill is valued by the individual or has direct application to meaningful activities is acknowledged (Downing & Perino, 1992).

Other approaches to measure progress of students over time are curriculum based assessment strategies (CBA). CBA are specifically related to the curriculum and provide a structure for planning interventions (McAllister, 1991). The assessment and goal identification is based on repeated, naturalistic observations of classroom behaviour. However, the developmental context may limit use for children with PMLD, as their disabilities may make whole sequences inappropriate for some children (McAllister, 1991). Alternative approaches (e.g. skills assessment within a developmental framework) are more appropriate for pupils with complex problems than are approaches that rely on standardized instruments. In addition, they offer more suggestions for practical programme ideas and goals (Mc Cornachie, 1995). Despite the volume of criticism concerning the application of standardized tests and testing procedures to this special category of pupils, little empirical research has been conducted that supports the use of alternative approaches (Downing & Perino, 1992). Furthermore, current trends in assessment such as portfolio assessment have been recommended as particularly appropriate for this population. However, critics warn that unreliability limits utility of this supposably more ecologically valid approach (Nidds et al., 1997).

In the last couple of years a lot of attention is being paid to support needs of persons with PMLD (Luckasson et al., 1992; WHO, 2002). Rather than assessing performance in every day activities, the amount of support someone needs in order to perform an activity is measured. Both Thompson et al. (2002; 2004) and Foreman et al. (2001) present typical instruments for addressing the support needs of persons with intellectual disabilities. However, both instruments are not specifically designed and validated for children with PMLD. As children with PMLD present a range of complex and challenging support needs (Roberts et al., 2005) a highly specialised instrument seems necessary. Furthermore Thompson et al. (2002) warns that only assessing the support needs of an individual is not enough, the level of personal competence should also be taken into account in order to identify educational or training related goals. A combination of measuring support needs and abilities, without assuming fixed developmental sequences seems best for children with PMLD.
In response to the criticism against the use of existing assessments with PMLD pupils, the absence of legitimate alternative assessments and the importance of appropriate assessment to the development of appropriate IEPs, a new instrument has been developed for use in the Netherlands: the Checklist of Child Characteristics (Tadema & Vlaskamp, 2004). It is based on the International Classification of Functioning, Disabilities and Health (ICF: WHO, 2002). The aim of this instrument is to determine the amount of support that the child needs when carrying out all sorts of activities, to look more closely at the functional abilities of the child and the degree of participation of the child in the group. The results should make it possible to prepare a support profile, showing clearly what forms of support (both educational and care) are necessary for the particular pupil on each of the factors, and allow the instrument’s use in programme planning. (Tadema et al., 2005).

The accuracy of the instrument and the conclusions that can be drawn from it depend upon the validity of the instrument (Meisels, 1994). In the selection of diagnostic instruments content validity is important to consider. Content validity is the representativeness of the test’s contents in terms of the domain being assessed (Appl, 2000; Yun & Ulrich, 2002). Yun & Ulrich (2002) provide instructions for assessing content validity. A panel of experts/raters should be selected who can evaluate the instrument according to specific criteria.

This article will describe how support profiles can be compiled using the raw scores from completed child characteristics checklists and the results of the validation of these profiles. Too, the article will consider possible applications for the instrument. Only when the content validity of Checklist of Child Characteristics is sufficient and the support profiles are capable of making adequate distinctions among pupils with a developmental perspective ranging up to twenty-four months (and additional problems) can it be determined whether the checklist can make a significant contribution to the design of instruction and care.

Method

Sample

To assess content validity, the researchers assembled a panel of carers and teachers of pupils with profound and multiple learning difficulties. Carers and teachers were chosen as their expertise is important when evaluating the information that the profiles provide about children. Carers and teachers are therefore the most preferable sources of judgement in this regard as they observe the pupils daily in relevant settings. An explicit criterion for participation was that the carers and teachers had known the pupils concerned for at least one year. It can therefore be assumed that the respondents knew the pupils well enough to provide reliable assessments.

In December 2003, researchers contacted four schools and eight centres for special education to solicit participation in the research. All of the schools and centres for special education agreed to complete checklists for one or more pupils. Thirty-seven checklist forms were sent to the participating schools and centres for special education. A number of checklists were not completed, due to
lack of time, illness on the part of personnel and the sudden death of one of the participants. The total response rate was therefore eighty-six percent. The panel of raters consisted of twenty-two carers and teachers from eleven different schools and centres for special education that had completed checklists for thirty-two pupils. The panel involved seven teachers and fifteen carers, who had an average of more than six years of experience in either the instruction or care of pupils with profound and multiple learning difficulties. The number of pupils for whom a given carer or teacher completed checklists ranged from one to five. The number of years that carers or teachers had known the pupils ranged from a minimum of one to a maximum of five.

Instruments

Two instruments were used in conducting this research. The first instrument was the Checklist of Child Characteristics. This checklist contains four sections: general information, functions, activities and participation, with a total of 118 items. In the categories of functions and participation the question is asked whether the child shows a particular behaviour ‘always’ ‘sometimes’ or ‘never’. In the category of activities it is important to know whether the child can carry out the activity ‘independently’, or ‘with support’, or ‘not at all even if complete support is given’. The question of the type of support that the child may need was also asked in the category of activities. This could be physical or verbal help, help from a suitable aid, or a combination of these.

The checklist was subjected to reliability and factor analyses. The results indicate that it is a reliable instrument (in all three categories alpha ranges from .091-.097) Exploratory analysis (principle component analysis) followed by a varimax rotation was used to obtain factors consisting of related items that are relevant as regards content. Based on the factor analysis the checklist is subdivided into eleven factors, each of which describes a specific component of pupil functioning. The distribution of the items over the factors is based on the factor loading of these items. The number of items within a factor ranges from 3 to 30 items. A number of factors encompass relatively few items. These factors were retained because of the relevance of their content, their contribution to the variance that is explained, and the essential contribution that these factors may make to the drawing up of the support profiles (Tadema et al., 2005).

The second instrument consisted of an interview that focused on the impression that the support profiles gave. It was an interview, with a structured and a non-structured part. The structured part consisted of six multiple-choice questions. With regard to the support profile and description the respondents were asked the following questions:

1. To what degree are the scores on the various factors (strengths and weaknesses) consistent with your own impression of how the pupil would score on these factors?
2. What impression does the profile description give you of the functional abilities of the child?
3. What impression does the profile description give you of the way in which the pupil can carry out activities?
4. What impression does the profile description give you of the degree and type of assistance that the pupil needs in order to carry out activities?
5. What impression does the profile description give you of way in which the pupil participates in the group/class?
6. Does the profile description contain enough information to give an appropriate conclusion?

Responses to the questions 1 to 5 were scored on a five-point (Likert-type) scale, with response categories ranging from 'very good impression' to 'very bad impression'. For the last question, the response categories ranged from 'strongly agree' to 'strongly disagree'. Higher scores reflect better impressions.

The unstructured part of the interview consisted of eight questions. Six were meant to give the respondent the opportunity to make explanatory remarks for every multiple choice question (e.g. 'Can you explain why the profile description gives you a good impression of the pupil’s functional abilities?'). Two more open questions involved aspects that were missing in the description and further comments or observations.

Procedure
The teachers or carers of the children concerned completed the Checklist of Child Characteristics and returned them to the researchers, who used the completed checklists to compile support profiles. The researchers subsequently presented the profiles to the teachers or carers during interviews, which focused on the extent to which the support profiles were appropriate to the children for whom they had been compiled. The questions were addressed to the teachers or carers who had completed the checklists.

The compilation of support profiles
To illustrate the process used by the researchers to compile support profiles, this section describes a three-phase plan that was developed specially for this purpose. The plan is tentative and can still be adapted according to the evaluations that teachers and carers make of the support profiles.

The first phase includes the calculation of raw scores and completing the support profile, the second phase consists of analysis of the results, and the third phase involves making a description. Each phase consists of a number of action steps.

All items can be answered on a scale from 0 to 2. A minimum score of 0 and a maximum score of 2 per item is possible. The summation of all scores on the items per factor allows a total score for a factor to be calculated. As the number of items per factor range from 3 to 30, the maximum raw scores per factor range from 6 to 60. In the first phase, the raw scores on all items for each factor are added together. Raw total scores on every factor will be converted into quartile scores that are based on the raw scores of a large group of children with PMLD (Tadema et al., 2005).
<table>
<thead>
<tr>
<th>Factor</th>
<th>Nr of items</th>
<th>Raw score</th>
<th>Quartile-scores W</th>
<th>M</th>
<th>Fs</th>
<th>S</th>
<th>Structure</th>
<th>Support</th>
</tr>
</thead>
<tbody>
<tr>
<td>1: Active orientation on the surroundings, possibility of recognizing events, images and noises from the surroundings and of reacting to these.</td>
<td>28</td>
<td>41</td>
<td>3</td>
<td>☐</td>
<td>☐</td>
<td>☑</td>
<td>☐</td>
<td>13</td>
</tr>
<tr>
<td>2: Muscle control over functions that are of importance for eating, drinking and care moments.</td>
<td>10</td>
<td>11</td>
<td>2</td>
<td>☑</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>4</td>
</tr>
<tr>
<td>3: Being able to express feelings of displeasure and tensions.</td>
<td>6</td>
<td>7</td>
<td>3</td>
<td>☐</td>
<td>☐</td>
<td>☑</td>
<td>☐</td>
<td>2</td>
</tr>
<tr>
<td>4: Being open to physical contact.</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>☑</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>1</td>
</tr>
<tr>
<td>5: Being able to carry out task-oriented activities and actions and to understand and communicate concrete messages.</td>
<td>30</td>
<td>5</td>
<td>1</td>
<td>☑</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>0</td>
</tr>
<tr>
<td>6: Control of basic motor skills that can increase the independence of the child.</td>
<td>17</td>
<td>20</td>
<td>2</td>
<td>☑</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>7</td>
</tr>
<tr>
<td>7: Control of basic communication skills.</td>
<td>5</td>
<td>8</td>
<td>3</td>
<td>☐</td>
<td>☐</td>
<td>☑</td>
<td>☐</td>
<td>4</td>
</tr>
<tr>
<td>8: Taking part in group activities when a carer takes the initiative.</td>
<td>5</td>
<td>1</td>
<td>1</td>
<td>☑</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>0</td>
</tr>
<tr>
<td>9: Taking part in group activities whereby the child is oriented on others (and assumes an active attitude)</td>
<td>5</td>
<td>1</td>
<td>2</td>
<td>☑</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>0</td>
</tr>
<tr>
<td>10: Personal orientation on another; seeking contact and reacting to contact.</td>
<td>5</td>
<td>7</td>
<td>3</td>
<td>☐</td>
<td>☐</td>
<td>☑</td>
<td>☐</td>
<td>2</td>
</tr>
<tr>
<td>11: Residual category, no further description.</td>
<td>3</td>
<td>3</td>
<td>3</td>
<td>☐</td>
<td>☐</td>
<td>☑</td>
<td>☐</td>
<td>1</td>
</tr>
</tbody>
</table>

**Figure 1** Structure of the scores
The conversion of these scores into quartile scores brings the strengths and weaknesses of the pupils into sharper contrast. The quartile scores are divided into the categories ‘weak’ (w), ‘moderate’ (m), ‘fairly strong’ (fs) and ‘strong’ (s). The structure of the scores is also important. For example, a score of ‘yes, sometimes’ on several items within a particular factor could indicate a sensitivity disorder, an alertness problem or epileptic seizures. Such information is important when developing an instructional programme for a pupil. The support profile provides a raw score for each factor along with the corresponding quartile score, which shows whether the factor is a relative strength or weakness for a given pupil. Finally, the items for the category of ‘activities’ also reflected the type of support. The letter ‘v’ corresponds to verbal support, ‘ph’ indicates physical help, and ‘a’ means that the pupil requires help from assistive device(s). Figure 1 illustrates the structure of the scores.

The figure indicates the raw score on each factor, and the corresponding quartile score, and what this means in terms of strengths and weaknesses. It also provides information on the structure of the factor scores. However, the profile needs to be interpreted. This requires the analysis of each profile at the following three levels: quartile scores, response categories and type of assistance. This analysis should lead to a clear profile description. Figure 2 presents an example of such a description.

Janet is a girl with severe intellectual and motor disabilities. She has a sleep disorder with hypersensitivity, which results in mood swings and shifting levels of alertness. She can walk for short distances with physical assistance, but she is otherwise confined to a wheelchair. She has slight visual problems. Janet receives her food in liquid form, and she suffers from frequent respiratory infections.

The following observations concern Janet’s functional abilities: Her focus on her surroundings is relatively strong. She has many abilities to recognise and react to events, images and sounds in her immediate environment. Because she exhibits varying levels of alertness, Janet does not always make use of all of these abilities. An additional relative strength is that Janet is able to express feelings of dissatisfaction and tension. She has moderate control of the muscles that are needed for eating, drinking and matters of personal care, but she requires assistance for these activities. Janet is otherwise unresponsive to physical contact, on which she received a moderate score.

We observed the following with regard to Janet’s ability to carry out activities: Janet has difficulty carrying out task-directed activities and actions and understanding and conveying concrete messages; her scores on these factors were weak. She can accomplish a number of tasks with verbal and physical assistance. One of Janet’s relative strengths is her command of basic communicative skills. She can make herself understood by using body language, gestures and sound. Janet received moderate scores on basic motor skills. She has a particular need for physical assistance or support through assistive devices.

With regard to participation, Janet’s personal focus on others is a relative strength. She is able to seek and react well to contact. Her participation in group activities, however, is relatively weak. Janet participates only slightly in group activities that are initiated by the carer. She is sometimes involved, but she often loses interest.

**Figure 2** example of a description of the support profile
With reference to the results of the support profile, the implications for the education and care of the pupil will be discussed in the ‘conclusion’ section. An example of this section can be seen in figure 3. A number of suggestions are provided for drawing a conclusion, including the consideration of the pupil’s strengths and the determination of whether these strengths provide an opening for instruction. It is also essential to define the type of approach that the pupil needs and the sorts of activities that would be appropriate. Finally, the extent and type of assistance that is necessary can be determined.

Janet has a reasonably strong focus on her surroundings, particularly when personal contact is involved. In addition, she can make her own wishes very clear, with the help of sounds and gestures. Because of her focus on and interest in her surroundings, Janet is able to participate in the class whenever a one-on-one approach is used. Because of her sleep disorder, Janet exhibits varying levels of alertness. For this reason, she requires considerable assistance from carers in order to become involved in anything. In determining the appropriate instruction and care for Janet, it is therefore important to consider these factors and to undertake activities with her during the times in which she is alert.

In addition, Janet requires considerable assistance in order to participate in group activities. For task-directed activities, it is important to consider which activities are suitable, and support must be available to help Janet. This concerns primarily physical and verbal assistance. Janet also requires assistance with matters of personal hygiene.

Each profile can be accomplished in the same manner by following, in turn, each of the three phases (calculation, analysis and description). The steps described above were followed for each of the 32 questionnaires that were completed. This procedure yielded 32 different support profiles. To assess their validity, the support profiles were subsequently presented to the teachers and carers.

Results

We first discuss the representativeness of the group of pupils for whom the checklists were completed. This will be followed by the results of the interviews.

Representativeness

Some degree of variation in the type and degree of problems of the pupils is important, as support profiles must be appropriate for all pupils with developmental perspectives up to twenty-four months and additional problems. Checklists were completed for 32 pupils, fifteen boys and seventeen girls. Table 1 provides an overview of the additional problems that were revealed for these pupils. Each pupil could have multiple problems.
The checklist revealed the following with regard to care activities: three pupils are tube-fed, but two of these three also receive food orally. Another three pupils are able to eat only liquid food. The other 26 pupils eat solid food. The age of the pupils ranged from four to seventeen years, with an average age of eleven years. The average age of the pupils in the centres for special education was 9.3 years. The average age of the pupils in the schools was 12.7 years.

<table>
<thead>
<tr>
<th>disability</th>
<th>frequency</th>
<th>percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Visual impairments</td>
<td>19</td>
<td>59.4 %</td>
</tr>
<tr>
<td>Hearing impairments</td>
<td>5</td>
<td>15.6 %</td>
</tr>
<tr>
<td>Motor disabilities</td>
<td>31</td>
<td>96.9 %</td>
</tr>
<tr>
<td>Epilepsy</td>
<td>15</td>
<td>46.9 %</td>
</tr>
<tr>
<td>Chronic illness</td>
<td>6</td>
<td>18.8 %</td>
</tr>
<tr>
<td>Autistic features</td>
<td>5</td>
<td>9.4 %</td>
</tr>
<tr>
<td>Heart diseases</td>
<td>2</td>
<td>6.3 %</td>
</tr>
<tr>
<td>Health problems</td>
<td>15</td>
<td>46.9 %</td>
</tr>
<tr>
<td>Other problems</td>
<td>8</td>
<td>25 %</td>
</tr>
</tbody>
</table>

Because of the heterogeneity of the group, it is important to evaluate several types of support profiles, as teachers must be able to recognise their pupils in the profiles regardless of the profile's appearance (the strengths and weaknesses of the pupils). This can only be determined when the results suggest many different support profiles. For this reason, it was determined whether the profiles of the thirty-two pupils contained sufficient variation. The quartile scores, which were derived from the raw scores, had to vary sufficiently.

As shown in table 2, there appears to be considerable variation in the quartile scores on the various factors. There is also sufficient variation in developmental level and the severity of problems. These results suggest that a number of support profiles will emerge and that the results are applicable to the broader population of pupils with profound and multiple learning difficulties.

**Overview of interview results**

In the interviews, a panel of teachers and carers rated each component of the profile on a scale from one to five. The following table presents the average score for each component. In this table a score of 5 indicates ‘very appropriate’, and a score of 1 indicates ‘very inappropriate’. Higher scores reflect higher appropriateness.

In order to identify the most frequent responses, both the mode and the average were calculated. This was necessary as a single divergent answer from one expert could have significant consequences for the average, particularly in a small research group, while having very little effect on the mode. The opinions for carers and teachers are presented separately, as teachers and carers might differ in their opinions due to different backgrounds. Table 3 also presents the responses that the teachers and carers gave to the interview questions.
### Table 2 Percentages by quartile score on each factor

<table>
<thead>
<tr>
<th>Factor</th>
<th>Factor description</th>
<th>Quartile scores</th>
</tr>
</thead>
<tbody>
<tr>
<td>F1</td>
<td>Active orientation on the surroundings, ability of recognizing events, images and noises from the surroundings and of reacting to these.</td>
<td>25.0 21.9 34.4 18.8</td>
</tr>
<tr>
<td>F2</td>
<td>Muscle control over functions that are of importance for eating, drinking and care moments.</td>
<td>9.4 40.6 18.8 31.3</td>
</tr>
<tr>
<td>F3</td>
<td>Being able to express feelings of displeasure and tensions.</td>
<td>15.6 25.0 40.6 18.8</td>
</tr>
<tr>
<td>F4</td>
<td>Being open to physical contact.</td>
<td>18.8 34.4 25.0 21.9</td>
</tr>
<tr>
<td>F5</td>
<td>Being able to carry out task-oriented activities and actions and to understand and communicate concrete messages.</td>
<td>18.8 34.4 25.0 21.9</td>
</tr>
<tr>
<td>F6</td>
<td>Control of basic motor skills that can increase the independence of the child.</td>
<td>34.4 21.9 6.3 37.5</td>
</tr>
<tr>
<td>F7</td>
<td>Control of basic communication skills.</td>
<td>18.8 34.4 21.9 25.0</td>
</tr>
<tr>
<td>F8</td>
<td>Taking part in group activities when a carer takes the initiative.</td>
<td>31.3 31.3 18.8 18.8</td>
</tr>
<tr>
<td>F9</td>
<td>Taking part in group activities whereby the child is oriented on others (and assumes an active attitude)</td>
<td>6.3 28.1 37.5 28.1</td>
</tr>
<tr>
<td>F10</td>
<td>Personal orientation on another; seeking contact and reacting to contact.</td>
<td>21.9 37.5 25.0 15.6</td>
</tr>
<tr>
<td>F11</td>
<td>Residual category, no further description.</td>
<td>28.1 31.3 12.5 28.1</td>
</tr>
</tbody>
</table>

### Table 3 Overview of interview results

<table>
<thead>
<tr>
<th>Appropriateness of</th>
<th>Carer</th>
<th>teacher</th>
<th>all</th>
<th>Mode</th>
<th>Range</th>
<th>t</th>
</tr>
</thead>
<tbody>
<tr>
<td>Quartile scores</td>
<td>M (sd)</td>
<td>M (sd)</td>
<td>M (sd)</td>
<td>4</td>
<td>2-5</td>
<td>-.486</td>
</tr>
<tr>
<td>Description of function</td>
<td>3.71 (.69)</td>
<td>3.8 (.78)</td>
<td>3.75 (.71)</td>
<td>4</td>
<td>2-5</td>
<td>-.486</td>
</tr>
<tr>
<td>Description of activities – degree of support</td>
<td>3.82 (.73)</td>
<td>3.73 (.80)</td>
<td>3.78 (.75)</td>
<td>4</td>
<td>2-5</td>
<td>.232</td>
</tr>
<tr>
<td>Description of activities – type of support</td>
<td>4.06 (.43)</td>
<td>3.93 (.70)</td>
<td>4.00 (.57)</td>
<td>4</td>
<td>2-5</td>
<td>.616</td>
</tr>
<tr>
<td>Description of participation</td>
<td>3.71 (.61)</td>
<td>4.07 (.70)</td>
<td>3.90 (.67)</td>
<td>4</td>
<td>2-5</td>
<td>-1.506</td>
</tr>
<tr>
<td>Sufficient information for conclusion</td>
<td>3.59 (.71)</td>
<td>3.67 (.90)</td>
<td>3.63 (.79)</td>
<td>4</td>
<td>2-5</td>
<td>-.440</td>
</tr>
<tr>
<td></td>
<td>3.94 (.56)</td>
<td>3.53 (1.13)</td>
<td>3.75 (.88)</td>
<td>4</td>
<td>2-5</td>
<td>.122</td>
</tr>
</tbody>
</table>
As shown in the table, the carers and teachers appeared generally satisfied with the support profiles. The average score on the six multiple-choice questions was 3.8, and the most common response for each question was ‘appropriate’. These results suggest support profile and descriptions provides an appropriate impression of all 32 pupil(s). T-tests reveal no significant differences between the opinions of teachers and carers. However the standard deviation and range of responses show somewhat more variation in the opinions of teachers compared to carers.

Further analysis of the qualitative data (explanatory remarks) show that all panel members give additional comments to the quartile scores of the pupils. Twelve panel members (six carers and six teachers) plead for a higher quartile score of their pupil on factor 4 (Being open to physical contact). They state that the children are more open to physical contact as is reflected by the quartile score. Six panel members have the impression that ‘their’ pupil should get a higher score on factor 3 (Being able to express feelings of displeasure and tensions). Three other panel members however, think their pupil has been rated too high on factor 3. Seven persons think that the child has been rated too high in factor 9. The other quartile scores seem to correspond with the ideas of the teachers and carers and are subject to little if any comments.

The carers and teachers also made comments or remarks with regard to the description. From this information, it appears that seven of the panel members would prefer the profiles to begin with a general section about the pupil, for example, a section that would report the medical diagnosis or additional problems. This would provide a more complete picture of the pupil than a profile containing only information about the various factors. Eleven carers and teachers would like to have seen behaviour-specific information, such as a description of the manner in which the teacher or carer is able to direct or correct the pupil’s behaviour. For example, some pupils may have skills but may not cooperate. This can have a decisive effect on the care and instruction of these pupils. Three carers found that the descriptions of motor skills did not contain enough detail. Two carers remarked that they would prefer to have seen information about the types of assistive devices needed by specific pupils. Two carers remarked that the profiles were not refined enough and that the tone was too business-like. Similarly, two carers/teachers were of the opinion that the profiles paid too little attention to the assistance that the pupils needed. According to two panel members, the profiles contained no information concerning the types of activities that could be offered to the pupils or about the interests of the pupils.

The definitive three-phase plan for compiling support profiles in the instructions for the checklist reflects several of the comments and remarks from the interviews. For example, the inclusion of a short section providing background information on the diagnosis and additional problems would indeed enhance the profile.
Conclusion and discussion

Our research into the content validation of the Checklist of Child Characteristics showed that the support profiles reflected the impression teachers and carers had of their pupils.

A number of comments can be made concerning the validation of the support profiles. First, the profiles were written by the researchers, who also developed the three-phase plan for drafting such support profiles. We did not examine the extent to which these instructions offer support for teachers or psychologists who attempt to compile profiles. It is possible that implementation would cause unforeseen problems for teachers and educational psychologists.

Another remark is that the research group consisting of slightly more than thirty pupils is small. Nonetheless, the composition of the research group with pupils who had diverse profiles, together with the results of the interviews, suggests that this applied to the support profiles in general. Finally, only a limited assessment of validity was conducted as the determination of concurrent validity was apparently impossible, as no similar instruments exist for children with profound and multiple learning difficulties.

Taking the limitations of the research into account, we can conclude that the results suggest that the checklist is useful and valid, and that it is able to provide recognizable and suitable images of pupils. In addition to the pupil’s strengths and weaknesses, the checklist can also provide an indication of the manner in which pupils participate in groups and of the support that is appropriate for particular pupils. The intent of the support profile is to give an overall view of a pupil that reflects both its strengths, challenges and support needs. The support profile offers both objective information (in the form of quartile scores) and qualitative information (in the form of descriptions). This is particularly important for pupils with PMLD. While numerical scores alone (e.g. indications of developmental age) are indeed the most objective and are the least subject to interpretation, they are also associated with a number of disadvantages. For example, such scores often provide insufficient support for the development of IEPs for these pupils (Downing & Perino, 1992). Beyond this, a score yields very few suggestions about what should happen in school and what the priorities in the IEP should be, even though it is quite important to incorporate assessment into programme planning (McNicholas, 2000). The combination of objective scores with descriptions in the support profiles does more than simply offer help for developing IEPs; by completing the checklist once each year, the performance of pupils can be compared over time. In this way, information about increases in pupils’ abilities becomes available, as does information about the degree of support that they need and about the ways in which they participate in group activities. The importance of such a means of measuring progress was noted earlier by Male (2000). The instrument makes no claim to be comprehensive. It provides no indications regarding preferences, interests or the most appropriate ways to work with particular pupils. Supplemental assessments are necessary for these purposes.
Results for a broad array of factors suggest that it is quite likely that the instrument can be used to compile appropriate instructional programmes for each pupil with PMLD. It has already been put to use by a number of schools and centres for special education within care and educational contexts. The instrument’s value in compiling IEPs requires further research, using practical information from these applications. Subsequent publications will discuss these results.

Regardless of the changes in the Dutch situation, not all pupils with PMLD are in schools yet. For example, parents of pupils who require extensive nursing services may decide to enrol their children in centres for special education if the school lacks the appropriate knowledge and facilities. Information about child characteristics can be used not only to report the meaning of these characteristics in terms of teaching, learning, caring and treatment but also to determine what is important in the school organization in terms of curriculum, the (specialized) knowledge of the personnel, facilities, resources and interdisciplinary cooperation (Aird, 2001). The ability to determine which pupils with which profiles are already in school and which are not yet in school is therefore important. Only when this is known will the demands on teachers’ expertise become clear and the facilities that are necessary to offering an adequate array of instructional and care services be identified. The list of child characteristics can provide insight for these purposes and, in the process, provide worthwhile guidance for care within the educational context.
References


