



DISCIT - MAKING PERSONS WITH DISABILITIES FULL CITIZENS

NEW KNOWLEDGE ON ACTIVE CITIZENSHIP FOR PERSONS WITH DISABILITIES

News December 2014

INTRODUCTION

DISCIT aims to produce new knowledge enabling Member States, European countries and the European Union to achieve full and effective participation of persons with disabilities in society, policymaking and the economy.

This Policy Brief provides findings and policy recommendations that have emerged from evidence gathered in nine European countries. From February until October 2014, Consortium Members in DISCIT have implemented and analysed 204 semi-structured life course interviews with persons with disabilities from nine countries, three birth cohorts and four disability types. The DISCIT team collected data in Germany, Italy, Ireland, the United Kingdom, the Czech Republic, Serbia, Switzerland, Sweden and Norway.

EVIDENCE AND ANALYSIS

DISCIT members interviewed persons with disabilities from three different birth cohorts (born around 1950, 1970 and 1990) and from four broad groups:

- o Persons experiencing restrictions in their mobility
- o Persons experiencing restrictions in seeing
- o Persons experiencing psychosocial disabilities or mental health issues
- o Persons with cognitive or learning disabilities

The full reports that provide further details are available at www.discit.eu/publications.

The reports contain analyses of the empirical data and describe trajectories of the informants both in the situations of health and ill health, of capability and disability. The accounts are placed in the context of country, gender, disability and birth cohort differences.

POLICY IMPLICATIONS AND RECOMMENDATIONS

The life course of persons with psychosocial disabilities

- Based on the findings, we argue that social policy has a major role to play, not only to prevent the occurrence of such moments of mental ill health and disability, but also to support the individual to regain a situation of health and capability. Helpful measures were among others mental health care settings where the individual can have a say in the treatments and medication, peer-support groups, various forms of access to art and art therapy, measures of support in the community, and flexible work arrangements which take into account the different needs of the individual.
- Social policy needs thus to focus both on measures helping the individual to increase his/her potential, and on measures designed to change the environment, such as the environment can meet the difficulties of the individual and adapt dynamically to his/her changing needs. In sum, the accounts of the informants pointed to the importance of taking into account both the frailty and the capability of persons with psychosocial difficulties, as underlined by the United Nation Convention on the Rights of Persons with Disabilities (UN CRPD).

Labour market careers of persons with disabilities

• Labour markets in Europe have only partially been able to provide jobs for persons with disabilities. The intersections of gender, age and generation, and impairment shapes the extent to which persons with disabilities have been able to find work. Specific kinds of accommodation for people with disabilities can benefit some but not necessarily others.

Such accommodations include for instance adaptations to working environments or, the provision of appropriate technologies and working practices may aid people with different disabilities differently. Any number of factors, including family obligations, lack of appropriate work, and experiences of ill health, may drive exits from the labour market. These diverse barriers or obstacles to employment require different kinds of policy solutions. DISCIT does not propose a model of the Active Citizen that is homogenous but one that recognises and takes into consideration people's differences.

- DISCIT members recommend ensuring a greater and more 'equal' participation through a range of responses that recognise the different needs people have, as well as the different places or positions from which people enter the labour market. Greater accessibility measures and improved anti-discrimination legislation may help many people enter the labour market on a more equitable basis to persons without disabilities. For others, who require more help, improved supported employment structures and services may work better. People also need access to support at times when they are not in work. Periods of ill health were common in the collected data. Clearly, one cannot reasonably expect people to work at all times. Supporting people to be active citizens during periods of unemployment requires appropriate out of work services and social security benefits to be in place, enabling them to 'active citizens' out of work.
- It is important to acknowledge that not all people might realise the notion of Active Citizenship in the same way. How people engage with the labour market and the extent to which they are able to do so, is also partly a matter of personal choice and preference, given their situation. The accounts of some of the people interviewed in the project challenge the assumption that being an 'active citizen' necessarily includes having paid work within the mainstream labour market. DISCIT recommends consideration of voluntary and caring roles or participation in other activities as equally giving to a person a sense of being an active citizen in ways that make participation in the labour market less important or even irrelevant.

Community living in Europe

• The majority of the people interviewed by DISCIT members were living in their own home, owned or rented either on their own or with their partner and/or children. This type of setting was most common for those with intellectual disabilities. In general, length of time in the current living situation varied by birth cohort but in some countries even those in the older cohorts had moved relatively recently into their current home. The majority of the sample felt that they had full choice over where they currently lived. However, those with intellectual disabilities were least likely to report choice over where they lived and whom they lived with. Those in the older cohorts most often reported full choice but this is likely to reflect the fact that many of those in the younger cohort were still living with their family.

- Just under one fifth of people interviewed by the DISCIT team had lived in an institution for children or adults at some point in their lives, with over one quarter of them having attended special boarding schools. An additional 15% of people had lived in other group settings for adults of varying sizes and characteristics. These were shared arrangements, giving people little choice over who they lived with or where they lived. Those who had experienced institutional provision were more likely to be those born in the 1950s and those with intellectual disabilities, whilst those who had been to special boarding schools tended to be those with visual impairments.
- In most countries, the majority of people received some form of financial support but with enormous variation in the nature and amount of that support. In terms of assistance and support for daily life, more than half the sample did not receive any formal support. Those with mobility difficulties most frequently reported higher levels of support. Of those receiving some formal support slightly less than a half reported that they had choice over the type of support they received. Fewer people with intellectual disability reported choice over the type of support they receive or from whom they received support
- The researchers identified three clear patterns in trajectories. Some people had
 experienced completely mainstream trajectories such as in education, employment, place
 of living and family situation. However, others, mainly those with intellectual disabilities,
 had experienced "special" trajectories. More mixed trajectory was more common in those
 with psychosocial disabilities and those with visual impairments, many of whom had been
 to special boarding schools.

Active citizenship with new technologies

- Differences in access to and use of accessible technology among disability types may constrain efforts for enhancing Active Citizenship, particularly among persons with intellectual disabilities.
- Gatekeepers including public agencies and insurance providers control access to physical and financial resources for procuring accessible technology and the way they function can inhibit access to accessible technology.
- Accessible technology influences changes in an individual's life course including shortterm transitions in education, employment and community living and long-term fundamental changes that improve economic independence and social inclusion.
- Financial, technological and availability barriers limit options for procuring and using
 accessible technology, informational barriers limit an individual's choice in the accessible
 technology market and procedural barriers limit efficient access to accessible technology.

In addition to these findings and recommendations, DISCIT proposes reflections on disability statistics and Indicators for Active Citizenship:

European disability statistics

• While the increasing cross-national disability statistics have a great potential for knowing more about the conditions for Active Citizenship, there are notable limitations that one need to overcome if the statistics are to play an important role in the monitoring and assessment of progress towards full and effective Active Citizenship for persons with disabilities in Europe. There is a need for a continued dialogue about defining and measuring in a comparable way disability between Member States.

Indicators for Active Citizenship

DISCIT recommends adopting measureable indicators to identify the obstacles to active
citizenship for persons with disabilities, and thus, promote empirically provable ways in
which one can succeed in removing obstacles to active citizenship and achieving the
reality of active citizenship.

RESEARCH PARAMETERS

The DISCIT team will complement the life course interviews by conducting a small number of interviews with other relevant informants (e.g. staff in organisations delivering services, stakeholder organisations, etc.).

Disabled People's Organizations (DPOs) are experts on the experiences of persons with disabilities and mainstreaming. DISCIT invite DPOs and other stakeholders at any time – also at their own initiative – to advise the project on scientific and policy matters.

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

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

FUNDING SCHEME FP7 Framework Programme for Research of the European Union

Collaborative research project, Activity 3 – Major trends in society and

their implications

DURATION February 2013 – January 2016 (36 months)

BUDGET EU contribution: € 2,463,304

WEBSITE www.discit.eu

FOR MORE INFORMATION

Bjørn Hvinden, Scientific Coordinator, HiOA - NOVA, Oslo bjorn.hvinden@nova.hioa.no

Bettina Uhrig, Project Manager, HiOA – NOVA bettina.uhrig@nova.hioa.no

G. Anthony Giannoumis, Dissemination Officer, HiOA – NOVA gagian@hioa.no

FURTHER READING

Change and current status in the life course of persons with psychosocial disabilities (Deliverable 4.2, responsibility: Uppsala University)

Diversity and change in the labour market careers of persons with disabilities (Deliverable 5.2, responsibility: University of York)

Change and diversity in community living in Europe – the experiences of persons with disabilities (Deliverable 6.2, responsibility: Charles University Prague)

Active Citizenship through the use of new technologies – the experiences of three generations of persons with disabilities (Deliverable 7.2, responsibility: National University of Ireland, Galway)

Active Citizenship for persons with disabilities – Findings from selected European countries (Deliverable 2.2, responsibility: HiOA - NOVA)

Proposal for a set of indicators for Active Citizenship (Deliverable 3.2, responsibility: Swiss Paraplegic Research)

See more at: http://discit.eu/publications