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

Janice Sandjojo
People with intellectual disabilities (ID)

DSM-V$^1$

- 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.

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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 ID
- Corresponding rising costs

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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) training
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

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Methods - Participants

Raamwerk, Noordwijkerhout

- Green: Staff was trained
- Blue: Staff was not trained

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 ± 61)
Comorbid psychiatric disorders
Methods - Measurements

Questionnaires, filled in by support staff/psychologist
- Social Functioning Scale for the Mentally Retarded\(^4\)
- Support Intensity Scale\(^5\)
- Developmental Behaviour Checklist\(^6\)

Focus groups, with trained staff members (n = 13)
- To evaluate the training
- To study whether they noticed any changes past half year

<table>
<thead>
<tr>
<th>Staff training</th>
<th>Focus groups</th>
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<tbody>
<tr>
<td>0 months</td>
<td>3 months</td>
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<tr>
<td>Questionnaires T0</td>
<td>Questionnaires T1</td>
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<tr>
<td>6 months</td>
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<td>Questionnaires T2</td>
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Results

<table>
<thead>
<tr>
<th></th>
<th>Intervention group</th>
<th>Comparison group</th>
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<tbody>
<tr>
<td></td>
<td>T0 (n = 15)</td>
<td>T0 (n = 11)</td>
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<tr>
<td></td>
<td>T1 (n = 15)</td>
<td>T1 (n = 11)</td>
</tr>
<tr>
<td></td>
<td>T2 (n = 12)</td>
<td>T2 (n = 11)</td>
</tr>
<tr>
<td>SFSMR⁴, M (SD)</td>
<td>105.7 (11.6)</td>
<td>112.1 (9.9)</td>
</tr>
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<td></td>
<td>109.1 (9.3)</td>
<td>111.9 (11.1)</td>
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<tr>
<td></td>
<td>108.5 (10.1)</td>
<td>111.0 (11.9)</td>
</tr>
<tr>
<td>SIS⁵ Section 1+2, M (SD)</td>
<td>284.9 (82.9)</td>
<td>291.9 (95.2)</td>
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<td>295.2 (63.8)</td>
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<td></td>
<td>303.7 (96.7)</td>
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<tr>
<td>DBC⁶, M (SD)</td>
<td>33.2 (15.6)</td>
<td>33.3 (27.0)</td>
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<td></td>
<td>34.3 (9.5)</td>
<td>35.9 (27.4)</td>
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<tr>
<td></td>
<td>33.0 (11.8)</td>
<td>36.8 (24.0)</td>
</tr>
</tbody>
</table>

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 Retarded\textsuperscript{4}

\begin{figure}
\centering
\includegraphics[width=\textwidth]{social_functioning_scale}
\caption{Comparison and intervention groups over time.}
\end{figure}

Results – Need for support

Support Intensity Scale\(^5\) (SIS)

![Bar chart showing Support Intensity Scale comparison between 0 months and 6 months for Comparison and Intervention groups.]

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Results – Behavioural problems

Developmental Behaviour Checklist\(^6\) (DBC)

![Bar chart showing comparison between comparison and intervention groups at 0, 3, and 6 months.]

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

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Thank you for your attention

Health, Medical and Neuropsychology Unit, Leiden University:
dr. Aglaia Zedlitz
dr. Winifred Gebhardt
prof. dr. Andrea Evers

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dr. Joop Hoekman

Methodology and Statistics Unit, Leiden University:
dr. Elise Dusseldorp

Raamwerk:
Jeanet den Haan
Questions?

j.sandjojo@fsw.leidenuniv.nl