University of Groningen

Shared responsibility: a load off your mind

Jansen, Suzanne

DOI:
[10.1016/j.ridd.2014.03.044](https://doi.org/10.1016/j.ridd.2014.03.044)

IMPORTANT NOTE: You are advised to consult the publisher's version (publisher's PDF) if you wish to cite from it. Please check the document version below.

Document Version
Publisher's PDF, also known as Version of record

Publication date:
2015

[Link to publication in University of Groningen/UMCG research database](#)

Citation for published version (APA):

Jansen, S. (2015). *Shared responsibility: a load off your mind: collaboration with parents in the support of children with Profound Intellectual and Multiple Disabilities*. [Thesis fully internal (DIV), University of Groningen]. University of Groningen. <https://doi.org/10.1016/j.ridd.2014.03.044>

Copyright

Other than for strictly personal use, it is not permitted to download or to forward/distribute the text or part of it without the consent of the author(s) and/or copyright holder(s), unless the work is under an open content license (like Creative Commons).

The publication may also be distributed here under the terms of Article 25fa of the Dutch Copyright Act, indicated by the "Taverne" license. More information can be found on the University of Groningen website: <https://www.rug.nl/library/open-access/self-archiving-pure/taverne-amendment>.

Take-down policy

If you believe that this document breaches copyright please contact us providing details, and we will remove access to the work immediately and investigate your claim.

Downloaded from the University of Groningen/UMCG research database (Pure): <http://www.rug.nl/research/portal>. For technical reasons the number of authors shown on this cover page is limited to 10 maximum.

Shared responsibility: a load off your mind

**Collaboration with parents in the support of children with Profound
Intellectual and Multiple Disabilities**

Suzanne Jansen

This study was funded by Stichting Wetenschappelijk Onderzoek 's Heeren Loo.

Shared responsibility: a load off your mind

Collaboration with parents in the support of children with Profound
Intellectual and Multiple Disabilities

Proefschrift

ter verkrijging van de graad van doctor aan de
Rijksuniversiteit Groningen
op gezag van de
rector magnificus prof. dr. E. Sterken
en volgens besluit van het College voor Promoties.

De openbare verdediging zal plaatsvinden op

donderdag 9 april 2015 om 12.45 uur

door

Suzanne Jansen
geboren op 27 november 1970

te Utrecht

Colofon

Ontwerp en opmaak

Doks ontwerpburo, Arnhem

Tekst:

Suzanne Jansen

Druk

EPC

ISBN: 9789462285996

© 2015 Suzanne Jansen. Niets uit deze uitgave mag worden verveelvoudigd en/of openbaar worden gemaakt door middel van druk, fotokopie, geluidsband, elektronisch of op welke wijze dan ook, zonder schriftelijke toestemming van de auteur.

Promotor

Prof. dr. C. Vlaskamp

Copromotor

Dr. A.A.J. van der Putten

Beoordelingscommissie

Prof. dr. B. Maes

Prof. dr. M.J. Jongmans

Prof. dr. E.J. Knorth

Contents

1 Introduction	9
1.1 Outline of the thesis	11
1.2 References	12
2 What makes a difference? Collaboration between parents and professionals in the support of persons with profound intellectual and multiple disabilities: a literature review	15
Abstract	16
2.1 Introduction	17
2.2 Method	19
2.2.1 Literature search	19
2.2.2 Analysis	19
2.3 Results	20
2.3.1 Literature selection process	20
2.3.2 Overview of the descriptive characteristics of the studies included	20
2.3.3 Study aims	21
2.3.4 Participants	21
2.3.5 Settings	21
2.3.6 Collaboration and related factors	26
2.4 Conclusion and Discussion	30
2.5 Acknowledgements	32
2.6 References	32
3 What parents find important in the support of a child with profound intellectual and multiple disabilities	37
Abstract	38
3.1 Introduction	39
3.2 Method	41
3.2.1 Participants	41
3.2.2 Measurements	41
3.2.3 Procedure	45
3.2.4 Analysis	45
3.3 Results	46
3.3.1 Characteristics of the participating parents and their children	46
3.3.2 MPOC-NL-PIMD	50
3.3.3 Relationship with sample characteristics	51
3.4 Discussion	56
3.5 Key messages	57
3.6 Acknowledgements	58
3.7 References	58

4 Family-centredness of professionals who support people with profound intellectual and multiple disabilities: validation of the Dutch 'Measure of Processes of Care for Service Providers' (MPOC-SP-PIMD) 61

Abstract	62
4.1 Introduction	63
4.2 Material and methods	65
4.2.1 Participants	65
4.2.2 Instrument	65
4.2.3 Analysis of the validity and reliability of the MPOC-SP-PIMD	68
4.3 Results	69
4.3.1 SIS scale	70
4.3.2 TPR scale	70
4.3.3 CSI scale	70
4.4 Discussion	73
4.5 Acknowledgements	75
4.6 References	75

5 Do they agree? How parents and professionals value the support provided to persons with profound intellectual and multiple disabilities 79

Abstract	80
5.1 Introduction	81
5.2 Method	83
5.2.1 Participants	83
5.2.2 Measurements	84
Parents	84
Professionals	84
5.2.3 Procedure	85
5.2.4 Analysis	86
5.3 Results	87
5.3.1 Characteristics of the parents and their children	87
5.3.2 Characteristics of the professionals	88
5.3.3 Comparisons between parents and professionals	89
5.3.4 Relationship with sample characteristics	92
5.4 Discussion	93
5.5 Acknowledgements	96
5.6 References	96

6 Parents' experiences of collaborating with professionals in the support of their child with profound intellectual and multiple disabilities: a multiple case study 101

Abstract	102
6.1 Introduction	103

6.2 Method	106
6.2.1 Participants and procedure	106
6.2.2 Design	108
6.2.3 Data collection	108
6.2.4 Analysis	108
6.3 Results	109
6.3.1 Contact characteristics	109
6.3.2 The function and the subject of communication	112
6.3.3 Mothers' experiences with communication	114
6.3.4 Differences between the mothers' experiences	117
6.3.5 Changes over time	117
6.4 Conclusion and discussion	118
6.5 Acknowledgements	120
6.6 References	120

7 General Discussion 126

7.1 Summary of the main findings	126
7.2 Methodological reflections and future research	128
7.3 Implications for practice	129
7.4 References	130

Summary	133
Samenvatting	137
Dankwoord	141
About the author	145