

Organisational perspectives on community participation for people with intellectual disabilities

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Liveable disabilities – across time

Pre-welfare society (c. 1800-1930) | Welfare society (c. 1930-1990) | Post-welfare society (c. 1990-2020)



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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



Organization and intellectual disability



Postdoc position. Dept of Education
Umeå University, Sweden

2014-2018

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*

	School	Social services	Healthcare
Staff, response rate (n =)	68 % 168	73 % 152	69 % 101
Leaders (response rate) (n =)	47 % 21	46 % 24	– 21

- **Analysis**

SPSS – means, medians, ratio, and standard deviation
Calculating frequencies and percentages
Thematic Content Analysis



What's been done so far?

- Ineland, J., Molin, M., & Sauer, L. (2017). Handling Plurality and Dealing with Difficult Work Experiences. A Comparative Study of Human Service Professionals' Work with Individuals with Intellectual Disabilities *Journal of Policy and Practice in Intellectual Disabilities*. doi:10.1111/jppi.12227
- Ineland, J., & Hjelte, J. (2017). Knowing, being or doing? A comparative study on human service professionals' perceptions of quality in day-to-day encounters with clients with intellectual disabilities. *Journal of Intellectual Disabilities*. doi:10.1177/ 1744629517694705
- Ineland, J., Sauer, L. & Molin, M. (2017). Sources of job satisfaction in intellectual disability services: a comparative analysis of experiences among human service professionals in schools, social services, and public health care in Sweden. *Journal of Intellectual & Developmental disabilities*. <http://dx.doi.org/10.3109/13668250.2017.1310817>
- Ineland, J. & Silfver, E. (2017). Assing and grading students with intellectual disabilities. Attitudes and experiences from teachers' perspective. *Pedagogisk forskning i Sverige*. [In press]
- Ineland J (2016) Hybrid structures and cultural diversity in welfare services for people with intellectual disabilities. The case of inclusive education and disability arts in Sweden. *ALTER, European Journal of Disability Research*. [http://dx.doi.org/ 10.1016/j.alter. 2016.06.002](http://dx.doi.org/10.1016/j.alter.2016.06.002)

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

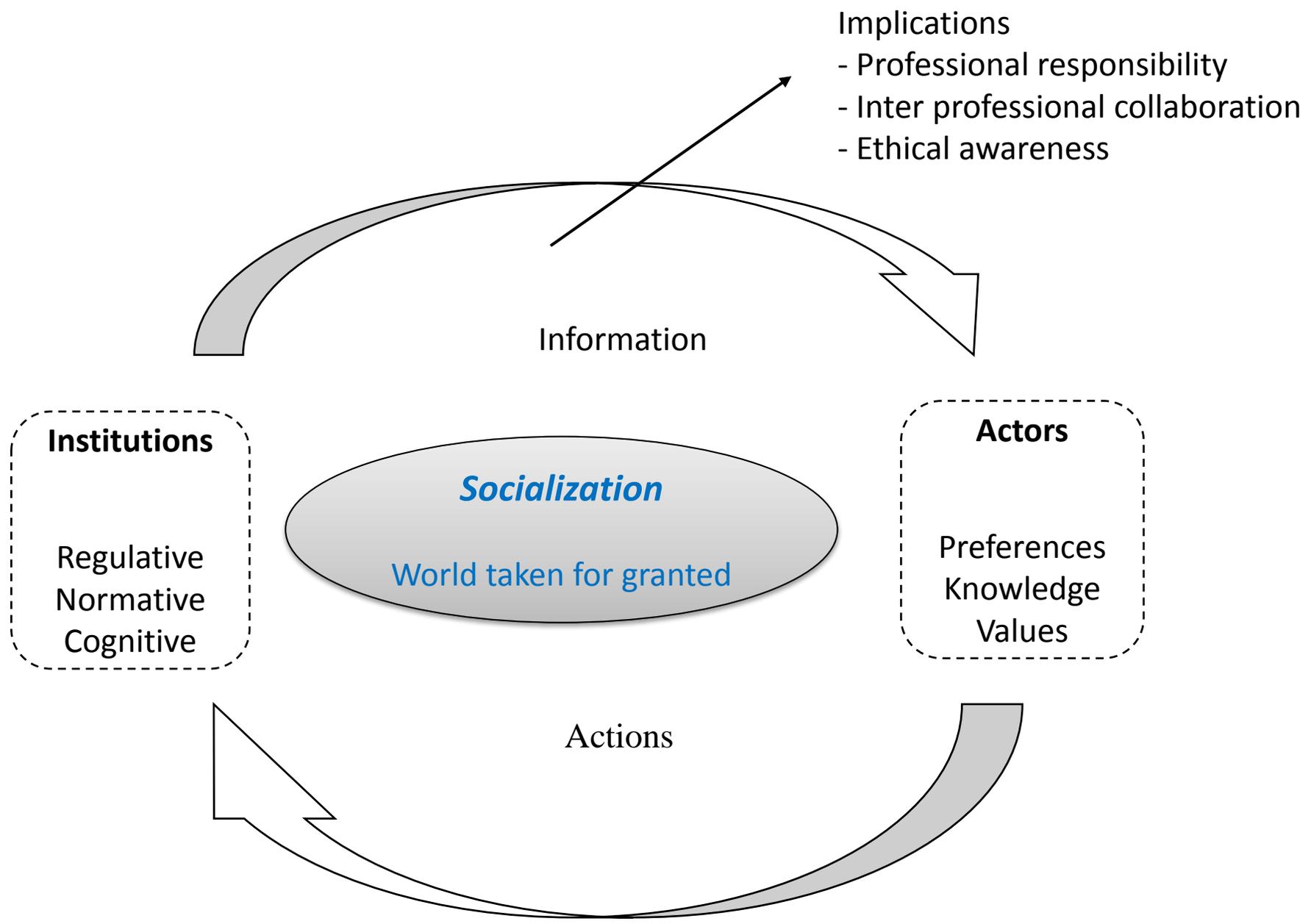
- **Managers, leadership**

- 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*



Example 1: Difficult work situations

<i>Themes</i>	Social services	Healthcare	Total
Difficulties associated with			
Structure	24	7	17
Professional role	26	30	28
Relationships	28	46	35
Collaboration	22	17	20

- *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)*



Example 2: Job satisfaction

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

	Target Group	Social Rewards	Social Relations	Professional Core Mission	Results and Outcomes
Social services	29	16	11	35	9
Schools	19	26	10	24	21
Health Care	18	21	18	29	14
Total	21	22	12	28	17



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

Social logic

Formal/ideological in character, closely linked associated with ideological ideal such as normality, equality and inclusion

Inclusive Education

Educational logic

If not informal, vague and pragmatic, where differentiation and disability were core concepts

- 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 analysis?

- 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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