

Lifestreaming under a Rights based approach

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Disabled people are rights holders

- The European Social Charter (Treaty of the Council of Europe) defines the fundamental rights of disabled people
- In line with this treaty, the national legislations of our Member States define the rights of the disabled people
- As a general rule, aside of the fact that disabled people must benefit from the same human rights, they may need a right to compensation of their disability

Disability & Dependency

- Some disabled people may have high or complex dependency needs:
 - Assistance in the activities of daily living (major criteria)
 - Need for a high level of support
 - Intensive care & technical aid
 - Intensive education
 - Continuing assistance for safety purpose

Mainstreaming & or vs. Lifestreaming

- For people with high or complex dependency needs, the mainstreaming approach may be either an inadequate response or only a partial response to cover their needs
- The fundamental rights of these people are rarely effective if positive measures are not adopted, if compensation is not effectively granted and put in place

Effectiveness of rights

- Definition of the individual project of life, adapted, flexible, evaluated all life long, taking into account the needs and desires of the person
- Definition of this project under the so called rights based approach, i.e. compensation based on each of the fundamental rights
- Quality of life, all life long under a global approach for the person, not for the society
- Needs are not standard – Situations are complex and diverse

Right to early diagnosis

- Early and systematic identification permits
 - not only an early and accurate diagnosis
 - but also, the introduction of early intervention
 - to reduce the degree of disability and prevent the aggravation of the disability
- Right to have a diagnosis based on international classifications (ICD 10)

Right to receive adapted care all life long

- Mentally disabled people, must have access to appropriate care and treatment
 - not only for their mental health
 - but also for their physical health
- Ordinary and common treatment must be performed
- Right to benefit from disease control and prevention programs

Treatment limited to needs

- Right not to receive any inappropriate and/or excessive medication
- No permanent treatment or medical care, unless indispensable
- No abusive or inappropriate recourse to irreversible means of contraception

Treatment as out-patients

- Treatment at home or in residential centres makes it possible for the person to benefit from the complete range of medical care
- This approach improves the quality of life of the person

Right to Life Long Education

- States must guarantee disabled children and adults the effective exercise of their right to education
 - in mainstream schools
 - in special schools only if inclusion in mainstream schools is not possible and if this decision is agreed with the parents
 - But special schools must still exist, in sufficient number and be suitably adapted
 - Special schools must be linked with mainstream schools

Early intervention

- Taking into account the principle of early intervention, it is in the child's interest
 - to begin educational measures at pre-school age, especially where they are intended to make it easier for the child to obtain a school education at a later stage

Continuum of provision

- The child's situation may require special education, mainstream education, or both
 - a "continuum of provision" is essential and requires close co-operation between special and mainstream schools,
 - transition between mainstream and special schools must be encouraged

Adapted education

- Apart from teaching academic skills, education of people with disabilities must include
 - preparation for an independent life
 - adaptive behaviours and social skills
- Adaptive skills are critical factors in determining the supports the person requires for success in school, work, community, and home environments

Education of adults

- Adult education should provide the maximum range of opportunities and include
 - not only special education or participation in mainstream adult educational programmes
 - but also training in basic skills, in access, self-management, living skills, at all ages (no retirement)

Right to work

- Adjusting the working conditions to the needs of the disabled person in the ordinary working environment
- Where this is not possible by reason of the disability: arranging for or creating sheltered employment according to the level of disability
- In certain cases, such measures may require recourse to specialised support services
- Principle: possibility of a true career with flexible transitions to and from the ordinary environment

Access to private housing & to private life

- Full integration and participation in the social life of those who are the most dependent and disabled require
 - Closing large institutions
 - Living at home as independently as possible with home services or, living in small, quality structures as an alternative to living in an institution.
 - Providing a broad range of community-based services with all safety measures, including transport - Need for qualified personnel
- Appropriate guardianship systems

Suitable personnel to achieve these goals

- Competent general practitioners & specialists
- Qualification of the personnel in charge of education, of training, of job-coaching
- Adequate formation and training
- Interdisciplinary teams

Role of organisations

- Third organisations (public or private) should assist the disabled people or their representatives to coordinate the services
 - Avoiding any conflict of interests
- Guaranteeing the permanent quality of the individual project
- Making sure that this project is not a kind of awful patchwork - Ensuring a co-ordinated approach
- The project must remain coherent
- Preventing ill-treatments: incoherence would be a kind of ill-treatment and a denial of some or all of the rights

Financing the individual project

- Positive measures have a cost but for the majority of our countries, the answer is possible
- The person and his/her needs must be at the heart of the project, not the supposed financial constraints
 - Easy to say, but not easy to do ? Wrong: this is possible to do
- No choice for the State – Effective rights for all oblige to positive measures
- National responsibility – same rights on the whole territory
- The financing must not influence the choice of the disabled person

Role of the society as a whole

- Reaffirming the dignity and worth of every person with a disability – The livestreaming approach may permit this essential respect of the dignity and unique life of every disabled person
- States must implement effective tools to end the injustice, discrimination and violation of rights that confront most persons with disabilities
- One of these tools is the UN Convention on the Rights of Persons with Disabilities.