

The Specific Risks of Discrimination Against Persons in  
Situation of Major Dependence or with Complex Needs

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## Shaping services to specific needs

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## Shaping services to specific needs Plan

- ❖ Basis of action against discrimination : full human rights
- ❖ Conceptual model : International Classification of Functioning, Disability and Health (WHO)
- ❖ What are the specific risks of discrimination?
- ❖ Main attributes of services to avoid specific risks
- ❖ Limits and prospects

## Basis of action against discrimination : full human rights

- ❖ In accordance with the UN Convention on the Rights of Persons with Disabilities, States :
- ❖ *have to recognize 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” (article 19)*

## Participation and The International Classification of Functioning, Disability and Health (ICF)

- ❖ In ICF functioning and disability are viewed as outcomes of interactions between health conditions and contextual factors
- ❖ Participation is a component of functioning
- ❖ Contextual factors are external environmental factors and internal personal factors

## Environmental factors (ICF)

- ❖ Products and technology
- ❖ Natural environment and human made changes to environment
- ❖ Support and relationships
- ❖ Attitudes
- ❖ Services, systems and policies

## Environmental factors (ICF)

- ❖ **An important distinction between « barriers » and « facilitators »**
- ❖ **Environmental factors act in one way or another**
- ❖ **A lack of facilitator is a barrier**

So,

- ❖ In all areas we have to identify not only barriers but also facilitators and
- ❖ Specially, for persons with complex needs, potential facilitators are essential

What are the risks of discrimination against persons with complex needs?

- ❖ **Environmental barriers in all areas and in all domains** : Products and technology ; Natural environment and human made changes to environment; Support and relationships, Attitudes, Services, systems and policies  
  
For example : architectural barriers at school,, lack of individualised curricula, lack of qualified teachers  
in the housing field : no services available to realize daily activities  
services reserved for less disabled people.
- ❖ **Lack of facilitators or potential facilitators** : lack of technical aids, lack of support for children with complex needs, lack of specialized counselling, Lack or not sufficient personal resources

## A case study: Margot

- ❖ Margot is a little girl who is ten years old.
- ❖ She has serious health problems (neurological disorders, chronic pain and breathing disorders) and severe functional limitations (she can't perform mobility task, she can't detect people or objects around her, she can't speak...).
- ❖ She is daily assisted by her parents, particularly her mother who has to stop her professional work.
- ❖ Margot needs constant attention. Her mother takes care of her (cleaning, feeding, drugs administration to ease her pain, enteral drinking, change of position).

## Why Margot doesn't go to school?

- ❖ A Sessad (Services of special education and care at home) intended to integrate Margot in school when she was three.
- ❖ But Margot's mum rejected this project :
  - because Margot was flabby at that time, she didn't wear a corset. Margot's mum didn't know how they could correctly take care of her either and what benefit she could get from that.
  - furthermore, the school was not accessible. For instance the library was not accessible and this could complicate her integration.
  - the school have not enough professionals to take care of Margot.

## The essential idea that Margot's mum wants to pass on

“When you have a child with multiple impairments, the main problem is that you are isolated without any assistance, without a psychologist or a social assistant.

Very often, you don't know where to go to have information. When I have a question to ask, I turn towards Internet.

I have no possibility to get into contact with a social assistant although this would be very useful for us.

But here in the countryside, we are with all our family (grand parents, uncles and ants) but services are very far away.”

## Main implications of this case study

- ❖ There is a strong discrimination against children in situation of major dependence and with complex needs and against his family.
- ❖ If situation of major dependence and complex needs are not identified and taken into account by an environmental but also a personalized approach, inclusion may not be possible.

## Shaping services to complex needs

### Purposes

Personalized services are important for giving people with severe disabilities the opportunity :

- ❖ to manage their life according to their own wishes and needs
- ❖ and to participate in mainstream activities.

## Shaping services

- ❖ Services need to be both flexible and reliable, with a lot of personalized offers
- ❖ Personalized service arrangements for people with severe disabilities need high quality assessment and planning efforts, experienced staff and appropriate financial resources.

## **Personalized service delivery in preschool education**

- ❖ To ensure personalized service delivery need 'institutionalised rules' to implement the idea of equal rights and the possibility for choice from the UN Convention.
- ❖ Mainstream organisations need means, sufficient human resources and assistance for doing their job.
- ❖ To deliver personalized services especially for people with complex needs good intersectoral cooperation is needed.
- ❖ It is necessary in education settings to arrange the environment of playing and learning as an inclusive one which will be able to take into account all the situations.
- ❖ Individualized service delivery must be embedded in a good system of early intervention and family support, which allows families to create an individual perspective for their future and for the future of their disabled member with complex support needs.

## **Personalized service delivery in the field of housing and work**

- ❖ Strong efforts to barrier-free
- ❖ Funds supports for personalized housing and work adaptations
- ❖ Personalized supports in housing and work

## Limits and prospects

### Limits

- ❖ Usual Cultures and politics generating environmental inhibitors factors :
- ❖ architectural barriers
- ❖ lack of personalized services
- ❖ exclusion attitudes

### Prospects

- ❖ Inclusive cultures and politics able to generate facilitators factors
- ❖ barrier-free environment
- ❖ Personalized adaptations
- ❖ personnalized seVICES