

Operationalizing quality of life for people with profound multiple disabilities: a Delphi study

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Abstract

Background In a recent study, we constructed an item pool that contains items on the quality of life (QOL) and related aspects of support of people with profound multiple disabilities (PMD). In the present study, a panel of experts assessed the content and the structure of this item pool in order to enhance its validity and usefulness.

Method A two-round Delphi study was set up. The panel consisted of 45 experts, of whom 12 were theory-experts, 12 practice-experts and 12 experience-experts from Belgium ($n = 12$), Germany ($n = 12$), the Netherlands ($n = 11$) and the UK/Ireland ($n = 10$). Both quantitative and qualitative methods of analysis were applied to the data.

Results The majority of the items were considered relevant for the QOL of people with PMD. In the first round, 91% of the items reached the 80% criterion of consensus. In the second round, 78.7% of the items reached the 85% criterion of consensus. There were no significant differences in opinion neither between types of experts nor between countries. Several items were reported as missing in the item pool and were added.

Conclusions The results provide some evidence that the item pool is a valid operationalization of QOL of

people with PMD and can be used in an instrument to measure the QOL of this target group.

Keywords Delphi study, intellectual disability, profound multiple disabilities, quality of life

Background

Over the past few decades, the concept of quality of life (QOL) has increasingly become a focus for research and application in the field of intellectual disability (ID) (Schalock & Verdugo 2002). During these years, a number of core ideas and principles have emerged in the international literature regarding the conceptualization and the application of this concept (Schalock *et al.* 2002). One of these core ideas pertains to the multidimensionality of the concept. QOL has a multi-element structure consisting of different domains. Nowadays, in the literature, there is a considerable consistency in the identification of these QOL domains. One finds reference to the critical role that factors such as emotional well-being, interpersonal relationships, material well-being, personal development, physical well-being, self-determination, social inclusion and rights play in a life of quality (Schalock & Felce 2004). Another core idea relates to the interpersonal variability of QOL, which means that the core domains of well-being will apply to, or be experienced variously by different individuals or groups according to their special needs. The operationalization of QOL can be different for different groups or individuals (Schalock *et al.* 2002).

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People with profound multiple disabilities (PMD) are a group for which the need for a specific operationalization of QOL is acknowledged in the literature (Borthwick-Duffy 1990; Goode & Hogg 1994; Ouellette-Kuntz & McCreary 1996). This group of people has such profound learning disabilities that hardly any standardized tests are applicable for a valid estimation of their intellectual capacity, and they possess profound neuromotor dysfunctions such as spastic tetraplegia. In addition to profound intellectual and physical disabilities, sensory impairments are also frequently experienced (Nakken & Vlaskamp 2002). People with PMD need support in almost every aspect of their daily life. This high level of dependency is reinforced by the fact that they have difficulties in communicating when and how support should be given. Their low level of functioning, their complex and specific needs, and their high level of dependency make their daily life in large part different from that of people with milder or without disabilities.

Models of QOL often contain indicators such as income, status, productivity and autonomy. Viewed from the perspective of people with PMD, the relevance of these outcomes may be questioned. There may be, on the other hand, some important aspects for this target group that are not mentioned in general models of QOL. Several authors therefore argue that the basic QOL domains that are relevant for and geared to people with and without disability should be 'translated' into specific indicators that take into account the special needs of people with PMD (Ouellette-Kuntz & McCreary 1996; Vlaskamp 2000). There is, however, no consensus on the specifications and the content of this 'translation'.

In a recent study, we attempted to operationalize the concept of QOL for people with PMD (Petry *et al.* 2005). As a starting point, we took the basic domains of QOL as described in the model of Felce & Perry (1995, 1996a,b). These authors distinguish five domains of QOL: physical well-being, material well-being, social well-being, development and activity, and emotional well-being (Felce & Perry 1995, p. 53). We explored whether these domains are valid and relevant for people with PMD, how these domains can be operationalized for this group of people and whether variables such as 'support setting' and 'age' have an effect on this operationalization. To answer these questions, we decided to take a proxy approach using parents and direct support staff of people with

PMD. We interviewed 40 parents and 36 direct support staff members of 42 children and 34 adults with PMD, of whom 36 received a form of day care and 40 were in 24-h residential care. The respondents were from Belgium ($n = 50$), Germany ($n = 6$) and the Netherlands ($n = 20$). The interview data were subjected to a qualitative content analysis. Results showed that the five basic domains as described in the model of Felce & Perry (1995, 1996a,b) were identified spontaneously by more than half of the respondents as being salient for the QOL of people with PMD. When the respondents were asked explicitly, this percentage rose to between 88.2% and 100%. Subsequently, we looked for indicators within each domain. As such a pool of items was obtained, structured into five domains of QOL, each of them divided into sub-domains with their accompanying indicators. Because neither age nor support setting turned out to have a significant effect on the operationalization, we decided to make one item pool that is geared to the characteristics of people with PMD.

In the present study, we attempted to assess this item pool in order to enhance its validity and usefulness. This assessment was a further step in the development of an instrument to measure the QOL of people with PMD. More specifically, we focused on the assessment of the content and the structure of the item pool. Regarding the content, we wanted to check if each item in the item pool is considered relevant for the QOL of people with PMD. We also examined if there were items missing in the item pool. With regard to the structure, we wanted to know if the classification in domains and sub-domains with their indicators is useful and valid. The main purpose of this assessment was to check whether we made a valid interpretation of the interview data and a valid conversion into items. We also wanted to present the item pool to a more diverse group of people.

Method

A two-round Delphi method was used to achieve the objectives of this study.

Delphi methodology

The Delphi method is a procedure involving a panel of experts to whom questionnaires and feedback are given in order to obtain consensus on a particular

topic (Polit & Hungler 1999). This takes place in a series of rounds. The Delphi method has three features: anonymity, controlled feedback and statistical group response (Adler & Ziglio 1996). Anonymity is secured through the use of questionnaires. The controlled feedback of information occurs in a series of rounds, in which the questionnaire is returned to the panellists, showing the responses made in the previous round. Statistical group responses ensure that each opinion is representative of the final response, thereby indicating the extent of the agreement among the panellists. The Delphi method allows each member to hold his or her view while collecting data on the group as a whole, and it avoids the dominance of one member as equal weight is accorded to each response.

Panel selection

The Delphi method requires a select composition of the panel in which the level of expertise is maximized (Ziglio 1996). This means that we were looking for panellists with specific knowledge and/or experience with regard to the topic of interest, in this case QOL of people with PMD. We chose to recruit three groups of experts: theory-experts, practice-experts and experience-experts. Theory-experts were defined as 'experts that are actively involved in research on the target group and have good contacts with the field of practice workers'. The group of practice-experts was composed of 'professional practice workers who on a regular basis (minimal three days a week) are directly involved in care, education or therapy for people with PMD (e.g. direct support staff, therapists, psychologists)'. Finally, experience-experts were described as 'people who are in contact with people with PMD outside of employment (e.g. parents, brothers/sisters, advocates and personal assistants)'. In the previous study, we interviewed only parents and direct support staff. For the assessment of the item pool, we chose to expand the group of proxies because other experts could also make a useful contribution in this matter. The panellists were recruited from Belgium, Germany, Ireland, the Netherlands and the UK. This recruitment is also broader than the one in the previous study.

The criteria for selecting the panellists were
1 at least 1 year of direct experience with people with PMD;

- 2** committed to the subject (e.g. membership of professional associations, taking part in training courses, working groups);
- 3** willing to contribute to the problem;
- 4** certain that enough time can be spent on the research project; and
- 5** adequate skills of written communication.

It has been suggested that, with a homogeneous group of experts, reasonable results can be obtained with small panels of 10–15 individuals (Adler & Ziglio 1996). We decided to recruit a panel of 10–15 individuals for each group of experts (theory-, practice- and experience-experts) as well as for each country. For the selection of the panellists, we addressed ourselves to the partners of a European network on the support of people with PMD, in which our research centre takes part. They were asked to recruit persons who according to them met the criteria. This resulted in a panel of 45 experts: 16 theory-experts, 15 practice-experts and 14 experience-experts, of whom 12 were from Belgium, 12 from Germany, 11 from the Netherlands and 10 from the UK/Ireland. Because of the lower response rate in the UK and in Ireland, we decided to join these countries into one group.

The Delphi procedure

Before commencement of the study, all panellists were assured anonymity and confidentiality. The research procedure complied with the ethical standards as proposed by our university. In total, there were two rounds in the Delphi procedure.

Round 1

The questionnaire for the first round consisted of 223 items regarding the five domains of QOL. These domains were divided into sub-domains, which were composed, on the one hand, of items that measure the person's QOL on that sub-domain ('outcomes') and, on the other hand, of items that evaluate the role that support plays in the person's QOL ('role of support'). We asked the panellists to indicate for each item whether it is relevant or irrelevant in an instrument to measure the QOL of people with PMD. Responses were to be completed using the following scale for each item: relevant = 1) or

irrelevant = 0). If an item was rated irrelevant, the panellists were requested to explain why. Next, we asked the panellists if there were items missing. Both quantitative and qualitative methods of analysis were applied to the data. First, we calculated the percentages of consensus for each item. The cut-off point for consensus was set at 80%. If less than 80% of the panellists agreed on the relevance of an item, the item was omitted. In order to check for differences of opinion between groups and between countries, chi-squared tests ($P < 0.05$) were executed. Next, a content analysis was performed on the question regarding the explanation of irrelevance of an item as well as on the question regarding the missing items.

Round 2

In the second round, the panellists were given feedback on the first round with a description of the results of the first round and the changes made to the item pool. The new questionnaire consisted of 211 items. The panellists were asked again to indicate for each item whether it should be kept in the final instrument. Responses were to be completed using the following scale: 0 = the item need not be included in the final instrument; 1 = the item may be kept in the final instrument but may as well be left out in case it is shortened; and 2 = the item must absolutely be included in the final instrument. In addition, we asked whether there were still items missing to ensure the comprehensiveness of the final instrument. We also asked the panellists' opinions about the wording of the item, the wording of the corresponding response categories and the classification of the item in a certain (sub)domain. These questions were open-ended. Both quantitative and qualitative methods of analysis were applied to the data. With regard to the first question, we calculated a total score for each item, which was the sum of the scores (0, 1 or 2) that the experts gave to that item. On that total score, we set the cut-off point for consensus at 85%. If the total score was less than 85% of the maximum score ($2 \times$ number of experts), the item was omitted. In order to check for differences of opinion between groups and between countries, Kruskal–Wallis tests ($P < 0.05$) were performed. The open-ended questions were analysed by means of a content analysis.

Finally, the panellists were given feedback on the second round and a description of the changes that were made to the item pool. In addition, they received the adapted version of the item pool, which is included in the Appendix 1.

Results

Round 1

The first questionnaire was sent to 45 panellists, and after a written reminder 34 questionnaires were returned (for an overall response rate of 76%). Twelve theory-experts (75%), 11 practice-experts (73%) and 11 experience-experts (79%) responded to the first round questionnaire. The response rate differed substantially between countries. In Belgium (83%), Germany (83%) and the Netherlands (91%) the response rate was high, whereas in the UK/Ireland the response rate was rather low (40%).

In the first round, we asked the panellists if the items in the item pool were relevant to measure the QOL of people with PMD. Twenty items of the 223 items did not meet the 80% criterion for consensus and were therefore omitted from the item pool: two physical well-being items, nine social well-being items, five development and activities items and four emotional well-being items.

Next, we looked for differences in opinion between countries. Overall, we noticed a high level of consensus in the group of panellists from Belgium (87.4%), the Netherlands (87.5%) and Germany (90.5%). The highest level of consensus was obtained in the group of panellists from the UK/Ireland (96.9%). In four sub-domains, we found considerable differences in consensus between countries. In two of these sub-domains, the panellists from the Netherlands scored below the 80% criterion for consensus, in contrast to the other panellists. This was the case for the sub-domain 'social relationships' (Belgium 80.6%, Germany 90.1%, the Netherlands 77.8% and the UK/Ireland 100%) and the sub-domain 'atmosphere' (Belgium 96.9%, Germany 88.9%, the Netherlands 72.2% and the UK/Ireland 87.5%). The panellists from the Netherlands as well as the panellists from Belgium scored below the criterion in the sub-domain 'social participation' (Belgium 66.7%, Germany 83.3%, the Netherlands 59.3% and the UK/Ireland 100%) and in the sub-

domain 'respect, status and self-esteem' (Belgium 79.7%, Germany 90.3%, the Netherlands 75.0% and the UK/Ireland 100%). Nevertheless, none of these differences were found to be significant neither on the level of the item nor on the level of the sub-domain using chi-squared tests.

With regard to the differences between groups of experts, there were also no significant differences found either on the level of the item or on the level of the sub-domain using chi-square tests. However, in three sub-domains, we observed that the group of experience-experts did not reach the criterion in contrast with the two other groups, namely, in the sub-domain 'social relationships' (theory-experts 91.1%; practice-experts 87.9%; experience-experts 75.3%), in the sub-domain 'influence and choices' (theory-experts 85.3%; practice-experts 88.5%; experience-experts 74.8%) and in the sub-domain 'respect, status and self-esteem' (theory-experts 86.3%; practice-experts 87.5%; experience-experts 77.8%). In the sub-domain 'atmosphere', the group of theory-experts (67.5%) scored below the level of consensus, contrary to the group of practice-experts (100%) and the group of experience-experts (88.9%). Finally, in the sub-domain of sub-domain 'social participation', consensus was reached by none of the groups of experts (theory-experts 78.3%; practice-experts 74.2%; experience-experts 68.5%).

The majority of the omitted items assessed the subjective experience of people with PMD (e.g. 'The person is satisfied with his/her freedom of choice'). In addition, the content analysis revealed that more than 60% of the panellists were of the opinion that items measuring the subjective experience of this target group are very difficult or nearly impossible to answer. Therefore, we decided to remove those items from the list. Because of the remarks of some panellists, we brought a number of items on the same level. An example was: 'The person's bodily functions and processes are being checked regularly (e.g. bowel movement, blood pressure, temperature, . . .)'. This item was a concrete example of the item: 'Concrete measures are taken to prevent and/or treat problems with physical health as much as possible'. The first item has therefore been removed from the list. Finally, on request of the panellists, a small number of items in the domain of development and activities was given a different content for children and adults with PMD.

Beside the relevance of the items, we asked the panellists if there were items missing in the list. On this question we got many responses. In the domain of physical well-being, indicators on mental health, problem behaviour and hospitalizations were reported as missing. In the domain of material well-being, indicators on living in the community, effect of technical aids, financial resources and personal belongings were suggested. In the domain of social well-being, following indicators were reported as missing: taking account of preferences, sexuality, making use of services in the community, defending and respecting their rights and protection against violence and abuse. Finally, in the domain of development and activities, the panellists mentioned indicators on education and developmental stimulation and supported employment and adult education. The suggested indicators were added to the item pool.

On advice of several panellists, we also made some changes to the structure of the item pool. We have joined the domains social and emotional well-being into one domain for the contents of these domains were closely related. In addition, we have made some changes in this joined domain. We created a new sub-domain 'treatment' in which a number of new items have been taken up plus all the existing items from the sub-domains 'individual attention', 'positive affect' and 'atmosphere'. Finally, on the one hand the sub-domains 'social relationships' and 'social participation' and on the other hand the sub-domains 'individuality' and 'influence and choices' were also joined.

Round 2

The second questionnaire was sent to 34 panellists and, after a written reminder, 24 panellists responded (overall response rate of 71%). The response rates for the different groups were: 83% for the theory-experts, 64% for the practice-experts and 64% for the experience-experts. As in round 1, there was a substantial difference in the response rates between the countries. In this round, the response rate in Belgium (90%) and in the UK/Ireland (100%) was high in contrast to Germany (60%) and the Netherlands (50%).

In the second round, the panellists were asked to indicate for each item whether it should be kept in the final instrument. Of the 211 items, 37 did not meet the 85% criterion for consensus: nine physical

well-being items, two material well-being items, nineteen social-emotional well-being items and seven development and activities items.

With regard to the differences in opinion between countries, we noticed on average a low level of consensus in the group of panellists from the Netherlands (84.0%), in contrast to panellists from Belgium (92.5%), Germany (91.6%) and the UK/Ireland (91.3%). In the group of panellists from the Netherlands, the 85% criterion for consensus was not reached in six sub-domains ('mobility' 83.5%, 'living environment' 83.7%, 'technical aids' 81.4%, 'communication' 80.0%, 'engagement in activities' 82.8% and 'influence & choices' 78.9%). Nevertheless, none of these differences between countries were found to be significant neither on the level of the item nor on the level of the sub-domain using Kruskal–Wallis tests.

With regard to the differences between groups of experts, there were also no significant differences found neither on the level of the item nor on the level of the sub-domain using Kruskal–Wallis tests. However, in two sub-domains, we observed that the group of experience-experts did not reach the criterion, in contrast to the two other groups, namely, in the sub-domain 'family bonds' (theory-experts 91.9%; practice-experts 93.9%; experience-experts 83.9%) and in the sub-domain 'influence & choices' (theory-experts 88.4%; practice-experts 91.0%; experience-experts 77.9%). Finally, in the sub-domain 'living environment', the group of practice-experts (84.7%) scored below the criterion, contrary to the group of theory-experts (91.1%) and the group of experience-experts (88.4%).

The response to the question whether there were items missing was relatively small. Only two new indicators were proposed in the domain of development and activities: 'early developmental stimulation of young children with PMD' and 'education for adults with PMD'. These two indicators were added to the final instrument. With regard to the item classification, only a few small changes were made on the advice of the panellists. The sub-domain 'relations outside the support context and social participation' was split into the sub-domain 'social relations' and the sub-domain 'social participation'. The items on the person's competence and independence that were spread over the sub-domains were brought together in the sub-domain 'development'.

Discussion

In the present study, we attempted to assess the content and the structure of an item pool containing items on QOL of people with PMD. Regarding the content, we checked if each item is considered relevant for the QOL of people with PMD. We were able to answer this question affirmatively for the majority of the items. In the first round, 91% of the items reached the 80% criterion of consensus. In the second round, 78.7% of the items reached the 85% criterion of consensus. These results provide some evidence that the item pool we constructed is a valid operationalization of QOL of people with PMD and can be used in an instrument to measure the QOL of this target group.

The items that were omitted from the item pool were items of which the content was already represented in another item or items assessing the subjective experience of people with PMD. More than 60% of the panellists were of the opinion that the latter are very difficult or nearly impossible to answer. Nevertheless, the decision to remove these items does not imply that the subjective component of QOL of people with PMD is not regarded as important. In the instrument that we are developing, we chose to use a proxy approach, which is considered to be not a valid indication of a person's own perception of his or her life (Schalock *et al.* 2002). The concordance between subjective and proxy ratings seems to be more of a problem in evaluations of emotional experiences and personal preferences than for more objective issues (Perry & Felce 2002). These findings caused us to restrict the item pool to objective indicators of QOL. However, full measurement of QOL requires a measurement of both the objective and the subjective components of QOL (Schalock *et al.* 2002).

The next aspect that was put up for assessment was the comprehensiveness of the item pool. With regard to this aspect, the item pool was found to be incomplete. New themes that were brought up by the panellists were, among others, mental health and problem behaviour, financial resources and personal belongings, sexuality, living and making use of services in the community, rights and adult education. To conclude that these themes were not considered relevant for the QOL of the target group by the respondents in the previous study is, however, premature. Some of these themes, such as financial

resources and personal belongings, and living and making use of services in the community, were mentioned by the respondents in the previous study but were not included explicitly in the item pool. Other themes, such as mental health, sexuality, rights and adult education/supported employment, did not come up in the interviews with parents and direct support staff of people with PMD. A remarkable finding is that these topics were almost all suggested by panellists from Germany, Ireland or the UK, countries which were not or minimally represented in the previous study. A plausible explanation might be that these topics are prominent themes in supporting the target group in these countries. The conclusion that these topics are not considered relevant in Belgium and the Netherlands is, however, not very likely, because consensus on including these themes in the item pool was also reached in these countries. Further research into this matter will be necessary.

The assessment in the Delphi format contributed to the quality of the item pool. The content and the structure of the original item pool have improved. They now meet with the approval of a group of international theory-, practice- and experience-experts. These three groups of experts did not differ significantly in their opinion, which might indicate that the item pool is considered valid by a large and diverse group of people acquainted with the target group. In addition, there was no significant difference in the level of consensus between countries. This might be an indication that the operationalization is valid across the countries that participated in this study. However, the panel size is too small to allow any inferences to be made on a population basis.

A severe limitation of this study is the use of a proxy approach. The assessment was performed by respondents who are acquainted with people with PMD ('proxies'). This means that the findings of this study must be identified and viewed as another person's perspective. The item pool is considered a valid operationalization of QOL by a group of proxies and not by people with PMD themselves. The literature yields conflicting results concerning the value of using a proxy approach. Several researchers have attempted to evaluate consumer-proxy agreement by comparing proxy responses about people who can respond for themselves with self-reports from these same people. In some of these studies, the answers given by people with an ID regarding their QOL

turned out to strongly disagree with the answers given by proxies (Stancliffe 1995; Heal & Sigelman 1996; Rapley *et al.* 1998); others find a greater concordance (McVilly *et al.* 2000). Despite these issues, we decided to take a proxy approach using theory-experts, practice-experts and experience-experts because it gave us the opportunity to get a picture of the validity and the content of the domains of QOL for people with PMD. Interviewing people with PMD concerning this matter was not an option because this group of people does not have the required skills to express their subjective experiences verbally (Selai & Rosser 1993). Making use of non-verbal means of communication or direct observation are alternatives. In future research, we will use these methods in confronting the findings by proxies with data obtained from direct contacts with people with PMD.

Finally, we would like to put up for discussion some methodological issues. A first methodological issue that requires discussion concerns the selection of the panellists. For the selection of the panellists, we addressed ourselves to the partners of a European network on the support of people with PMD, in which our research centre takes part. One disadvantage of this selection method is the limited number and geographical range of the countries involved in this study. They are all Western European countries, which makes inferences on a larger cultural scale impossible. Further research with an expansion of the number and geographical range of the countries involved remains necessary. Another disadvantage of this way of working might be a limited range of viewpoints because we only had one person responsible for the selection in each country.

A second methodological issue that requires discussion is the response rate. In the first round the overall response rate was fairly good (76%). There was, however, a substantial difference between the countries. In Belgium (83%), Germany (83%) and the Netherlands (91%) the response rate was high, whereas in the UK/Ireland the response rate was low (40%). A possible explanation for this difference might be that the countries with high response rates were involved in the previous study whereas the UK/Ireland was not. Five of the 11 non-responders indicated that the questionnaire was too time-consuming. The others did not give an explanation. In the second round the overall response rate was 71%. In this round, the response rate in Belgium (90%) and in the

UK/Ireland (100%) was high, in contrast to Germany (60%) and the Netherlands (50%). Six of the ten non-responders indicated that the first round was too time-consuming and refused to do this a second time.

References

- Adler M. & Ziglio E. (1996) *Gazing into the Oracle: The Delphi Method and Its Application to Social Policy and Public Health*. Jessica Kingsley Publishers, London.
- Borthwick-Duffy S. (1990) *Quality of Life of Persons with Severe and Profound Mental Retardation*. In: *Quality of Life: Perspectives and Issues* (ed. R. Schalock), pp. 177–92. American Association on Mental Retardation, Washington, DC.
- Felce D. & Perry J. (1995) Quality of life: its definition and measurement. *Research in Developmental Disabilities* **16**, 51–74.
- Felce D. & Perry J. (1996a) Exploring current conceptions of quality of life: a model for people with and without disabilities. In: *Quality of Life in Health Promotion and Rehabilitation Conceptual Approaches, Issues and Applications* (eds R. Renwick, I. Brown & M. Nagler), pp. 51–62. Sage publications, London.
- Felce D. & Perry J. (1996b) Assessment of quality of life. In: *Quality of Life, Vol. I: Conceptualization and Measurement* (ed. R. L. Schalock), pp. 63–72. American Association on Mental Retardation, Washington, DC.
- Goode D. A. & Hogg J. (1994) Towards an understanding of holistic quality of life in people with profound intellectual and multiple disabilities. In: *Quality of Life for People with Disabilities: International Perspectives and Issues* (ed. D. Goode), pp. 197–207. Brookline Books, Cambridge.
- Heal L. W. & Sigelman C. K. (1996) *Methodological Issues in Quality of Life Measurement*. In: *Quality of Life, Vol. I: Conceptualization and Measurement* (ed. R. L. Schalock), pp. 91–104. American Association on Mental Retardation, Washington, DC.
- McVilly K. R., Burton-Smith R. M. & Davidson J. A. (2000) Concurrence between subject and proxy ratings of quality of life for people with and without intellectual disabilities. *Journal of Intellectual and Developmental Disabilities* **25**, 19–40.
- Nakken H. & Vlaskamp C. (2002) Joining forces: supporting individuals with profound multiple learning disabilities. *Tizard Learning Disability Review* **7**, 10–15.
- Ouellette-Kuntz H. & McCreary B. (1996) Quality of life assessment for persons with severe developmental disabilities. In: *Quality of Life in Health Promotion and Rehabilitation Conceptual Approaches, Issues and Applications* (eds R. Renwick, I. Brown & M. Nagler), pp. 268–78. Sage publications, London.
- Perry J. & Felce D. (2002) Subjective and objective quality of life assessment: responsiveness, response bias, and resident-proxy concordance. *Mental Retardation* **40**, 445–56.
- Petry K., Maes B. & Vlaskamp C. (2005) Domains of quality of life of people with profound multiple disabilities: the perspective of parents and direct support staff. *Journal of Applied Research in Intellectual Disabilities* **18**, 35–46.
- Polit D. & Hungler B. (1999) *Nursing Research Principles and Methods*. J.B. Lippincott Co., Philadelphia, PA.
- Rapley M., Ridgeway J. & Beyer S. (1998) Staff:staff and staff:client reliability of the Schalock & Keith (1993) quality of life questionnaire. *Journal of Intellectual Disability Research* **42**, 37–42.
- Schalock R. L. & Felce D. (2004) Quality of life and subjective well-being: conceptual and measurement issues. In: *The International Handbook of Applied Research in Intellectual Disabilities* (eds E. Emerson, C. Hatton, T. Thompson & T. R. Parmenter), pp. 261–79. John Wiley & Sons Ltd., West Sussex.
- Schalock R. L. & Verdugo M. A. (2002) *Handbook on Quality of Life for Human Service Practitioners*. American Association on Mental Retardation, Washington, DC.
- Schalock R. L., Brown I., Brown R., Cummins R. A., Felce D., Matikka L., Keith K. D. & Parmenter T. (2002) Conceptualization, measurement, and application of quality of life for people with intellectual disabilities: report of an international panel of experts. *Mental Retardation* **40**, 457–70.
- Selai C. E. & Rosser R. M. (1993) Good quality quality? – Some methodological issues. *Journal of the Royal Society of Medicine* **86**, 440–3.
- Stancliffe R. J. (1995) Assessing opportunities for choice making: a comparison of self- and staff reports. *American Journal on Mental Retardation* **99**, 418–29.
- Vlaskamp C. (2000) De betekenis van het ‘nieuwe paradigma’ in de zorg voor mensen met ernstig meervoudige beperkingen. In: *Van zorg naar ondersteuning: ontwikkelingen in de begeleiding van personen met een verstandelijke handicap* (eds P. Ghesquière & J. M. A. M. Janssens), pp. 53–64. Bohn Stafleu Van Loghum, Houten.
- Ziglio E. (1996) The Delphi-method and its contribution to decision-making. In: *Gazing into the Oracle. The Delphi-Method and Its Application to Social Policy and Public Health* (eds M. Adler & E. Ziglio), pp. 3–33. Jessica Kingsley Publishers, London.

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Appendix I: Final item pool (n = 176) (O = outcomes; S = role of support)

Physical well-being (n = 51)

Mobility (n = 14)

- O
- The person experiences problems during daily activities because of difficulties arising from physical disabilities (e.g. spasticity, deformity).
 - During the last year, the individual's problems arising from physical disabilities (e.g. spasticity, deformity) have decreased.
 - The person is in an adequate position.
 - The person explores different rooms indoors.
 - The person explores different spaces outdoors.
- S
- Direct support staff are aware of and have access to information regarding the individual's needs in this area.
 - In daily contact, direct support staff take account of the individual's needs in this area.
 - Concrete measures are taken to increase the individual's physical capabilities.
 - Concrete measures are taken to prevent and/or treat problems arising from physical disabilities (e.g. spasticity, deformity).
 - Concrete measures are taken to stimulate the individual's independence regarding mobility.
 - Concrete measures are taken to promote the individual's mobility indoors.
 - Concrete measures are taken to promote the individual's mobility outdoors.
 - The place and the position of the person in a room are geared to his/her needs and wishes.
 - An expert is available for advice, consultation and treatment regarding the individual's mobility.

Health (n = 16)

- O
- The individual's physical health status is good.
 - The individual's mental health status is good.
 - The person experiences discomfort because of his/her medical problems.
 - The person experiences discomfort because of side effects of the administered medication.
 - The person experiences problems during daily activities because of sensory impairments.
 - The person exhibits self-injuring behaviour.
- S
- Direct support staff are aware and have access to information regarding the individual's needs in this area.
 - In daily contact, direct support staff take account of the individual's needs in this area.
 - Concrete measures are taken to prevent and/or treat problems regarding the individual's physical health.
 - Concrete measures are taken to prevent and/or treat problems regarding the individual's mental health.
 - Concrete measures are taken to prevent and/or treat pain.
 - Specific attention is paid to the diagnostics and treatment of the individual's sensory impairments.
 - Direct support staff pay extra attention to the person during hospitalization or treatments in hospital and are alert for specific reactions resulting from them.
 - The use of medication is evaluated regularly (e.g. benefits, side effects).
 - The individual's health status is monitored regularly with attention for his/her age and gender (e.g. medical problems related to ageing, typically feminine diseases).
 - An expert is available for advice, consultation and treatment regarding the individual's health.

Hygiene (n = 6)

- O
- The person is clean and well-groomed (e.g. teeth, hair, nails, body).
- S
- Direct support staff are aware of and have access to information regarding the individual's needs in this area.
 - In daily contact, direct support staff take account of the individual's needs in this area.
 - Attention is given to the person's clothes (e.g. comfortable to wear, age appropriate).
 - Concrete measures are taken to promote the individual's independence regarding hygiene.
 - A dentist checks the person's teeth.

Appendix I: *Continued*Nourishment (*n* = 9)

- O The person takes on a sufficient amount of food to remain in good health.
The person takes on a sufficient amount of fluids to remain in good health.
The person receives tasty and balanced nutrition.
The person experiences discomfort from feeding problems.
- S Direct support staff are aware and have access to information regarding the individual's needs in this area.
In daily contact, direct support staff take account of the individual's needs in this area.
Attention is given to the preparation and the presentation of the nutrition (e.g. composition, taste, temperature, variation).
Concrete measures are taken to ensure that the person is in an adequate position during mealtimes.
An expert is available for consultation and advice with regard to feeding.

Rest (*n* = 6)

- O The person is well-rested during the daytime.
The person has a consistent sleep pattern.
- S Direct support staff are aware of and have access to information regarding the individual's needs in this area.
In daily contact, direct support staff take account of the individual's needs in this area.
Concrete measures are taken to improve the individual's comfort while sleeping.
Direct support staff have investigated whether sleeping during the daytime illustrates boredom and not tiredness.

Material well-being (*n* = 20)Living environment (*n* = 7)

- O The person stays in rooms that are geared to his/her needs and wishes with regard to:
 - temperature, lighting, ventilation, air humidity, acoustics;
 - hygiene;
 - decoration;
 - accessibility;
 - safety;
 - privacy.
The living environment is adapted for less mobile persons and for wheelchair users (e.g. garden, street, neighbourhood).
- S The person lives in a community together with a limited number of people (less than five).
Direct support staff are aware of and have access to information regarding the individual's needs in this area.
In daily contact, direct support staff take account of the individual's needs in this area.
Concrete measures are taken to adapt the living environment to the individual's abilities and limitations.
Concrete measures are taken to adapt the living environment to the individual's wishes and preferences.

Appendix I: *Continued*Technical aids (*n* = 13)

- O
- The person has at his/her disposal all technical aids and adaptations that he/she needs regarding:
- communication;
 - independence;
 - mobility;
 - health;
 - sensory functioning;
 - activities/leisure.
- All these technical aids are individually adapted with regard to:
- fit;
 - comfort;
 - safety;
 - user-friendliness;
 - functionality.
- The technical aids are available and accessible at all times for the person and those directly concerned.
- The use of technical aids has a positive effect on the individual's behaviour and functioning.
- The person has financial resources and allowances that are sufficient to meet his/her needs and desires.
- S
- The person has personal possessions.
- Direct support staff is aware of and have access to information regarding the individual's needs in this area.
- In daily contact, direct support staff take account of the individual's needs in this area.
- The technical aids are checked for their adaptability with regard to fit, comfort, safety, user-friendliness and functionality.
- Concrete measures are taken to ensure the maintenance and the hygiene of the technical aids.
- The effect of the technical aids on the individual's functioning and behaviour is evaluated.
- The technical aids are used consistently and correctly.
- An expert is available for consultation about the purchase, the utilization and the maintenance of technical aids.

Social-emotional well-being (*n* = 68)Communication (*n* = 23)

- O
- The person expresses or shows that he/she is happy/feels well.
- The person expresses or shows that he/she is not happy/doesn't feel well.
- The person expresses or shows that he/she wants something.
- The person expresses or shows that he/she does not want something.
- The person gets the opportunity to make clear his/her feelings, needs and wishes. The person is 'heard'.
- The person is personally addressed during the daytime.
- The person is well understood.
- The person understands what the people in his environment want to make clear.
- The person takes initiative and makes a personal contribution to the communication process.

Appendix I: *Continued*

-
- S
- Direct support staff know how the individual expresses well-being.
 Direct support staff know how the individual expresses distress.
 Direct support staff know how the individual expresses what he/she wants.
 Direct support staff know how the individual expresses what he/she does not want.
 Direct support staff have access to information regarding the individual's needs in this area.
 In daily contact, direct support staff take account of the individual's needs in this area.
 Direct support staff are sensitive and responsive towards the individual's signals.
 In supporting the individual, direct support staff pay particular attention to:
- facial expression;
 - glance and direction of eyesight;
 - voice;
 - muscular tension;
 - posture;
 - movement;
 - physiological reactions.
- The person is addressed in a manner that suits:
- his/her age;
 - his/her level of functioning;
 - his/her chosen means of communication;
 - the intonation and the volume to which the person reacts best.
- In interacting with the person, enough time is given for him/her to respond.
 When the person exhibits certain behaviour, the meaning of the behaviour is checked systematically.
 Direct support staff check on the basis of the individual's reactions if they understood him/her correctly.
 Concrete measures are taken to enhance the individual's communication skills.
 An expert is available for advice on communicating with the individual.
- Treatment (*n* = 15)
-
- The person gets individual attention, when needed, during:
- personal care;
 - mealtimes;
 - activities;
 - therapy;
 - developmental stimulation;
 - in between;
 - outside the support system.
- During the sessions of individual attention both parties are disturbed as little as possible.
 The person experiences privacy.
 The person experiences affection.
 The person gets the opportunity to express affection.
 The person is involved in activities/actions (e.g. personal care, nourishment, leisure):
- with the direct support staff that he/she prefers;
 - in the social context that he/she prefers (alone or in group);
 - on the place that he/she prefers;
 - at the time that he/she prefers;
 - in the pace that he/she prefers.
- The atmosphere in the group (living group/activity group) is positive.

Appendix I: *Continued*

S	<p>Direct support staff are aware of and have access to information regarding the individual's needs in this area.</p> <p>In daily contact, direct support staff take account of the individual's needs in this area.</p> <p>In contact with the person there is room for warmth, affection and appropriate physical contact, if preferred by the person.</p> <p>Concrete measures are taken to respect the person's privacy (e.g. during personal care, with regard to sexuality).</p> <p>Direct support staff treat the person with respect.</p> <p>The person is supported in a way that takes into account his/her needs, wishes and preferences regarding:</p> <ul style="list-style-type: none"> • direct support staff • social context: single or in group • location/setting • time • pace <p>Careful consideration is taken about the decision to carry out an action (e.g. during personal care, mealtimes, activities) if the person experiences this action as unpleasant.</p> <p>Concrete measures are taken to optimize the atmosphere/the ambience in the group.</p>
Basic security (n = 11)	
O	<p>The individual has a personal bond with the people around him/her.</p> <p>The person has a key worker or a stable team of direct support staff.</p> <p>The person can follow, recognize, predict and influence the coming and going of people who support him/her during the day.</p>
S	<p>The person can follow, recognize, predict and influence what is happening around him/her.</p> <p>Direct support staff are aware of the importance of relationship building with the individual.</p> <p>Direct support staff are aware of and have access to information on the individual's needs in this area.</p> <p>In daily contact, direct support staff take account of the individual's needs in this area.</p> <p>The changeover between direct support staff (e.g. because of changing of shifts) is made clear to the person.</p> <p>New direct support staff as well as the person get the chance to gradually build up a relationship with each other.</p> <p>Concrete measures are taken to make the environment surrounding the person recognizable and predictable with regard to:</p> <ul style="list-style-type: none"> • space; • day structure; • direct support staff; • activities. <p>Concrete measures are taken to secure/safeguard the surroundings of the person.</p>
Family bonds (n = 6)	
O	<p>The person has a good relationship with his/her parents.</p> <p>The person has a good relationship with his/her siblings and/or other family members.</p>
S	<p>Children: Contacts between the person and his/her parents are encouraged and supported.</p> <p>Adults: Contacts between the person and his/her parents are made possible and supported.</p> <p>Children: Contacts between the person and his/her sibling(s) and/or other family members are encouraged and supported.</p> <p>Adults: Contacts between the person and his/her sibling(s) and/or other family members are made possible and supported.</p> <p>The family is engaged in the daily activities of the person if preferred by both parties.</p> <p>The family can have contact with the person as often as possible if preferred by both parties.</p>

Appendix I: *Continued*Social relationships (*n* = 8)

- O The person has social contacts that are meaningful to him/her with people outside the context of support (e.g. friends, acquaintances, neighbours).
The person has social contacts which are meaningful to him/her with group members (e.g. living group/activity group/class group).
The person gets the opportunity to be alone with his/her friends/acquaintances.
The person gets the opportunity to meet people outside the context of support.
- S Direct support are aware of and have access to information regarding the individual's needs in this area.
Concrete measures are taken to maintain and/or expand the person's social network.
Direct support staff are attentive to and stimulate mutual relationships between persons with a disability.
Direct support staff are attentive to the individual's desires and emotions with regard to sexuality and actively guide the person in experiencing his/her sexuality.

Social participation (*n* = 5)

- O The person participates in social activities outside the support setting.
The person makes use of community services and facilities.
- S Direct support staff are aware of and have access to information regarding the individual's needs in this area.
Concrete measures are taken to promote the individual's participation in the community.
Concrete measures are taken to present a positive image of persons with profound multiple disabilities to the society.

Development & activities (*n* = 37)Engagement in activities (*n* = 12)

- O The person actively participates in several activities, which include group activities as well as individual activities.
The time in which the person is involved in activities meets his/her needs.
The person participates in activities that he/she can cope with physically and mentally.
The person participates in activities that interest him/her.
The person acquires new skills and/or new experiences by participating in activities.
- S Direct support are aware and have access to information regarding the individual's needs in this area.
In daily contact, direct support staff take account of the individual's needs in this area.
The type and success of activities is determined by:
 - the person's state of health;
 - the person's ability to concentrate and attend;
 - the person's age;
 - what a person can cope with at that moment;
 - the person's capabilities and limitations;
 - the person's interests and preferences.
Activities take account of the leisure facilities and appropriate culture in the area.
Concrete measures are taken to put as much variation in the range of activities as possible (e.g. adding new activities).
Concrete measures are taken to offer some of the activities in open air, which take account of the person's state of health and the weather conditions.
An expert is available for advice and consultation about the range of activities offered to the person.

Appendix I: *Continued*Influence and choices (*n* = 13)

- O
- The person exerts influence on his/her physical and material environment.
 The person exerts influence on his/her social environment.
 The person makes with/without support choices regarding:
- mobility;
 - medical and personal care;
 - clothing;
 - food/drinks;
 - sleep pattern;
 - living environment;
 - technical aids;
 - treatment;
 - relationships within the context of support;
 - relationships outside the context of support;
 - activities;
 - developmental stimulation;
 - leisure;
 - employment (adults).
- The individual's rights are respected.
- S
- The person has an advocate outside the support setting who defends his/her rights.
 Direct support staff are aware of the individual's likes and dislikes regarding:
- mobility;
 - medical and personal care;
 - clothing;
 - food/drinks;
 - sleep-wake rhythm;
 - living environment;
 - technical aids;
 - treatment;
 - relationships within the context of support;
 - relationships outside the context of support;
 - activities;
 - developmental stimulation;
 - leisure;
 - employment (adults).
- Direct support staff have access to information regarding the individual's needs in this area.
 In daily contact, direct support staff take account of the individual's needs in this area.
 Concrete measures are taken to allow the person to exert influence on his/her physical and material environment.
 Concrete measures are taken to allow the person to exert influence on his/her social environment.
 Concrete measures are taken to allow the person to make his/her own choices.
 Direct support staff take account of the person's preferences and choices.
 Direct support staff aim to enforce the person's individual lifestyle.

Appendix I: *Continued*Development (*n* = 12)

- O
- The person has developed new competencies during the last year (children)/the last two years (adults) with regard to:
- motor development;
 - sensory development;
 - social development;
 - emotional development;
 - intellectual development;
 - communication skills;
 - personality development.
- The person optimally uses his/her abilities with regard to:
- motor development;
 - sensory development;
 - social development;
 - emotional development;
 - intellectual development;
 - communication skills;
 - personality development.
- Children: The person receives schooling/education or developmental stimulation.
Adults: The person is employed (with/without support) or receives adult education.
The person gets the opportunity to perform activities/actions independently.
- S
- Direct support staff have a clear understanding of the individual's developmental potential in the domains of:
- motor development;
 - sensory development;
 - social development;
 - emotional development;
 - intellectual development;
 - communication skills;
 - personality development;
- Direct support staff are aware of and have access to information regarding the individual's needs in this area.
In daily contact, direct support staff take account of the individual's needs in this area.
The person's development is stimulated in the domain of:
- motor development;
 - sensory development;
 - social development;
 - emotional development;
 - intellectual development;
 - communication skills;
 - personality development.
- Concrete measures are taken to promote the individual's independence.
The existing skills/abilities of the person are maintained and/or new skills/abilities are taught.
Stimulating the individual's development is carried out at his/her pace and in a way he/she can manage. (avoiding under- and overstimulation).
An expert in the field of developmental stimulation is available for advice and counselling.

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