

**Self-determination of people with
disabilities in institutions – problem
or challenge?**

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Schedule

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- Objective of this workshop
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 - **Discussion**
- Arguments in favour of deinstitutionalisation
 - **Discussion**
- Possible ways towards deinstitutionalisation
 - **Discussion**
- A possible scheme for implementation

Info-Handicap

- Non profit organisation created in 1993
- Contract with the Ministry for Family and Integration for running a “national disability information and meeting centre”
- 8 staff members having full or part time contracts = in total 5,4 funded salaries (1 educator, 2 social pedagogues, 2 social workers, 1 teacher, 2 secretaries)

You (in 3 sentences)

- My name is ...
- I come from
- My professional activity ...

Objective of this workshop

→ This workshop aims at **sharing practical experience** and at **identifying possible answers to the question:**

- **Does the United Nations' Convention on the Rights of Persons with Disabilities impact on the daily work of social pedagogues in their professional context?**
- **Is it possible to conciliate the internal rules of service providers and the right to self-determination of people with disabilities?**

Reference documents

- **Convention on the Rights of Persons with Disabilities**
→ <http://www.un.org/disabilities/convention/conventionfull.shtml>
- **Common European Guidelines on the Transition from Institutional to Community-based Care**
© European Expert Group on the Transition from Institutional to Community-based Care, November 2012
→ <http://deinstitutionalisationguide.eu>

Working context Info-Handicap

- Our main missions include information, awareness raising and training
- Our orientation work and advice is based on human rights and empowerment of the users
- Our aim is to allow a maximum of autonomy and self-determination
- Our clients expect us to provide them with concrete solutions that work in practice and within the short term
- Our clients are not always able or prepared to take initiative in case of inappropriate treatment. Sometimes difficulties may be a result of their own (non)initiative.
- Many clients ask for assistance from “official parties” rather than trying to take initiatives on their own.

Info-Handicap and our clients

Some arguments used by people with disabilities:

- *Too much public money is spent in favour of institutions and thus is not available for setting up policies towards self-determination*
- *Professionals earn their money because of disabled people's needs, but their services are organised with respect to the professionals' rules and not with respect to the users' expectations*
- *Users know better about their needs and the way of their satisfaction, than professionals do*

Info-Handicap and institutions

- Some of our 54 member organisations are managers of residential institutions and others are users organisations. Our challenge is to **conciliate a consequent and honest commitment to human rights with a fair negotiation process with service providers.**
- In general, the staff of institutions does a professional and engaged job. **Our challenge is to make clear that the focus of our actions points to the "system" and not to the staff.**
- For the time being, **the full range of non-institutional services needed for covering all kinds of needs is not guaranteed** in Luxembourg and **our challenge is to identify acceptable compromise** on the way to final solutions.

UN Convention article 19

Living independently and being included in the community

*States Parties to the present Convention recognise the **equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:***

- a) Persons with disabilities have the **opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;***
- b) Persons with disabilities have **access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community; and***
- c) **Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.***

National CRPD Action Plan

- In July 2011 Luxembourg ratified the CRPD
- In March 2012 the Luxembourgish Government published a national action plan for the implementation of the CRPD
- The action plan does not include a specific chapter about institutions, however the right for autonomy and self-determination is repeatedly pointed out throughout the 11 chapters of the document.
→ **Info-Handicap, as many other organisations, is strongly committed to the action plan and its implementation.**

UN Convention(s) in your professional contexts

Questions:

- Do you know if UN Convention(s) have been ratified in your countries?
- Are there national action plans on the implementation of such Conventions?
- Do Conventions or national action plans impact on your daily work?

Arguments in favour of deinstitutionalisation

- *More than one million children and adults live in institutions across Europe*
- *Institutions were once seen as the best way of caring for vulnerable children, children at risk and adults with a variety of support needs*
- **However, evidence has shown that institutional care invariably provides poorer outcomes in terms of quality of life than quality services in the community...**

Quotations **for discussion**

WHAT IS "AN INSTITUTION"?

- residents are isolated from the broader community and/or compelled to live together;
- **True or false? What do you think?**
- residents do not have sufficient control over their lives and over decisions which affect them; and
- **True or false? What do you think?**
- the requirements of the organisation itself tend to take precedence over the residents' individual need
- **True or false? What do you think?**

Possible ways towards deinstitutionalisation

- Many countries have embarked on the process of transforming the way they provide care and support to children and adults by **replacing some or all long-stay residential institutions with family and community-based services.**
- A key challenge is ensuring that the process of **deinstitutionalisation** itself is carried out in a way that
 - respects the rights of the user groups,
 - minimises risk of harm and
 - ensures positive outcomes for all individuals involved.
- The process needs to ensure that the **new systems of care and support** respect the rights, dignity, needs and wishes of each individual and their family.

Suggested solutions **for discussion**

Key lessons that have emerged over the years include:

- the importance of a vision;
- **Who should develop the vision or contribute to?**
- the need to engage with civil society;
- **How can that happen?**
- the need to bring all the stakeholders on board; and
- **Who are the possible stakeholders?**
- the crucial role of leadership in driving this process.
- **How can the leadership be promoted?**

A possible scheme for implementation:

Interdependent success factors:

1. Commitment of decision makers
2. Coordination
3. Networking
4. Action plan
5. Knowledge management
6. Optimising resources
7. Marketing and communication