



EUROPEAN POLICY BRIEF



DISCIT – MAKING PERSONS WITH DISABILITIES FULL CITIZENS

New Knowledge for an Inclusive and Sustainable
European Social Model

May 2016

INTRODUCTION

Against the background of the Europe 2020 strategy, the European Disability Strategy 2010-2020 and the UN Convention on the Rights of Persons with Disabilities, DISCIT has examined the conditions for the full and effective participation of men and women with disabilities on an equal basis with others. Drawing upon existing conceptualisations of social citizenship, DISCIT has explored three dimensions of citizenship:

- **Security:** Enjoying social protection against major life risks (such as illness, poverty, violence etc.), diminishing major uncertainties or the need for individual risk-taking (for instance in relation to financial matters) and avoiding constant worries about the future.
- **Autonomy:** Enjoying opportunities to live independently, exercising the freedom to choose the life one has reasons to value and avoiding dependence on or interference from others.
- **Influence:** Participating in the discussions and decisions that set the framework for one's own life as well as the decisions that aim to promote the common good and regulate social behaviour, given the interdependence of human action.

DISCIT has examined the opportunities for community living, labour market participation and political participation. The research team has given particular attention to accessible new technology, social security and social services as conversion factors to enable more persons with disabilities to exercise Active Citizenship. DISCIT has not only studied how things work today but has also asked what needs to change in order to create the conditions for persons with disabilities to exercise Active Citizenship in the future.

The EU has a track record of working to achieve inclusive growth which is defined in Europe 2020 as follows: “Inclusive growth means empowering people through high levels of employment, investing in skills, fighting poverty and modernising labour markets, social protection so as to help people anticipate and manage change, and build a cohesive society” (COM (2010) 2020 final, p.17). DISCIT findings are relevant to at least five of the seven flagship initiatives in Europe 2020, namely: Innovation Union, Youth on the move, A digital agenda for Europe, An agenda for new skills and jobs, and the European platform against poverty.

According to the European Disability Strategy 2010-2020 “(f)ull economic and social participation of people with disabilities is essential if the EU’s Europe 2020 strategy is to succeed in creating smart, sustainable and inclusive growth” (COM (2010) 636 final, p.4). Under the European Disability Strategy 2010-2020, the European Community has set itself the goal to “achieve full participation of people with disabilities in society” (p.6) and to “(e)nable many more people with disabilities to earn their living on the open labour market” (p.7). To this end, the Commission has planned actions on *inter alia* accessibility, participation, equality, employment and social protection.

One important precondition for change is the overhaul of the national and supranational disability policy architecture. DISCIT data demonstrate that to achieve more active participation of persons with disabilities in society and the market, Member States and Associated Countries need to recalibrate their disability policy systems.

- ***Income maintenance subsystem:*** In many European countries, the disability-related social security systems prevent wealth accumulation and social participation, as benefits do not lift people out of poverty.
- ***Social services subsystem:*** Policies and legislation in all nine countries include provisions for deinstitutionalisation and independent 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.
- ***Social regulation subsystem:*** Although all countries have transposed the framework employment directive, the implementation of statutory provisions are often weak or unsystematic. Some countries could benefit to a larger extent from wage subsidies and/or reimbursement of employers’ costs to reasonable accommodation. The data collected as part of the DISCIT project also highlights that existing national policies are insufficient and too fragmented to ensure accessibility for all, including persons with disabilities. DISCIT has pointed out that ‘design for all’ is largely underdeveloped in Europe. The project team also finds that the European accessible technology market is wide and growing, but patchy and largely dominated by small and medium-sized enterprises. As the market is fragmented, the relative average costs of developing prototypes are high.

DISICT data have demonstrated the need for the ***incorporation of a life-course perspective in policies to promote more Active Citizenship among persons with disabilities.*** Stakeholders, working with the disability policy system, should reflect on the permanent and temporary changes in people’s capabilities over the life-course. Overall DISCIT findings suggest that European and national authorities should adopt a ***dynamic and multi-dimensional approach to promote Active Citizenship.***

Policies to encourage Active Citizenship have often been based on a narrow conceptualisation of what counts as economically and socially valuable citizen activities. In their current welfare reforms, few governments recognize participation in activities which are *not* oriented towards paid employment or do not serve as ‘stepping-stones’ to the fulfilment of what they consider as citizens’ duties, although there are some cross-national nuances in this respect. Governments tend not to fully acknowledge the value of women’s unpaid care in the family. Governments appear to have been somewhat more willing to recognize participation in voluntary social and cultural work, self-help activities, organizational, co-operative or ‘social economy’ work as alternatives for people who are deemed to be distant from the mainstream labour market - though this is not rewarding in monetary terms for the individual. Yet, persons with disabilities have struggled to achieve recognition of activities other than paid work as valuable to the local community or society.

It is important to acknowledge that ***not all people might realize the notion of Active Citizenship in the same way.*** Voluntary and caring roles or participation in other activities may equally give a person a sense of being an Active Citizen in ways that make participation in the labour market less important or even irrelevant. For persons outside the ordinary labour market and in receipt of social services in cash and in kind, notions of Active Citizenship that involve mutual aid and collective self-help, participation in civil society and political activities – including voluntary work as board members and activists in Disabled People’s Organisations (DPOs) and in politics – can be seen as an avenue of activation. Recognition of these types of activities as valuable to society could provide more for reciprocal relations, in terms of opportunities to give and not only receive, for more persons with disabilities. A one-sided focus on participation in the ordinary labour market appears to have blocked off other and alternative forms of societal participation, either in transition phases or on a permanent basis for those with few prospects of achieving paid work, or those who chose other paths.

Active EU citizenship of people with disabilities requires that persons with disabilities are able to exercise ***the right of free movement and to experience the minimum of barriers when doing so.*** Such barriers do exist. They range from uncertainty regarding the entitlement to be recognised as EU workers in some circumstances, to difficulties in acquiring sufficient support – through the exportability of disability-related benefits or the right to claim equivalent benefits in the host Member State – to enable the person to work, study and live in another country. Other barriers relate to difficulties experienced in recognition of disability status in a country other than the country of origin. It is absolutely necessary to ensure the political will to overcome these barriers.

POLICY IMPLICATIONS AND RECOMMENDATIONS

Given DISCIT’s broader understanding of some of the themes identified in the European Disability Strategy (EDS), the DISCIT team takes the liberty to suggest that in the next iteration of the EDS, the achievement of Active Citizenship for persons with disabilities could be an overarching theme (defined broadly, using the DISCIT framework of security, autonomy and influence). In DISCIT, the influence dimension relates specifically to organisational and political participation as a means to exert influence on decisions of great importance for the lives of persons with disabilities as well as on the full implementation and systematic enforcement of their human rights. While the current version of the EDS deals with several general issues of social participation, the barriers and facilitators for the involvement of persons with disabilities in organisational and political activities receive too little attention. Findings from DISCIT confirm that a strengthening of this involvement is of utmost importance to ensuring the full and effective implementation of the UN CRPD in all European countries.

DISCIT has identified a need for the EU to fund further human rights-based research on disability, through the lens of Active Citizenship, and using a life-course approach. So far, no calls under Horizon 2020 have explicitly focused on persons with disabilities and the achievement of their human rights, or on issues of social exclusion. This gap should be rectified in future Horizon 2020 calls, including the calls under the Work Programmes for the Societal Challenges ‘Health, demographic change and wellbeing’ (SC1) and ‘Europe in a changing world - inclusive, innovative and reflective Societies’ (SC6), and by emphasizing the importance of interdisciplinary research.

The European Commission should review existing EU programmes and instruments designed to encourage (temporary) mobility of EU citizens, including the Erasmus+ and the Horizon 2020 programmes, as well as the EURES portal, in order to enable persons with disabilities to use them.

The European Commission should continue to monitor how European funds are used and should set conditions on their use so that accommodation and support developed for people with disabilities are consistent with the UN Convention on the Rights of Persons with Disabilities (UN CRPD) and so that they have the chance of achieving Active Citizenship.

Future EU directives on accessibility may help to overcome some of the shortcomings in existing disability policies. Additionally, the EU may want to consider the use of State aid (the social funds) to provide financial incentives for Member States, regional and local authorities to work towards more accessible goods and services and inclusive social services.

Under the European semester, the Commission services may want to consider the opportunities for policy learning from asset and wealth accumulation strategies adopted in the USA, Canada and Australia. Through asset and wealth accumulation strategies, the purchase of a home, a retirement fund, education and business capitalisation can become a reality for this largely economically marginalised group. Assets not only provide an economic cushion and enable people to make investments in their future; they also enable persons with disabilities to focus on their long-term development, provide psychological orientation and play a vital role in poverty alleviation.

In order to realise the aim of the UN CRPD of full and effective participation, the European Union, Member States and Associated Countries should create new and improved opportunities for effective participation of persons with disabilities in political and other decision-making processes.

The opportunity to participate in the labour market continues to be one, if not the most, important source for income, wealth accumulation and social respect. Given this, the EU, Member States and Associated Countries should continue to strengthen their efforts to improve the opportunities for men and women with disabilities to participate in the labour market. One opportunity is the support of small-scale job creation, e.g. ‘social enterprises’. These small-scale businesses are driven by a social purpose to provide meaningful activity for persons at the margins of society. In the future, trade unions and employers should be involved more often in discussions about what jobs can be created for everybody.

DISCIT recommends that the next iteration of the European Disability Strategy stresses the need for the EU and national governments to take steps to strengthen the quality (reliability and validity) and comparability of the disability-relevant statistical data collected through broad population surveys (for research purposes) and the routine collection of data by statistical agencies (for administrative agencies). DISCIT has identified substantial weaknesses in the existing disability-related data and a lack of representative and sufficiently precise quantitative indicators pertaining to the achievement of Active Citizenship for persons with disabilities. While the increasing cross-national disability statistics have a great potential for increasing our knowledge about the conditions for Active Citizenship, there are notable limitations that need to be overcome if the statistics are to play an important role in the monitoring and assessment of progress towards full and effective participation

for persons with disabilities in Europe. There is a need for a continued dialogue about defining and measuring disability in a comparable way between Member States. DISCIT would welcome further discussions with Eurostat on this issue. Statistical agencies and research institutions should align their operationalisations and data collections to the principles and definitions of the UN CRPD. DISCIT recommends adopting measurable indicators to identify the obstacles to Active Citizenship for persons with disabilities and in this way to promote empirically provable ways in which one can succeed in removing obstacles to Active Citizenship.

RESEARCH PARAMETERS

The main source of primary data has been a coordinated set of 217 semi-structured life-course interviews with persons with disabilities born around 1950, 1970 and 1990 from four broad groups:

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

The life-course interviews have been complemented by reviewing existing studies and documents, by reanalysing existing statistical data and by undertaking 85 interviews with other relevant interviewees (Disabled People's Organisations, public agencies, staff in organisations delivering services, etc.). The DISCIT team collected data in the Czech Republic, Germany, Ireland, Italy, Norway, Serbia, Sweden, Switzerland and the UK.

Through the involvement of the European Disability Forum and the Mental Disability Rights Initiative of Serbia as Consortium Members, an International Scientific Advisory Committee, a European Stakeholder Committee and National Stakeholder Committees, the DISCIT team was able to involve civil society and policy makers in the discussions on research parameters and outcomes during the lifetime of the project.

PROJECT IDENTITY

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

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FUNDING SCHEME

FP7 – European Union’s Seventh Framework Programme for research,
technological development and demonstration, Collaborative research
project, Activity 3 – Major trends in society and their implications

DURATION

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BUDGET

EU contribution: max. € 2,463,304

WEBSITES

www.discit.eu
<https://blogg.hioa.no/discit>

**FOR MORE
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FURTHER READING

DISCIT working papers (Deliverables), Policy Briefs and videos are
available at www.discit.eu / <https://blogg.hioa.no/discit>.