Would you call this 'home'?
What is De-Institutionalisation (DI)-
From institutional to community-based care

EASPD
IMPROVING SERVICES
IMPROVING LIVES

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What is EASPD?

1. European NGO in the disability sector

2. It represents over 12,000 social service provider organizations across the EU

3. Based in Brussels

4. Established in 1996

5. EASPD plays a key role on the European level as the representative of disability service providers

6. Objective: Promote equal opportunities for persons with disabilities through effective and high quality service systems in Europe

What is EASPD?

Key activities:

- Implementation of the UN CRPD

- 3 pillars: Innovation, Impact & Information

- 3 key areas: employment, education and independent living

- EASPD is part of the European Expert Group on DI and CBC

European Expert Group (EEG)

- Ad Hoc Expert Group convened in 2009 by the then European Commissioner for Employment and Social Affairs Vladimir Špidla

- Broad coalition gathering stakeholders representing people with care or support needs

- Mission: the promotion of person-centred, quality and empowering models of services and formal and informal care that fully respect the human rights of all people with care or support needs

- Provides expert support on EU policy, legislation and funding

EUROPEAN EXPERT GROUP ON TRANSITION FROM INSTITUTIONAL TO COMMUNITY-BASED CARE

Outline

I. Challenges

II. Towards Community Living

III. Risks and Opportunities

IV. Conclusions

A Changing Society

➢ Shift in paradigm with regard to persons with disabilities

➢ Demographic change

➢ Economic change

➢ Knowledge society and ICT

The policy and legal case for DI

International and European policy and legal framework

- UN Convention on the Rights of the Persons with Disabilities (Art 19)
- European Disability Strategy (2010-2020)
- UN Convention on the Rights of the Child (Art. 7; 9; 19; 23; 24; 28)
- Agenda for the rights of the child (2011)
- European Convention on Human Rights (Art. 3; 8)
- EU Charter of Fundamental Rights
- Europe 2020
- UN Principles for Older Persons (Art. 3; 8)
- Madrid Action plan on Aging

De-Institutionalisation

There is an urgent need for the development of community based and person centred services across Europe in 3 areas of life: **Education**, **Employment** and **Day to day support**.

Key issues:

➢ Training and retraining of staff

➢ Twin-track approach (DI & CBC)

➢ Development of community-based services

➢ Development of person-centred support

Differences in the 'cultures'

Institutional care	Community care (CBS)
➢ Isolation from broader community	➢ Inclusion in the community
➢ Clients have not sufficient control over their life	➢ Involvements of the clients in all decisions concerning their lives
➢ Paternalistic relationship	➢ Partnership
➢ Routine	➢ Flexibility
➢ Block treatment	➢ Individual approach
➢ Rules of the institution are more important than the needs of the clients	➢ Client at the centre

Risky scenarios of the transition process

➢ Over-investment in current institutions

➢ Maintaining parallel services

➢ Alternatives with institutional culture

➢ Closure of institutions without community alternatives

Challenges for the sector

Staff

First line workers in the social sector are mainly female (up to 95 %)

Key issues:

- ➢ Few career opportunities

- ➢ Low wages

- ➢ Few LLL opportunities: investment in human capital

- ➢ Needs for retraining due to paradigm shift: adaptability of workers

Availability of Services

Availability of a services spectrum and free choice for families are crucial for the well-being of persons with disabilities. Innovation in social service provision could contribute to sustainable solutions.

Key issues:

- ➢ Capacity building
- ➢ Development of assessment tools
- ➢ Funding
- ➢ New types of services: call centres, distant support, respite care, etc.

Stakeholder and Mainstream Cooperation

All stakeholders have to contribute to the development of efficient and cost effective service systems.

Today's society is complex. Only through well-organised cooperation and shared responsibility, effective and efficient policy developments and implementation is possible.

Key issues:

➢ Identification of stakeholders (users must be included)

➢ Agreement on different roles and responsibilities

➢ Development of tools and instruments facilitating cooperation

➢ Funding of stakeholder cooperation

1. The Frog Phenomenon

So, needed is:

- ➤ Focus on needs and needs assessment
- ➤ Developing and showing alternatives (availability)
- ➤ Explaining the importance of the change in paradigm
- ➤ Training change management
- ➤ Training new skills for first line staff
- ➤ Identify bottlenecks in legislation and underlying frameworks
- ➤ Alternative employment opportunities for staff

2. Family Support

So, needed is:

➢ Socio-economic support mechanism for poor families

➢ Communication support

➢ Recognition of different roles: parents/brothers, sisters

3. Service Spectrum

So, needed is:

➢ Available information services

➢ Aware and trained staff in maternity hospitals

➢ Early intervention and ambulant services

➢ Personal assistants in day care and schools

➢ Respite care services and temporary care

➢ Family support combined with support for persons with disabilities

➢ Focus on transition in life stages

➢ Available support in mainstream education and health care

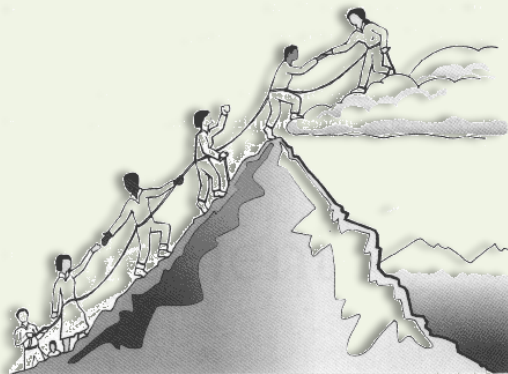*The end of the total "institutions" means more flexible solutions*

4. Develop Partnerships

So, needed is:

- ➢ Invest in stakeholder cooperation and involvement of people with disabilities
- ➢ Recognition of different roles
- ➢ Commitment of all partners
- ➢ Mainstreaming

5. Cut the Supply Line

So, needed is:

- ➢ Flexible time frames for services (pre-school programs)
- ➢ Identify the number of persons living in the institutions
- ➢ Stop investment in the buildings
- ➢ Agreed plans for breakdown
- ➢ Legal 'stop'

6. Install Snowball Mechanism

So, needed is:

➢ Structural involvement of persons with disabilities

➢ Identify perverting effects of not specific legislation

➢ Include quality of life in quality of services instruments

Risks

- Invest in alternatives that are "institutional"

- Bureacracy

- Privitasation and over-commercialisation

- Economic crises and collapse of care system

Opportunities

- ✓ Availability of ESIF funds from the European Commission

- ✓ Commitment and support of the European Commission

- ✓ Existing reform processes in EU Member States are an opportunity for shared learning

- ✓ Ratification of the CRPD by the EU and 26 EU Member States – opportunity for synergies and harmonized implementation

If you fail to plan, you plan to fail

So needed is:

- ✓ (Re)confirmation of the policy objectives
- ✓ Feasible Action plans
- ✓ Overlap of systems
- ✓ Clearly allocated budget
- ✓ Monitoring and Quality Assurance Systems
- ✓ Investment in training
- ✓ Pre-conditions for Quality
- ✓ Leadership

How to move forward

So needed is:

✓ Use EU funds as bridging funds

✓ Implement recommendation by international human rights treaties

✓ Use the Toolkit and the Guidelines of the European Expert Group:
http://deinstitutionalisationguide.eu/

Any questions?

Thank You!

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