



# EUROPEAN POLICY BRIEF



ACTIVE CITIZENSHIP AS COMMUNITY LIVING

THE EXPERIENCES OF PERSONS WITH DISABILITIES

September 2014

## INTRODUCTION

According to European Commission data, there are more than one million children and adults with disabilities living in institutions in the European Union and in Turkey.

Article 19 of the UN Convention on the Rights of Persons with Disabilities (UN CRPD) establishes a right for persons with disabilities to live in the community as equal citizens. The Convention also states that segregation of persons with disabilities in institutions is a human rights violation. State Parties to the Convention must develop community living services that replace institutional care by “a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community”. The CRPD also obligates State Parties to ensure that all persons with disabilities have choice and control over how, where and with whom they live, and that mainstream services are available and accessible to them. Thus, living in the Community is a key pre-requisite for active citizenship.

Despite the existence of human rights norms, and considerable developments occurring in the countries covered by the project, there is still much to do. In particular persons with more severe and multiple disabilities have not benefitted much from de-institutionalisation. Furthermore, even in more advanced countries there is a worrying process towards re-institutionalisation because of the economic crisis or inadequate implementation of policies.

In addition, persons with disabilities and more particularly those requiring a high level of support and persons with intellectual disabilities still have little choice over their lives, where and with

whom to live, and do not receive sufficient support in order to participate and work in the community, despite the existence of policy and legislation.

## EVIDENCE AND ANALYSIS

The project has analysed policy developments, statistics and trends in community living as well as the role of community care services in nine European countries: Czech Republic, Germany, Ireland, Italy, Norway, Serbia, Sweden, Switzerland and the UK. This was achieved through the support of national researchers and through life course interviews of persons with disabilities with different support needs. A common template and guidelines were used in order to ensure maximum consistency in data collection.

The report constitutes the basis of an analytical framework for understanding the interaction of persons with disabilities with social services and other service providers.

Data collected includes prevalence of persons with disabilities in countries, number of people in residential establishments, policies and legislation promoting deinstitutionalisation and the development of community based support, information on choice of living situation and support, information on policies, legislation and practices available to support their active engagement in their own lives and in their local community.

Among the countries covered there are important variations on the number of persons with disabilities (from 4.8% of the population in Italy to 19-21% in the UK) and information on the different types of disability is not always available. There are very limited data and studies across the nine countries on the number and type of services available to persons with disabilities.

In thinking about the differences between residential institutions and community based services, researchers based their definition on previous studies that indicate that institutions are large establishments, physically and socially segregated from society, from which residents are not able to move easily either by policy or lack of alternative services, where material conditions are worse than for most people in society, and where more in general persons are isolated or obliged to live in a collective setting, they do not have control over their lives and day to day decisions. However, research has shown that small community based settings can become institutions if staff do not enable and empower people to take part in meaningful activities and relationships, at home and in their community, relationships as well as opportunities to have choice and control over their lives. Staff attitudes, training and leadership have been found to be important here. However, information on the nature of services – size, quality, location nature, culture etc. – was not available in most countries, apart from Ireland. As such, a very broad definition of an institution as somewhere with over 30 places was used as an equivalent to that used in the DECLOC study to allow comparisons of change over time (DECLOC study, see: <http://inclusion-europe.org/en/projects/past-projects/decloc-report>). Using this very conservative definition, institutions still exist in all countries but Sweden (where larger services only exist for acute mental health admissions), and it is especially widespread in countries such as Italy, Serbia, Czech Republic and Germany. The numbers of people in institutions and the quality of the data available have not changed substantially since the DECLOC report in 2007, despite supportive policy and systems existing in all countries. In fact, in Italy, the number of people in institutions has risen since 2007.

Sometimes deinstitutionalisation has occurred more on paper than in practice as the same services have been reclassified, such as in the Czech Republic (as well as in other countries not in this study such as Hungary and Finland). In addition, the length of the engagement of countries in the deinstitutionalisation process varies significantly among the countries covered. In all countries residential institutions host mostly persons with more severe disabilities, intellectual disabilities, and mental health issues. In addition, in some countries such as Germany persons with severe physical and intellectual disabilities are forced to live in institutions, as they would not be provided with enough staff support in the community.

There is also a trend towards re-institutionalisation in countries where large institutions have already closed. This trend appears at least partly to be caused by cuts in public spending and changes in public governance mainly due to the economic recession. There is also a trend towards an increase in the average size of care homes and sheltered apartments or towards clustering group homes or sheltered apartments with homes for other groups on the same site – this is a particular issue in Norway and the UK.

Although there is little detailed research other than in the UK and Ireland, people appear to have little choice about services received, where they live, whom they live with, who supports them etc. The lack of choice and access is especially difficult for persons with the most severe disabilities, in particular those with intellectual disabilities. In Serbia, people are placed in residential services according to their disability and not their place of residence, as a result living far from their own community. In most countries, there is a sense that people have to take whatever is available to them. However, choice and autonomy was greater when people were receiving personal budgets or direct payments.

Lack of training and support for staff were identified as some of the reasons for lack of choice and control.

Studies on the impact and outcome of deinstitutionalisation show that the best results for persons with disabilities in terms of quality of life and participation are achieved in community-based settings. However, this data comes primarily from the UK and other countries outside of the group of countries studied here. There was very little research on the quality of life and day-to-day experiences of people with disabilities or the quality of services they receive.

The study also shows that the main challenge is not the closure of institutions, but to replace them with a coordinated collection of community based arrangements that offer the support and opportunity needed and wanted by disabled people. Concrete national plans and legislation contain obligations regarding deinstitutionalisation and key principles to guide the development of community based services such as self-determination. However, only in two countries (Norway and Sweden) is the building of institutions illegal and size of community based services limited. In addition, overall and concrete provisions on the full replacement with other services and a corresponding allocation of budget are missing in national action plans.

Analyses of the national data show that measures supportive of the development of the community-based services include the availability of personal budgets, direct payments or other personalised funding systems. Individual assessment and planning was also found to be a useful way of promoting choice and control. There is a growing trend to develop these systems along with support, with adaptation of housing or assistive equipment but the range of services still remains limited, as well as the number of persons benefitting from these measures. Other positive practices

include the availability of respite care, day centres, home help, as well as the support to move out of family homes as part of normal life transition.

Research in a small number of countries identified that personal budgets or personal assistance schemes improved the self-determination of persons with disabilities in their everyday affairs and the exercise of active citizenship, experiencing more choice over the activities in which they participate and over their assistant. However, the success of personal budgets depended on how the money is handled, the availability of services to spend the budget on and the skills and attitudes of the support staff or other facilitators. Another barrier identified was the bureaucracy that people had to go through to access personal budgets.

There is still scarce information on the involvement of persons with disabilities in their lives and their community. However, even in countries with a longer history of deinstitutionalisation, persons with disabilities are less likely to have a job or be involved in volunteering.

Other factors recognised as key enablers of active citizenship are related to the level of accessibility of built environment, transport and information. In this regard, some countries have forms of funding or favourable bank loans to help people buy, build or adapt their own home to meet their needs.

Furthermore, the deprivation of legal capacity, as well as the views and actions of other members of the community are key barriers to exercise active citizenship. In relation to the latter, researchers also reported that there have been cases of persons with disabilities, especially with intellectual disabilities, being victims of hate crimes or victimisation in some countries, such as the UK.

## POLICY IMPLICATIONS AND RECOMMENDATIONS

Analysis of national data has shown that there is a lack of data that enable us to acquire a comprehensive picture about the living situation of persons with disabilities and their participation in community life in any of the countries studied. Measures must be put in place in order to ensure the regular collection of such data as well as indicators to measure the impact of policy change.

Policies and legislation in all countries include provisions for deinstitutionalisation and community living, however in most countries much has to be done to improve the availability of such services and prevent the risks of re-institutionalisation especially for persons with multiple or severe disabilities.

Furthermore, such policies must be accompanied by measures favouring training and retaining of staff in order to ensure that the user's perspective, involvement, and the ability to fully exercise active citizenship are ensured.

Community living can only be ensured if policies and legislation on accessibility, employment of persons with disabilities, and civic participation are developed and support is available in a wide range of forms to promote active citizenship.

## RESEARCH PARAMETERS

Having regard to the “Comparative analysis of the current state of affairs in community living” in which the available data on disability, policies and system supporting deinstitutionalization from the nine research teams involved in DISCIT, another objective was to gather information about the changes from institutional to community-based living through a set of life-course interviews to persons with disabilities.

The interviews were carried out with men and women with disabilities born around 1950, 1970 and 1990, including persons with visual impairments, mild or moderate psycho-social disabilities, intellectual disabilities and reduced mobility. The purpose is to compare to which extent current social services and other provisions are meeting the needs of persons with disabilities to support their independent living, and how this has changed over their life. This exercise is based on the defining concepts set up by DISCIT of security, autonomy and influence.

## PROJECT IDENTITY

**PROJECT NAME** Making Persons with Disabilities Full Citizens - New Knowledge for an Inclusive and Sustainable European Social Model (DISCIT)

**COORDINATOR** HiOA - NOVA Norwegian Social Research  
Oslo, Norway, [www.hioa.no/nova](http://www.hioa.no/nova)

**CONSORTIUM**

ARCO PIN University of Florence - PIN SCRL - Action Research for CO-Development  
Florence, Italy

Charles University Prague - Universita Karlova v - Faculty of Education  
Prague, Czech Republic

European Disability Forum - EDF  
Brussels, Belgium

Mental Disability Rights Initiative of Serbia - MDRI-S  
Beograd, Serbia

National University of Ireland - NUI Galway - Centre for Disability  
Law and Policy  
Galway, Ireland

Swiss Paraplegic Research - SPF - Disability Policy Unit  
Nottwil, Switzerland

University of Cologne - UCO - International Research Unit Disability  
Studies

Cologne, Germany

University of York - UOY - Social Policy Research Unit  
York, United Kingdom

Uppsala University - UU - Department of Sociology  
Uppsala, Sweden

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**FUNDING SCHEME**

FP7 Framework Programme for Research of the European Union  
Collaborative research project, Activity 3 – Major trends in society and  
their implications

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**DURATION**

February 2013 – January 2016 (36 months)

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**BUDGET**

EU contribution: € 2,463,304

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**WEBSITE**

[www.discit.eu](http://www.discit.eu)

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**FOR MORE  
INFORMATION**

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**FURTHER READING**

*Working Paper ‘Comparative analysis of the current state of affairs in  
community living’, January 2014*

*Working Paper ‘Change and diversity in community living in Europe –  
the experiences of persons with disabilities - findings based on life  
course interviews’, available November 2014*