

Erasmus School of  
Health Policy  
& Management



Participatory quality improvement  
in complex care relationships  
in long-term care



pameijer



# Participatory quality improvement in complex care relationships in long term care

Serious mental  
illness (SMI)  
assisted living

Intellectual  
disabilities  
assisted living

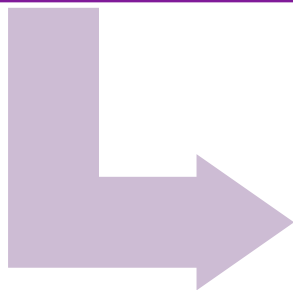
Elderly  
rehabilitation

Insight into complex care  
relationship:  
balancing  
a caring approach and  
fostering an independent lifestyle

Develop a  
deliberation & quality  
improvement tool  
for quality improvement of  
the care relationship

## Aim (1)

Insight into complex care relationship:  
balancing  
a caring approach and  
fostering an independent lifestyle



Develop a  
deliberation & quality  
improvement tool  
for quality improvement of  
the care relationship



DOSSIER

WAT WERKT BIJ  
eigen regie



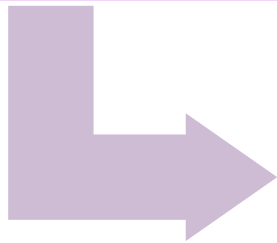
MOVISIE  
kennis en contact van  
sociale organisaties



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## Aim (2)

Insight into complex care  
relationship:  
balancing  
a caring approach and  
fostering an independent lifestyle

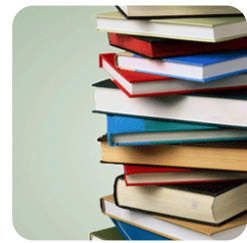


Develop a  
Deliberation & quality  
improvement tool  
for quality improvement of the  
care relationship



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# Insight into complex care relationship: balancing a caring approach and fostering an independent lifestyle.



Review  
scientific  
literature  
&  
Books  
describing  
experiences

Ethnographic  
research  
complex care  
relationship

Participatory  
design of  
deliberation &  
quality  
improvement  
tool

Evaluating  
deliberation &  
quality  
improvement  
tool

Spreading  
deliberation &  
quality  
improvement  
tool  
to other care  
organizations

## Families' views on their relatives with intellectual disability moving from a long-stay psychiatric institution to a community-based intellectual disability service: an Irish context

Owen Doody, Department of Nursing and Midwifery, North Bank Campus, University of Limerick, Limerick, Ireland (E-mail: owen.doody@ul.ie)

JARID

Journal of Applied Research in Intellectual Disabilities

bild

Published for the British Institute of Learning Disabilities

Journal of Applied Research in Intellectual Disabilities 2013, 26, 119–132

## Family Voices: Life for Family Carers of People with Intellectual Disabilities in Ireland

Darren D. Chadwick\*, Hasheem Mannan†, Edume Garcia Iriarte‡, Roy McConkey§, Patricia O'Brien¶, Frieda Finlay‡, Anne Lawlor‡ and Gerry Harrington‡

\*School of Applied Sciences, The University of Wolverhampton, Wolverhampton, UK; †Centre for Global Health, Trinity College Dublin, Dublin, Ireland; ‡National Institute for Intellectual Disability, Trinity College Dublin, Dublin, Ireland; §Institute of Nursing Research, University of Ulster, Belfast, UK; ¶Centre for Disability Studies, The University of Sydney, Sydney, NSW, Australia

Between control and freedom in the care for persons with Prader-Willi syndrome: An analysis of preferred interventions by caregivers

Patient Education  
and Counseling

Rob H. van Hooren<sup>a,\*</sup>, Guy A.M. Widdershoven<sup>a</sup>, Math J.J.M. Candel<sup>b</sup>,  
Bart W. van den Borne<sup>c</sup>, Leopold M.G. Curfs<sup>d</sup>

## Inputs and outcomes: What do staff in services for people with intellectual disabilities perceive they bring to and receive from their work-based relationships?

Philip Disley  
Lancaster University, UK

Chris Hatton  
Lancaster University, UK

Dave Dagnan  
Cumbria Partnership NHS Foundation Trust, UK



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Journal of Intellectual Disability Research

doi: 10.1111/j.1365-2788.2012.01638.x

VOLUME 58 PART 3 pp 221–232 MARCH 2014

## The human degree of care. Professional loving care for people with a mild intellectual disability: an explorative study

M.A. Hermsen,<sup>1,2</sup> P.J.C.M. Embregts,<sup>1,2,3,4</sup> A.H.C. Hendriks<sup>4,5</sup> & N. Frielink<sup>1,2</sup>

## **Empowering words, disempowering actions: an analysis of interactions between staff members and people with learning disabilities in residents' meetings**

**T. Jingree, W. M. L. Finlay & C. Antaki**

*School of Human Sciences, Department of Psychology, University of Surrey, Guildford, UK*

## **Offering choices to people with intellectual disabilities: an interactional study**

**C. Antaki<sup>1</sup>, W. Finlay<sup>2</sup>, C. Walton<sup>3</sup> & L. Pate<sup>4</sup>**



## Journal of Intellectual & Developmental Disability

ISSN: 1366-8250 (Print) 1469-9532 (Online) Journal homepage: <http://www.tandfonline.com/loi/cjid20>

### Perceptions and expectations of regular support meetings between staff and people with an intellectual disability

Ellen Reuzel, Anna M. T. Bosman, Petri J. C. M. Embregts, Maroesjka van Nieuwenhuijzen & Andrew Jahoda

**JARID**  
Journal of Applied Research in Intellectual Disabilities

Journal of Applied Research in Intellectual Disabilities 2013, 26, 3–13

**bild**  
Published for the British Institute of Learning Disabilities

### **Mental Health Services for Adults with Intellectual Disabilities – What Do Service Users and Staff Think of Them?**

Biza Stenfert Kroese, John Rose, Kuljit Heer and Alexis O'Brien  
School of Psychology, University of Birmingham, Birmingham, UK



Analyzing books with experiences of receiving care  
(people with ID, professional carers and family)

# Patientervaringsverhalen.nl

Uw gids voor ervaringsverhalen over (chronische) ziekten, aandoeningen en handicaps.



**Stichting CCC**  
*opent bronnen...*

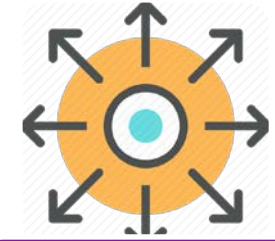
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# Ethnographic research



*Ezopus*

# Developing a deliberation & quality improvement tool for quality improvement of the care relationship



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# Developing a deliberation & quality improvement tool – experienced based co-design

1. Deliberation about the care relationship  
(balancing a caring approach with fostering an independent lifestyle)



2. Sharing experiences...  
that lead to quality improvement



3. Deliberation between people who receive services, people who provide services and family carers.



4. Input for deliberation by use of video



# Participatory design of the deliberation & quality improvement tool

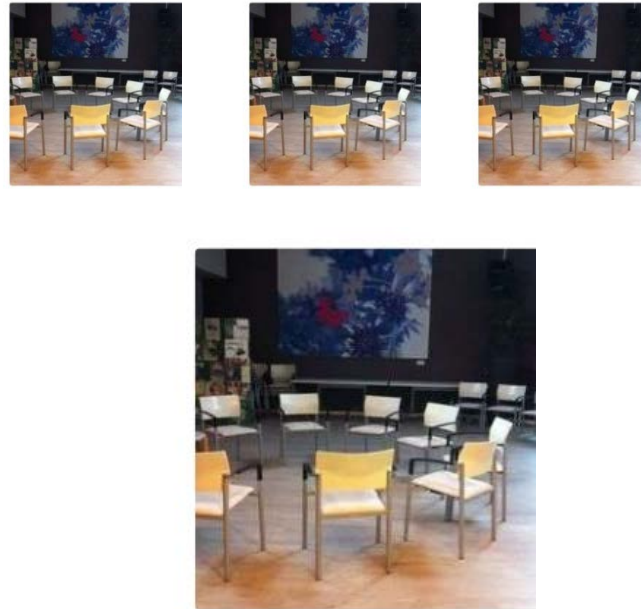


- Workshops with people with ID;  
professional carers and family  
members  
to develop the themes  
on dilemmas & care burdens from  
the ethnographic fieldwork &  
literature study

- Translate the themes to a visual  
representation

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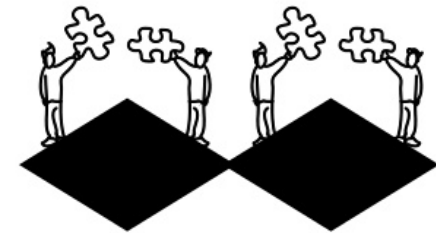
# Deliberation & quality improvement tool (based on experienced based co-design)



Visual representation of dilemmas & burdens

Reflexive exercises on dilemmas & burdens  
Deliberate themes for quality improvement

DOING **CO-DESIGN**



Co-design  
quality improvement

@pennyhagen  
@redrollers



**Contact:**

Marjolijn Heerings

[heerings@eshpm.eur.nl](mailto:heerings@eshpm.eur.nl)

Erasmus School of  
Health Policy  
& Management



Marjolijn Heerings

Hester van de Bovenkamp

Roland Bal



Mariëlle van Esch

Huib Hoogendijk



Mieke Cardol

