

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



**Jan Šiška, Kateřina Hádková**

**Study on the Specific Risks of Discrimination  
Against Persons in Situation of Major Dependence  
or With Complex Needs**

**The Research Methodology and Conclusions**

# The Study

- Comparative Study in 12 European countries: Belgium, the Czech Republic, France, Germany, Italy, Lithuania, the Netherlands, Poland, Romania, Spain, Sweden and the United Kingdom
- Coordination: Inclusion Europe
- Lead Researcher: ZPE, University of Siegen
- December 2006 – June 2008

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## **Forms of Discrimination according to EU-Law**

- **Direct discrimination**
  - **Indirect discrimination**
  - **Harrassment**
  - **Victimisation**
- **What are specific risks of discrimination for people with severe disabilities and/or complex needs?**
  - **How can they be analysed?**

# The Study: Objectives

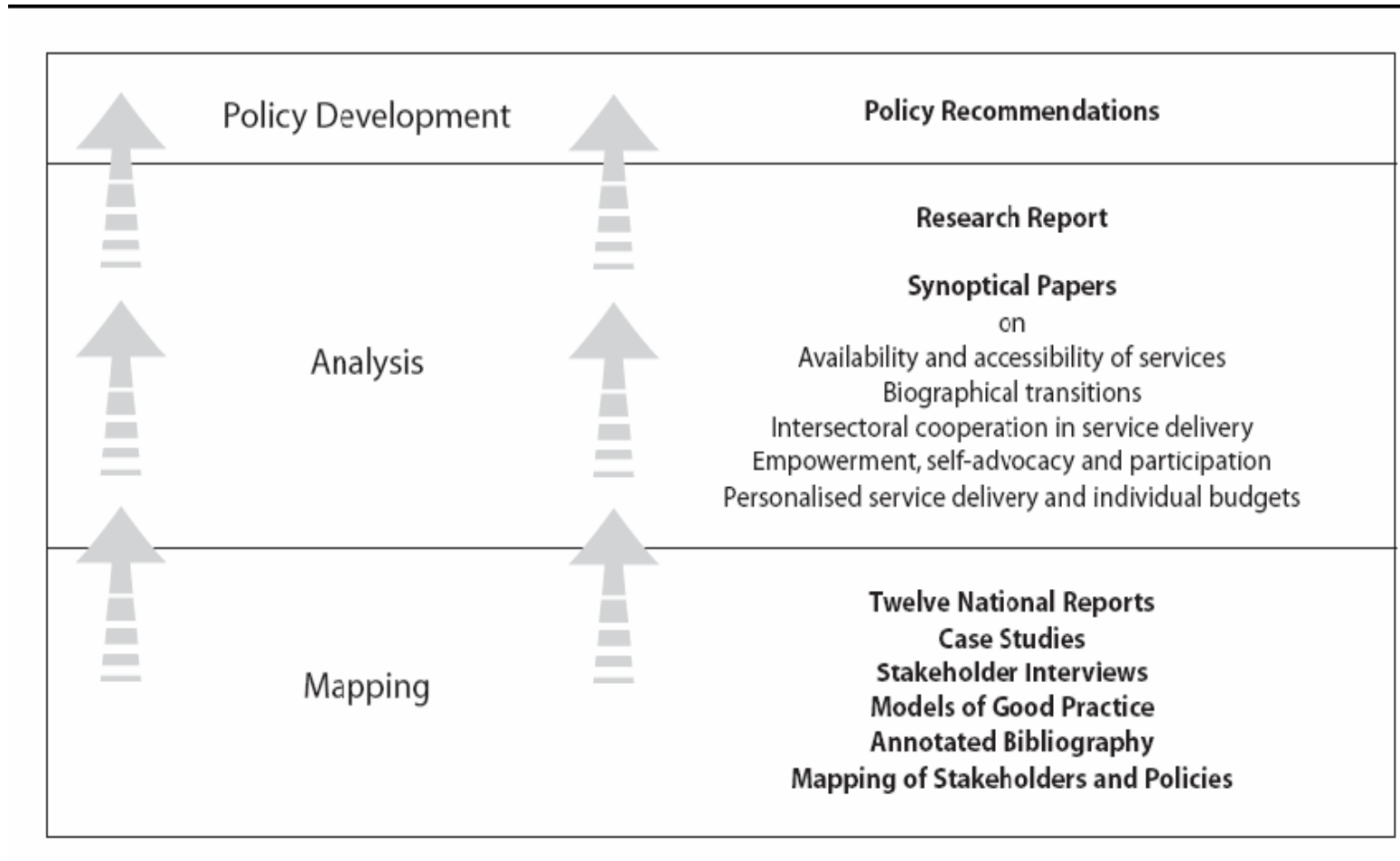
- Improve the understanding of issues related to severe disability
- Identify specific risks of discrimination in relevant policy and life areas
- Provide information for Stakeholders and Policy Makers
- Improve the living conditions and close delivery gaps
- Prevent exclusion and inequality

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# The Study: Project Stages



## Life-course approach

Life-course is a 'product' of modern societies, structured by three major institutions as orientation for individual biographies:



- with markers for beginnings and ends of a life- stage,
- with expectation and sanctions for individuals;
- with collectively organised transitions
- with partly de-standardised phases and sequences,
- but nevertheless with high stability

## Life-course approach: Assumptions

- All members of our societies develop their biographies in the same framework of an institutionalised life-course: the “normal” life-course
- Transitions form biographies
- Life-course institutions are ‘secondary institutions’ with soft sanctions, when expectations remain unfulfilled (U. Beck)
- Unmet life-course expectations can strongly harm the individuals identity and can produce deep feelings of shame

## Life-Course Approach and People with Severe Disabilities

High risk of exclusion from ,normal' life-course, especially in phases of ,transition' because of changes in support arrangements

Exclusion and Discrimination can happen

- because of lack of services
- because of services
- because of procedures for services

## Overview on Results: General Risks of Discrimination

- People with severe disabilities face typical and specific risks of discrimination in all European countries and in all areas of life, but to a different extent.
- High needs for support services, but low possibility to pay for them: “negative consumers”. Risk to be left behind in old service structures.
- Small and diverse group that creates no interesting market for goods and services, and therefore product innovation is often restricted.

## Overview on Results: General Risks of Discrimination

- The more mainstream-oriented a service system becomes, the higher is the risk of persons with severe disabilities to be placed in traditional settings or to be excluded from support.
- People with complex needs are not sufficiently considered in the implementation of non-discrimination or equality legislation.
- Perception as not being able to take over socially accepted mainstream roles in life.
- Lack of statistical data on people with severe disabilities

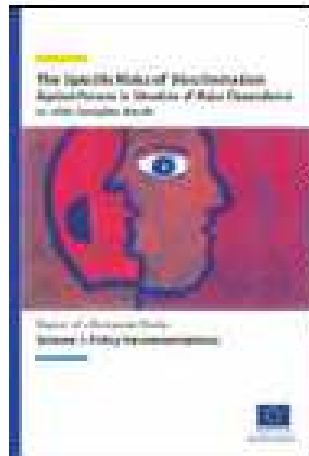
## Overview on Results: General Risks of Discrimination

- Assumption that people with complex needs and/or severe disabilities should be in residential institutions
- Community-based services are often neither designed nor staffed to care for this group of people
- Personal support services often target their services only to other groups of disabled people (creaming of the poor')
- Unshared care obligations in families, leading to discrimination and disadvantages, most often of female family members

## Summary of Recommendations

- **European Level:**
  - Strengthen non-discrimination as a principle in EU-law
  - Develop a policy for 'universal design' and mainstreaming that explicitly includes people with severe disability
- **National Level:**
  - Promote inclusion and mainstreaming
  - Establish and monitor high quality of support services
  - Ensure that the special needs of this group of citizens are considered in all decisions

# The Complete Results of the Study



Volume 1: Policy Recommendations



Volume 2: Research and Analysis



Volume 3: Country Reports and Stakeholder Interviews



Volume 4: Examples of Good Practice

***Thank you!***

**jan.siska@pedf.cuni.cz**

**With contribution of Dr. Johannes Schädler**

All volumes are available at

**[ec.europa.eu/employment\\_social/disability](http://ec.europa.eu/employment_social/disability)**