Organisational perspectives on community participation for people with intellectual disabilities

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Liveable disabilities – across time


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Four Research Themes
1. Health and well-being
2. Education and work
3. Partner relationship and family
4. Other opportunity structures (leisure, sports, culture, Internet)

EXPERIENCES OF DISABILITIES BOTH BY NUMBERS AND NARRATIVES
• Statistical life course analyses and interviews
• (Non-)Mainstream views & voices, off- and online (mass media, films/TV serials, online communities)
• Opportunities to health, education, work, partner, family & thru leisure structures
The cross-disciplinary DISLIFE team

- Professor Lotta Vikström: History
- Dr. Karin Ljuslander: Cultural Studies
- Dr. Josefine Wåltaara: Cinema Studies
- Professor Nawi Ng: Epidemiology
- Dr. Jens Insland: Social Work
- Dr. Céspedes Cocq: Folklore & Sámi Studies
- Dr. Erling Häggström: Statistics
- Dr. Mikael Stattin: Sociology
- Dr. Daniel Larsson: Sociology
- Dr. Glenn Sandström: History
- Dr. Fredinah Namatevu: Epidemiology
- Dr. Kim Wickman: Special Education
- Christine Bylund: Ethnology

[http://www.idesam.umu.se/english/research/research-projects/dislife/?languageId=1]
A comparative research project on policy, leadership and direct care work with clients with intellectual disabilities in schools, social services and healthcare in Sweden
Methods and data collection

• Digital web-based questionnaire (Google Drive) to human service professionals working with people with intellectual disabilities in Sweden
  • Schools, Social Services and Healthcare
  • Standardized and open-ended questions

<table>
<thead>
<tr>
<th></th>
<th>School</th>
<th>Social services</th>
<th>Healthcare</th>
</tr>
</thead>
<tbody>
<tr>
<td>Staff, response rate (n =)</td>
<td>68 %</td>
<td>73 %</td>
<td>69 %</td>
</tr>
<tr>
<td>168</td>
<td>152</td>
<td>101</td>
<td></td>
</tr>
<tr>
<td>Leaders (response rate)</td>
<td>47 %</td>
<td>46 %</td>
<td>–</td>
</tr>
<tr>
<td>(n =)</td>
<td>21</td>
<td>24</td>
<td>21</td>
</tr>
</tbody>
</table>

• Analysis
  SPSS – means, medians, ratio, and standard deviation
  Calculating frequencies and percentages
  Thematic Content Analysis
What´s been done so far?


Work in progress... (late 2017 – 2018)

• **Support staff**
  • Challenging work situations
  • Positive and negative work experiences
  • Methods and methodology
  • Understanding the impact of institutions and organizational context

• **Managers, leadership**
  • Norms and values? Definitions and follow up strategies.
  • What is competence in services for people with intellectual disabilities?
  • What is success and good performances in services for people with intellectual disabilities?
  • Organizational risks and strategies.
  • Experiences of inter-professional collaboration
Why organisational perspectives?

- Scandinavian disability research linked to welfare state interventions, obtained its legitimacy from evaluations of social reforms – often described as evaluative and non-theoretical
  - Institutional and organisational analysis is still scarce
- Welfare organisations operate within different regulative frameworks and thus have their own specific rule- and norm systems. Organisational context needs to be acknowledged
- Organisational context an important analytical theme, not at least because context—structure, culture, norms and values—frames and influence the way organisational actors act, think and behave
  - Much miss-directed critique towards professionals (behaviour, power, knowledge, ethical awareness, collaboration, etc.)
  - Neglecting context: risk consolidating existing institutional orders, reproducing asymmetric power relations, reduce individual influence and participation
Institutions
- Regulative
- Normative
- Cognitive

Socialization
World taken for granted

Information

Implications
- Professional responsibility
- Inter professional collaboration
- Ethical awareness

Actors
- Preferences
- Knowledge
- Values

Actions
Example 1: Difficult work situations

- When the clients’ needs are in the grey zone and the law does not cover up (Social services- STRUCTURE)
- It is often about how motivated the clients and the parents are. Difficulties in motivating when the individual is not interested in change. The (habilitation) team usually helps with new ways of approaching... (Healthcare- RELATIONSHIPS)

<table>
<thead>
<tr>
<th>Themes</th>
<th>Social services</th>
<th>Healthcare</th>
<th>Total</th>
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</thead>
<tbody>
<tr>
<td>Difficulties associated with</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Structure</td>
<td>24</td>
<td>7</td>
<td>17</td>
</tr>
<tr>
<td>Professional role</td>
<td>26</td>
<td>30</td>
<td>28</td>
</tr>
<tr>
<td>Relationships</td>
<td>28</td>
<td>46</td>
<td>35</td>
</tr>
<tr>
<td>Collaboration</td>
<td>22</td>
<td>17</td>
<td>20</td>
</tr>
</tbody>
</table>
Example 2: Job satisfaction

Aim: analyze how sources of job satisfaction was articulated by human service professionals in Sweden

<table>
<thead>
<tr>
<th>Target Group</th>
<th>Social Rewards</th>
<th>Social Relations</th>
<th>Professional Core Mission</th>
<th>Results and Outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social services</td>
<td>29</td>
<td>16</td>
<td>11</td>
<td>35</td>
</tr>
<tr>
<td>Schools</td>
<td>19</td>
<td>26</td>
<td>10</td>
<td>24</td>
</tr>
<tr>
<td>Health Care</td>
<td>18</td>
<td>21</td>
<td>18</td>
<td>29</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>21</strong></td>
<td><strong>22</strong></td>
<td><strong>12</strong></td>
<td><strong>28</strong></td>
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Example 3: Inclusive education

- An hybridized welfare environment
  - Operate in the border area between different institutional (school-) contexts
  - Incorporate what is viewed as unusual or different (ID) into more ordinary practices
  - Need to relate aims, ambitions, and activities to a broader variety of expectations

Conclusion

- Ambivalence as to when, how, and with what potential consequences students with intellectual disabilities should be included in the school environment.
- Inclusion was social constructed as a high-risk activity for students with intellectual disabilities.
Example 4: cultural activities

- Disability arts in Sweden has been more or less incorporated into the formal structure of welfare services
  - Less associated with radical political initiatives and emancipatory prerequisites as in other countries

Conclusion:

**Artistic logic**
emphasizes identity formation and the cultural/creative dimensions of daily practice

*Cultural activities as a goal in itself*

**Therapeutic logic**
builds on organizational belonging and welfare state responsibility

*Cultural activities as method*
Why organisational analaysis?

• Opens up for critical research on how institutions influence professional behaviors, standards, and attitudes which guide them in their work with people with intellectual disabilities

• Support analyses of how, when, and with what social consequences “taken-for-granted” ideas and logics are negotiated in face-to-face interactions with people with intellectual disabilities

• Helps to understand the dilemma between conformity and individual authority in service provision; between the normative basis for is understood as normal, appropriate and legitimate at any given time (organizational perspective) and individual freedom to form their own identities and life projects (individual perspective)

• Raises ethical concerns; to what extent must people with intellectual disabilities adjust to norms- and rule systems in different welfare organisation?
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