

Training support staff to promote self-management in people with intellectual disabilities: A mixed methods study

Janice Sandjojo

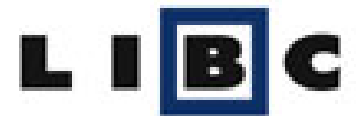
International Disability Studies Conference

1 December 2017



Universiteit
Leiden
The Netherlands

Raamwerk



People with intellectual disabilities (ID)

DSM-V¹

- Deficits in intellectual functions (e.g. reasoning, learning) ($IQ \leq 70 \pm 5$)



- Deficits in adaptive functioning ..., which limit functioning in daily life (e.g. communication, social participation, home, school, work, recreation)

Many comorbid health and psychiatric problems.

¹American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Arlington, VA: American Psychiatric Publishing,

Background

People with ID:
Find being independent important
More difficulties managing their own affairs



Growing demand for care



Increase in costs

Meanwhile: Cuts and savings
Staff cannot meet their clients' needs
Burden on family members

Why promote self-management?

To improve clients':

- Independence and self-reliance
- Inclusion/participation in society
- Self-worth
- Mood
- Behaviour
- Quality of life



To reduce:

- Burden on support staff and family members
- Growing demand for care for people with ID²
- Corresponding rising costs

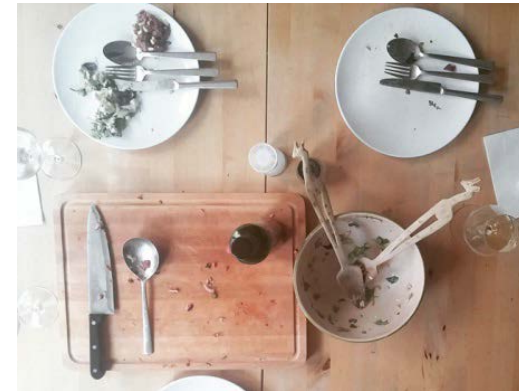
² Sociaal en Cultureel Planbureau (2014). *Zorg Beter Begrepen. Verklaringen voor de groeiende vraag naar zorg voor mensen met een verstandelijke beperking*. Den Haag: Sociaal en Cultureel Planbureau.

Implementation of staff training

- Focus on disabilities
- Nurturing, taking over
- 'Hospitalising' clients



- Focus on abilities and possibilities
- Stimulating independence and self-reliance
- Learning new skills
- Letting clients think and do things themselves



Hypotheses: Staff training has a positive effect on independence and self-reliance, support needs, and behaviour in people with ID

Methods – Staff training

28 staff members: 'Op eigen benen' (OEB) training³

Aimed at improving self-management

Theory, practical exercises and role-play

Trains staff to view and guide clients differently:

- Focus on strengths, abilities, interests and wishes
- Let clients think, find out, handle things themselves
- Facilitate learning, expand abilities
- Mediating, coaching, moderating
- Respect, trust, reciprocity



³ Scholten, G. & Schuurman, M. (2008). *Eigenwaarde. Leermethodiek Op Eigen Benen achtergrond en toepassing*. Wezep: INVRA BV.

Methods - Participants

Raamwerk, Noordwijkerhout



5 5 5 (n=15)



4 4 2 1 (n=11)

Age = 31.1 (9.9)

8 male / 7 female

Staff was trained

Age = 35.8 (11.2)

8 male / 3 female

Staff was not trained

Mostly mild ID (mean IQ \pm 61)

Comorbid psychiatric disorders

Methods - Measurements

Questionnaires, filled in by support staff/psychologist

- Social Functioning Scale for the Mentally Retarded⁴
- Support Intensity Scale⁵
- Developmental Behaviour Checklist⁶

Focus groups, with trained staff members (n = 13)

- To evaluate the training
- To study whether they noticed any changes past half year



Results

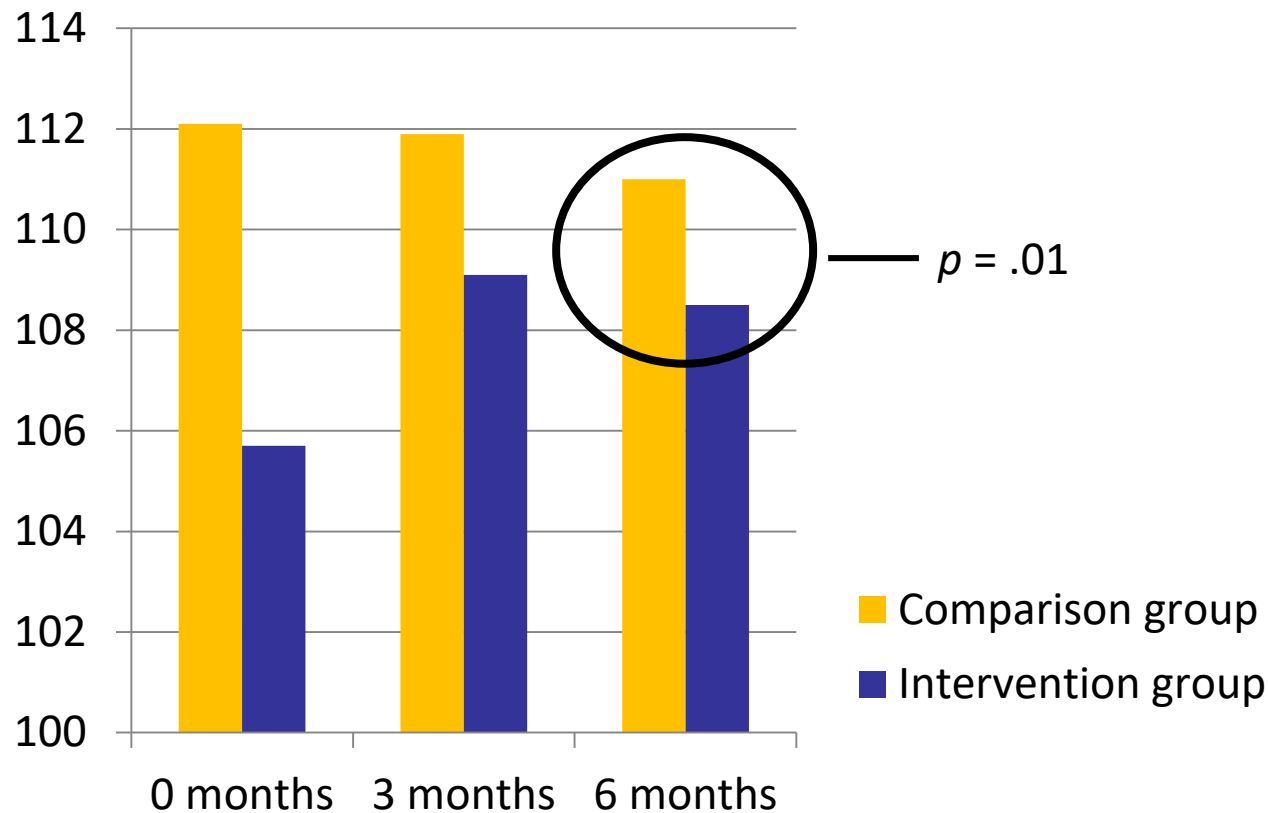
	Intervention group			Comparison group		
	T0 (n = 15)	T1 (n = 15)	T2 (n = 12)	T0 (n = 11)	T1 (n = 11)	T2 (n = 11)
SFSMR ⁴ , <i>M (SD)</i>	105.7 (11.6)	109.1 (9.3)	108.5 (10.1)	112.1 (9.9)	111.9 (11.1)	111.0 (11.9)
SIS ⁵ Section 1+2, <i>M (SD)</i>	284.9 (82.9)		295.2 (63.8)	303.7 (96.7)		291.9 (95.2)
DBC ⁶ , <i>M (SD)</i>	33.2 (15.6)	34.3 (9.5)	33.0 (11.8)	33.3 (27.0)	35.9 (27.4)	36.8 (24.0)

All baseline scores do not differ between groups

Longitudinal multilevel analyses & Nonparametric Mann-Whitney tests

Results – Independence/self-reliance

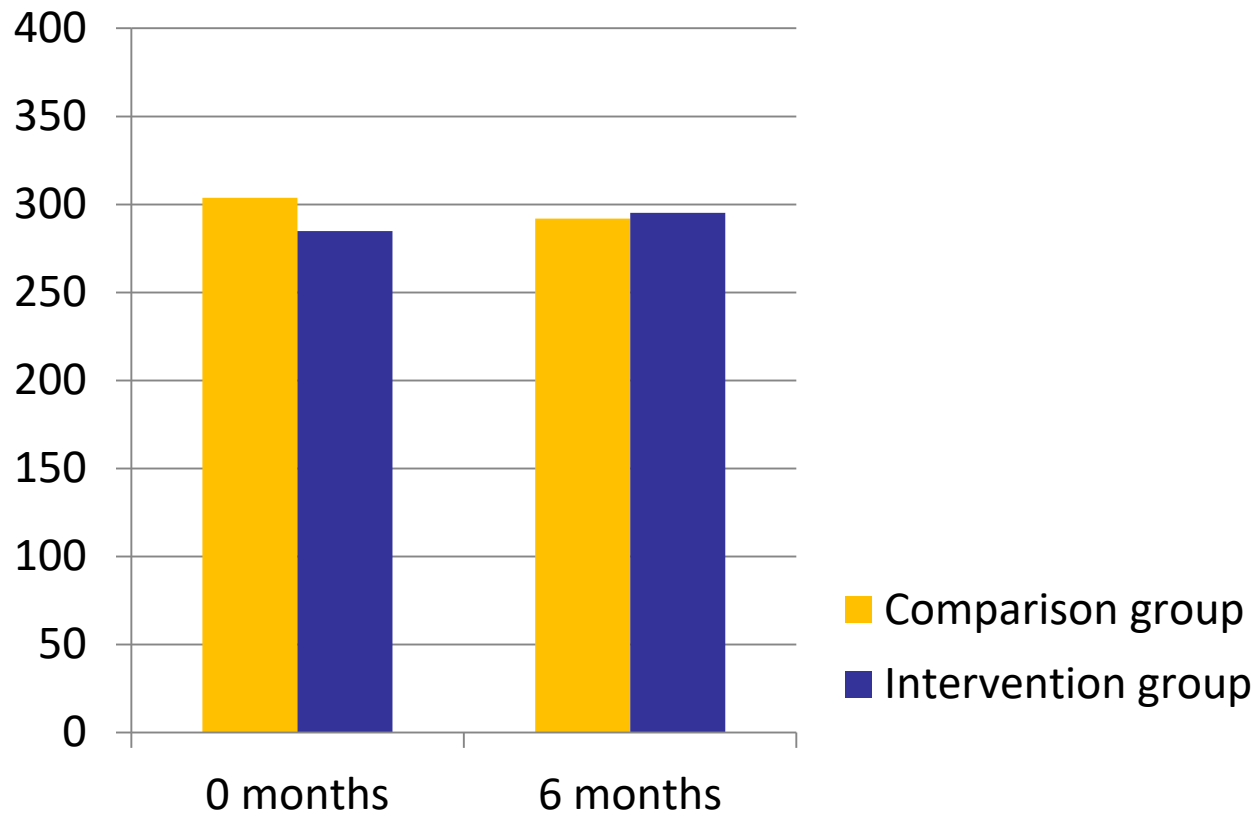
Social Functioning Scale for the Mentally Retarded⁴



⁴ Kraijer, D.W., Kema, G.N. & De Bildt, A.A. (2004). *SRZ/SRZ-I | Sociale Redzaamheidsschaal voor verstandelijk gehandicapten*. Amsterdam: Pearson.

Results – Need for support

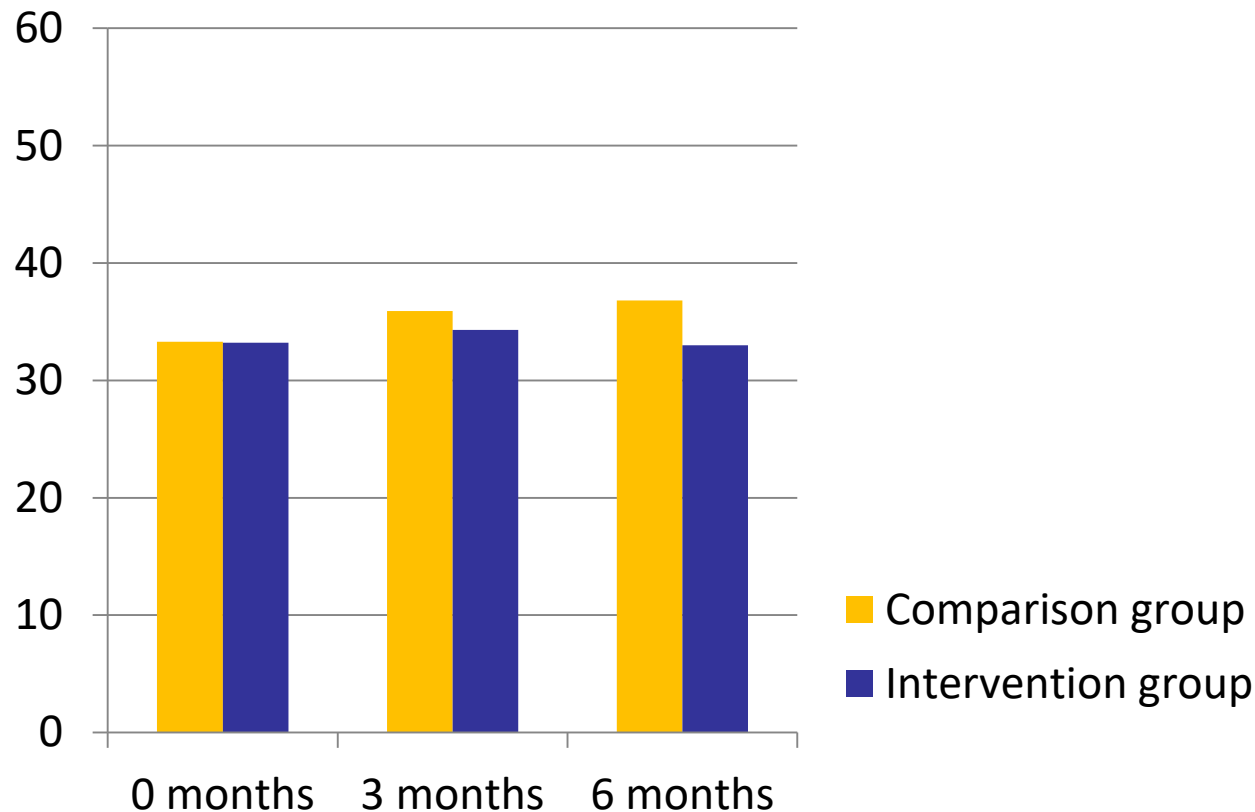
Support Intensity Scale⁵ (SIS)



⁵Thompson, J.R., Bryant, B.R., Campbell, E.M., Craig, E.M., Hughes, C.M., Rotholz, D.A., Schalock, R.L., Silverman, W.P., Tassé, M.J., & Wehmeyer, M.L. (2004). *Support Intensity Scale*. Washington: American Association on Mental Retardation.

Results – Behavioural problems

Developmental Behaviour Checklist⁶ (DBC)



⁶Koot, H.M. & Dekker, M.C. (2001). *Handleiding voor de VOG. Ouder- en leerkrachtversie*. Rotterdam: Erasmus Universiteit.

Results – Focus groups

Staff training:

- Mainly confirmation
- Learned (how) to ask clients more questions
- Little about application into daily practice
- Future: own case studies, coaching-on-the-job

‘To me it was more a confirmation. What was said in the training, yes, that is how we work as well’.

‘Shadow me for a day, a couple of hours, and observe how I am doing within my group home’.

Results – Focus groups

Afterwards:

- No new agreements in teams
- Changes in attitude, awareness, and method of working

I now focus more on client's possibilities to develop.

I tend to take things over a lot from clients, but I am now more aware that I should do that less frequently.

Conclusion

Staff training:

- No effect on support needs and behaviour of people with ID
- Small effect on independence/self-reliance of people with ID
- Afterwards, trained staff members experienced changes in attitude/awareness/method of working

More attention is needed for:

- Application to daily practice
- Implementation
- Coaching-on-the-job

Conclusion

Limitations:

- Small sample size
- Inadequate questionnaires
- Only 6-M follow up: people with ID need more time
- Non-random allocation, no matching of participants

Future research:

- How can self-management in people with ID be promoted more effectively?
- Carefully consider the content, format, implementation, application of interventions

Our next study...

Academy of Independence (avZ)⁸

- Goal-directed self-management training for people with ID
- Self selected goals for daily life and work
- Tailored to individual
- Every week, guided by trainers
- Effectiveness
 - Independence and self-reliance
 - Support needs
 - Behaviour
 - Quality of life
 - Self-worth

⁸ www.zelfstandigzijn.nl



Amelrijk krijgt breder contact met eigen appartement. Op de zolder is een zelfstandig huistje met een kleine woonkamer. Daarheen kan de bewoner van de zolder, Peter van Tol, zijn eigen huis terugkijken. Dit huistje is bedoeld voor mensen met een beperking die zelfstandig wonen wil. Het huistje is bedoeld voor mensen met een beperking die zelfstandig wonen wil. Het huistje is bedoeld voor mensen met een beperking die zelfstandig wonen wil.

'Talenten naar boven halen'

Wetenschappelijk onderzoek
Het onderzoek van Tol en zijn collega's is gericht op het verbeteren van de zelfstandigheid van mensen met een beperking. Het onderzoek is gericht op het verbeteren van de zelfstandigheid van mensen met een beperking. Het onderzoek is gericht op het verbeteren van de zelfstandigheid van mensen met een beperking.

Leidsch Dagblad 21-01-2016

Thank you for your attention

Health, Medical and Neuropsychology Unit, Leiden University:

dr. Aglaia Zedlitz
dr. Winifred Gebhardt
prof. dr. Andrea Evers

Clinical Child and Adolescent Studies, Leiden University:

dr. Joop Hoekman

Methodology and Statistics Unit, Leiden University:

dr. Elise Dusseldorp

Raamwerk:

Jeanet den Haan



**Universiteit
Leiden**
The Netherlands

Raamwerk



Questions?

