Deinstitutionalization as necessary condittion for quality of services for people wit disability

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UN Relevant documents

- Convention on the Rights of Persons with Disabilities
- Declaration on the Rights of Disabled Persons
- Standards Rules on the Equalization of Opportunities for Persons with Disabilities
- Declaration on the Rights of Mentally Retarded Persons
- Convention on the Rights of the Child
- Guidelines for the Alternative Care of Children
- UN Principles fro Older Persons
- CM/Rec(2010)on deinstitutionalization and community living of children with disabilities

Article 19 UN CRD

Living independently and being included in the community

- live in the community- with needed assistance
- full inclusion and participation – accessibility of the services for general public
- choices equal to others:
  - with whom to live
  - where to live

Guiding principles concerning care

- Respect for inherent dignity
- Individual autonomy
- Equality of opportunity
- Non-discrimination
- Full effective participation and inclusion in society
- Accessibility
- Equality between men and women
- Rights of children preserved their identity

Differences in the “cultures”

In Institutional care

- Isolation from broader community
- Clients have not sufficient control over their live
- Paternalistic relationship
- Rigidity of routine
- Block treatment
- Rules of the institution are more important the needs of the clients

In Community care

- Inclusion to the community
- Involvements of the clients to all decisions
- Partnership
- Flexibility
- Individual approach
- Client in the centre

I. Case study: Jana
CR 1986

- Jana had first episode of schizoaffective psychoses when 19th old.
- Become pregnant when she was 23 years
- After delivery Jana admitted to ps. hospital , baby to baby home.
- Baby put to an adoption when 1year old.
- Jana had many admission to ps. Hospital after that.
- Put on full guardianship when she was 30 years , admitted for “permanent” stay to specialized social care home.

II. Case study : Lisa UK 2006 /slide 1./

- Lisa had first episode schizoaffective psychoses when 20 years old.
- Had three children, all in foster care of her mother and sister.
- Several readmission to psychiatric unit.
- Poor cooperation with usual community services.
- 2006 referred to Assertive Outreach Team / AOT/
- When Lisa was 38 years age in 7th month of pregnancy unborn baby put on “child in the risk register”, having its own social worker as case manager.

Lisa- slide 2.

- Several case conferences held where where Lisa and representatives of all services around her and her unborn baby were present. Care plane shared .
- Lisa admitted to psychiatric department involuntarily and stays for 2 month until delivery , later on voluntary base.
- Lisa and Rosy three month on mother and baby unit, after that both in specialized foster care for placement for 8 month.

Lisa- slide 3.

- Lisa moved to a new accommodation near her mother.
- Process of hand over from AOT original address to AOT new address started.
- Integrated to a local community resources as support club for single mothers, baby centre…
- Lisa start volunteering in library, later formally employed.
- When Rosy was about 2 years court decided to return to Lisa full mother responsibility and Rosy was put out of risk register.

Comparison of two models of care slide I.

Jana

- Needs and rights of the clients not in the focus.
- Orientation on what client can not
- Services provide limited and rigid block of treatment.
- Episodic character of treatment and support.
- Focus on” treatment”.

Lisa

- Needs and rights of the clients leading principle.
- Orientation on what client can.
- Services provide flexible, on the client needs oriented treatment.
- Continual character of treatment and support.
- Focus on prevention

Ad Hoc Expert Group

Report on the Transition from institutional to Community –based Care made by:

- AGE Older people
- Lumos /CHLG/ Children
- EDF Disabled
- MHE Mental Illness
- Inclusion Europe Mentally Disabled
- COFACE Family
- ECCL Community Living
- EASPD Care provider

Components of Institutional care

- **Size**

is indicator of difficulties in guarantee individualized, needs tailored services as well as participation and inclusion in the community.

- **Institutional culture**

Institutional x Community care

- Community services shove higher level of satisfaction of clients and their family members
- Most of the staff , if adequately supported, prefer working in community models.
- Community-based models of care are not more costly then institutional care if comparison is made on comparable quality of care.
- But there is extra cost needed for transition period

Principles of transition process

- Involvement of users
- Prevention of institutionalization
- Restriction of investment to institutions
- Development of community services
- Closure of institutions
- Effective use of all resources
- Development of human resources
- Control of quality
- Holistic coordination
- Continual awareness

Risks of Transformation I.

Risks

- Over-investment in current institutions
- Maintaining parallel services.
- Closure of institutions without community alternatives
- Alternatives with institutional culture

Solutions

- National – local DI policy
- Comprehensive plan
- Standards and quality assurance system

Risks of Transformation II.

Risks

- Fear of unemployment.
- Fear of adaptation to new conditions and way of working.
- Rejection by the community.
- Rejection by “authority” because of increasing of the cost.

Solutions

- Early inclusion of all the staff to a planning process.
- Requalification, trainings, supervision, complex support program.
- Awareness, information, inclusion to planning.
- Good timing of the process , cost benefice analyses.

Long way but up to the sky

Thanks for your attention