

Assessment of family needs in children with physical disabilities: Development of a family needs inventory



Brain Center
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Background

Care for children with (physical) disabilities is deemed to be family-centered; the family of a child is considered as important as the child itself. Moreover, since every family is unique, getting insight in individual family needs is not easy.

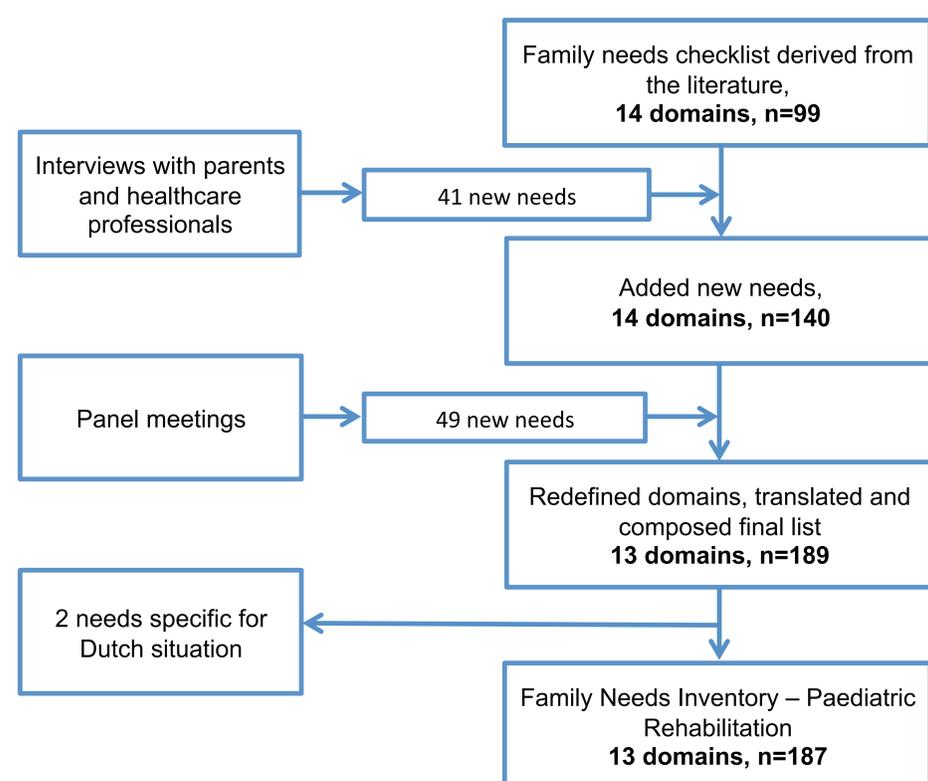
Objective

To create a tool to help parents of children with a physical disability identify and formulate their family needs.

Methods

1. A literature review was conducted to identify family needs already reported on.
2. In a field study, these needs were presented to parents and healthcare professionals for comments and additions.
 - Forty-nine families of children with a physical disability and 14 healthcare professionals participated in semi-structured interviews.
 - Panel meetings with 30 healthcare professionals and parents were held.

This resulted in a 187-item list of possible family needs, of which examples can be found below:



I'd like to have help with...	yes	no
Training in home therapy techniques	<input type="checkbox"/>	<input type="checkbox"/>
More sympathy and understanding	<input type="checkbox"/>	<input type="checkbox"/>
To have more time for myself	<input type="checkbox"/>	<input type="checkbox"/>
Information about children with a similar disability	<input type="checkbox"/>	<input type="checkbox"/>
Information about financial resources available and how to access them	<input type="checkbox"/>	<input type="checkbox"/>
To try out equipment before purchasing it	<input type="checkbox"/>	<input type="checkbox"/>
Information about insurance plans	<input type="checkbox"/>	<input type="checkbox"/>
To read about experiences of other families with children with disabilities	<input type="checkbox"/>	<input type="checkbox"/>
Special equipment (wheelchair, walking aids, communication aids)	<input type="checkbox"/>	<input type="checkbox"/>
Information about how to integrate therapy into daily activities	<input type="checkbox"/>	<input type="checkbox"/>
Information about my child's development	<input type="checkbox"/>	<input type="checkbox"/>
Information about services that are presently available for my child	<input type="checkbox"/>	<input type="checkbox"/>
Advice about what to expect as my child gets older	<input type="checkbox"/>	<input type="checkbox"/>

For the complete FNI-PR scan this code:
(research version)



Conclusions

- The combined literature and field research resulted in 187 possible family needs, which are brought together in the Family Needs Inventory – Paediatric Rehabilitation (FNI-PR).
- Using the FNI-PR raised significantly more family needs than an open question, and helped parents in formulating their family needs.

Sources:

Siebes, R. C., Ketelaar, M., Gorter, J. W., Alsem, M., & Jongmans, M. J. (2012). Needs of families with children who have a physical disability: A literature review. *Crit Rev Phys Rehab Med*, 24(1-2), 85-108.



Alsem, M. W., Siebes, R. C., Gorter, J. W., Jongmans, M. J., Nijhuis, B. G. J., & Ketelaar, M. (2013). Assessment of family needs in children with physical disabilities: development of a family needs inventory. *Child Care Health Dev.*



This study was supported by a grant from the Johanna Kinderfonds and Stichting Rotterdams Kinderrevalidatie Fonds Adriaanstichting.

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