

Assessing needs of families with children who have physical disabilities



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Objective

To determine the optimal method to assess needs of Dutch families with children who have physical disabilities.

Method

Families were recruited from a paediatric rehabilitation centre (De Hoogstraat, Utrecht, The Netherlands) and through the Dutch Association of Physically Disabled Persons and their Parents (BOSK). Inclusion criteria were:

1. child's age within range 0-18 years
2. child has a (primarily) physical disability
3. child lives with the respondent
4. respondent speaks and understands Dutch

Participants

Within 49 recruited families, 31 mothers, 8 fathers, and 10 parent couples were interviewed. Family characteristics are provided in **Table 1**.

Procedure and instruments

Parents were interviewed at home ($n=47$) or at a venue of their choice ($n=2$) by one or two trained interviewers (members of the research team and graduate students). Interviews ranged from 45 min to 2.5 h, but usually lasted between 1-1.5 h. The interviews were semi-structured, guided by an interview template (**Table 2**). As a part of the interview (half-way) parents filled out the OBI checklist (OndersteuningsBehoeftel Inventarisatie [Family Support & Needs Inventory]) of 103 items, divided into 15 domains regarding their family needs (**Table 3**). This checklist resulted from a systematic review of the international literature on family needs.

Part 1

- **Respondent** demographic and economic status of the respondent, including their age, ethnicity, marital status, education level, and employment status
- **Child** age, number of siblings, gender, health condition or disability, mobility, rating of ability and independency on a 3-point scale (1=totally independent; 2=needs help; 3=totally dependent) on four specific ADL skills (having a meal, getting dressed and undressed, personal care, and going to the toilet)

Part 2

- Case about an imaginary family to ensure all parents met our definition of family needs before they entered the next part of the interview
- Question: *For what activities or in which circumstances did you ever think: I could use some help with this?*

Part 3

- Respondents filled out the 103-item OBI checklist of family needs, divided into 15 domains.

Part 4

- Which method –interview or checklist– do you prefer to express family needs?
- Have you missed items in the checklist?
- Further questions about the study?

Part 5

- Unstructured conversation.

Table 2
Interview template

Parents' age range	29-52 y ($M=40.8$; $SD=6.4$)
Family size	3-7 ($M=4.2$; $SD=1.0$)
Family's socioeconomic level	
Upper	8 (16.0%)
Upper-middle	27 (54.0%)
Middle	11 (22.0%)
Lower-middle	3 (6.0%)
Children's age range	1-18 y ($M=7.7$; $SD=4.6$)
Boys	26 (53.1%)
Child's mobility	
Can walk without aids	22 (44.9%)
Can walk with aids	7 (14.3%)
Wheelchair bound	18 (36.7%)
Too young to walk	2 (4.1%)
Child's score on ability index (range 4 [high independency] - 12 [low independency])	$M=8.4$ ($SD=3.1$)

Table 1
Family characteristics ($N=49$)

Domain	n items
Diagnosis, development and expectations	9
About rehabilitative therapy (physical, occupational and speech-language therapy)	12
Equipment, aids and adaptations	8
Partner in care	8
Practical support	7
Raising my child	11
Emotional/psychological support	3
Talk about my child	5
Family	8
Recreational activities	3
Transportation	3
Law, legislation and funding	6
Medical treatment	5
Education/employment	4
Other family members	11

Table 3
Domains OBI

Results

All interviews were transcribed literally and anonymized. Subsequently, family needs were marked in the interviews independently by two members of the research team and linked to the checklist items. New needs were added to the appropriate domain.

The interview revealed significantly less family needs ($M=10.8$; $SD=6.0$) than the OBI checklist ($M=31.7$; $SD=19.7$) ($p<.000$).

As expected, we found a significant correlation between the number of family needs ticked in the OBI and mentioned in the semi-structured interview ($r=.456$; $p=.004$). Items that were ticked or mentioned most concerned information on the child's development and treatment, aids, and information about legislation and rules relating to compensation of costs.

Parents' preferences to express their family needs are displayed in **Table 4**. Nine parents (18.4%) prefer the OBI to express family needs, 11 parents (22.4%) prefer an interview with a health care professional, or an interview with the OBI as a template (2 parents; 4.1%). A large group ($n=21$; 42.6%) prefers a combination of filling out the OBI prior to, or after, an interview with a health care professional. Ten parents favor a digital OBI over a paper version.

Method	n (%)
OBI	9 (18.4)
Interview	11 (22.4)
Combination of OBI and interview	21 (42.6)
OBI as a template for interview	2 (4.1)
No preferences	4 (8.2)
Missing	2 (4.1)

Table 4
Parents' preference to express family needs ($N=49$)

Conclusions and significance

- Using a checklist to identify family needs reveals more family needs than an open-ended question.
- An open-ended question, on the other hand, may list more urgent family needs.
- We recommend applying a combination of both methods when assessing family needs in paediatric rehabilitation.