Hidden Treasures

Results of a preliminary study

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Meet the team

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Hidden Treasures

Target group
Adults (aged 18+) with a visual impairment and additional disabilities:
• mainly psychiatric impairments (e.g. autism, personality disorders, depression), but also:
• intellectual disabilities (ID)
• physical disabilities (e.g. motor impairments)
• cognitive impairments (e.g. acquired brain injury, dementia)
Hidden Treasures

Three components

1. **Retrieving data** regarding target group (e.g. number of persons and type of additional disabilities)

2. **Scoping review** of available literature about the target group

3. **Interviews** with clients of the target group and professionals supporting them
1) Retrieving data

- Current data based on estimates
- No systematic records available

→ Approaching 18 public institutions and organisations in the Netherlands
→ Survey among 621 care organisations for persons with mental disorders (via GGZ NL), with learning disabilities (via VGN) and among nursing homes (via Actiz)
First indications

• Institutions/organisations could not provide aggregated data on the target group
  • Within RCS: 256 clients with visual impairments and additional disabilities

• Survey response
  • Raw data: 22% (136 completed survey forms)
  • Corrected data: 15% (93 different organisations completed the survey)
Survey results

80.7% of organisations supported clients with visual impairments*
86.7% of those clients had additional disabilities

<table>
<thead>
<tr>
<th>Type of additional disabilities</th>
<th>Percentages (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Psychiatric</td>
<td>51</td>
</tr>
<tr>
<td>Physical</td>
<td>70</td>
</tr>
<tr>
<td>Cognitive</td>
<td>62</td>
</tr>
<tr>
<td>Intellectual</td>
<td>43</td>
</tr>
<tr>
<td>Other</td>
<td>14</td>
</tr>
<tr>
<td>I don know</td>
<td>5</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Number of additional disabilities</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>18</td>
</tr>
<tr>
<td>2</td>
<td>37</td>
</tr>
<tr>
<td>3</td>
<td>26</td>
</tr>
<tr>
<td>4</td>
<td>16</td>
</tr>
<tr>
<td>5</td>
<td>3</td>
</tr>
</tbody>
</table>

*The survey was mainly completed by organisations that supported clients with visual impairments.
2) Scoping review

Literature search in:
- PubMed
- CINAHL
- PsychINFO

→ Based on broad search strategy with different categories representing the type of disability (e.g. visual, psychiatric, intellectual/cognitive, physical/somatic, comorbidity)
Flow chart

1. Search result PubMed, CINAHL, PsycINFO
   N=4024, N=1065, N=1646

2. Total search result
   N=6735

3. Doubles, published before 1990
   N=2129, N=1066

4. Number of scored articles
   N=3540

5. Non relevant based on title, abstract
   N=2444, N=469

6. Total number of reviewed articles
   N=631

7. Category 1 articles (met target group criterium)
   N=448

8. Lancioni et al.
   N=50

9. Category 2 articles (met target group + subject criteria)
   N=183

10. Not English- or Dutch (N=2), age < 17 years (N=17), no visual or additional disability (N=9), medical interventions (N=17), doubles (N=3) other (N=15)

11. Intervention description, implications for practice
    N=40, N=30
## Results category 1 and Lancioni

### Category 1 articles (n=448)

<table>
<thead>
<tr>
<th>Category</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Incidence, prevalence</td>
<td>6%</td>
</tr>
<tr>
<td>Association</td>
<td>47%</td>
</tr>
<tr>
<td>Etiology</td>
<td>18%</td>
</tr>
<tr>
<td>Diagnosis, assessment</td>
<td>14%</td>
</tr>
<tr>
<td>Case report</td>
<td>11%</td>
</tr>
<tr>
<td>Other</td>
<td>5%</td>
</tr>
</tbody>
</table>

### Articles by Lancioni et al. (n=50)

<table>
<thead>
<tr>
<th>Technology</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Orientation/indoor travel technology systems</td>
<td>54%</td>
</tr>
<tr>
<td>Robot/technologies to improve mobility and performance of simple activities</td>
<td>10%</td>
</tr>
<tr>
<td>Technologies for telephone use (messages, calls)</td>
<td>10%</td>
</tr>
<tr>
<td>Instruction systems to support activity performance</td>
<td>8%</td>
</tr>
<tr>
<td>Choice stimulation technologies</td>
<td>6%</td>
</tr>
<tr>
<td>Other (e.g. technology concerning urinary accidents, speech generation, head positions, independent dressing and physical activity)</td>
<td>12%</td>
</tr>
</tbody>
</table>
Results category 2

Interventions or articles with implications mainly covers subjects such as:

• Deaf-blindness and communication
• Visual impairments and depression/anxiety
• Severe intellectual disabilities in visually impaired persons (interaction)
• Complex multiple additional disabilities (case studies)
• Least represented: visual impairments combined with psychiatric disorders
3) Interviews

Main question: which knowledge is necessary to provide good support to adults with visual and psychiatric (or other) impairments?

<table>
<thead>
<tr>
<th>Clients</th>
<th>n=10</th>
<th>Professionals</th>
<th>n=29</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean age (SD)</td>
<td>48.5 (14.1)</td>
<td>Mean age (SD)</td>
<td>45.5 (12.2)</td>
</tr>
<tr>
<td>Gender (m/f)</td>
<td>4/6</td>
<td>Gender (m/f)</td>
<td>5/24</td>
</tr>
<tr>
<td>Mean number of years in visual care sector (SD)</td>
<td>9.4 (7.3)</td>
<td>Mean work experience in years (SD)</td>
<td>12.9 (10.2)</td>
</tr>
<tr>
<td>Functions:</td>
<td></td>
<td>Functions:</td>
<td></td>
</tr>
<tr>
<td>Support staff (outreaching, day care centre or residential)</td>
<td>7</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Care coordinator</td>
<td>4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Behavioural scientist</td>
<td>10</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Management</td>
<td>5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>3</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Your experiences

- What are your experiences regarding the provision of support to adults with visual impairments in combination with psychiatric (or other) impairments?
Your experiences

• What are your experiences regarding the provision of support to adults with visual impairments in combination with psychiatric (or other) impairments?

• Which challenges did you already encounter or do you foresee in the support of this target group?
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• Which methods or approaches are effective in the support of this target group?
Your experiences

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• Which challenges did you already encounter or do you foresee in the support of this target group?

• Which methods or approaches are effective in the support of this target group?

• Does this target group favour specific personal approaches?
Themes of interest

Clients
- Trust
- Self-management
- Sincerity
- Creativity
- Sociability
- Continuity
- Collaboration
- Valued and equal

Professionals
- Trust
- Move along with client
- Professional knowledge
- Individuality
- Facilitating organisation
- Collaboration
- Multi-methodical approach
Trust

Character
- Intent
  - Caring
  - Transparency
  - Openness
- Integrity
  - Honesty
  - Fairness
  - Authenticity

Competence
- Capability
  - Skills
  - Knowledge
  - Experience
- Results
  - Reputation
  - Credibility
  - Performance
Challenges

Clients
- Relationship with professionals
- Basic knowledge vs. specific knowledge
- Group process
- Separation of work and private life

Professionals
- Fundamental approach
- Knowledge gaps
- Support self-management
- Policy frameworks
Self-management

Self-determination
Autonomy

Self-Determination Theory

Competence
- need to be effective in dealing with environment

Humans' three basic needs

Relatedness
- need to have a close, affectionate relationships with others

Autonomy
- need to control the course of their lives
Self-management

Self-determination
Autonomy

VS.

Professional responsibility
Self-management

Self-determination
Autonomy

VS.

Professional
responsibility

Case studies & discussion
CASE A

- Women, 39 years old
- Blind, only light perception
- Physical conditions (Spina Bifida, obesity)
- Intelligence is below average, but verbally strong
- Traumatic past, probably PTSS
- Social-emotional age between 3 -7
- Attachment problems

DILEMMA: Professional responsibility vs client autonomy
CASE B

- Man, 29 years old,
- Partially sighted
- Below average intelligence
- Gypsy culture
- Limited family contact, no contact with direct family
- Family: Girlfriend is mentally disabled, one son
- Traumatic past
- Unable to deal with emotions
- Survived cancer, now chemo free
- Somatic problems

DILEMMA: Currently debt restructuring. Client lies in court. Moral codes of social workers vs client autonomy
Any questions?

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