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Bjørn Hvinden, HiOA NOVA, Beneficiary number
1

Bjørn Hvinden, bjorn.hvinden@nova.hioa.no

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EUROPEAN POLICY BRIEF



MAKING PERSONS WITH DISABILITIES FULL CITIZENS

ACTIVE CITIZENSHIP THROUGH THE USE OF
NEW TECHNOLOGIES

September 2015

INTRODUCTION

The UN Convention on the Rights of Persons with Disabilities (UN CRPD) is the first international human rights treaty which addresses information and communication technologies (ICT) by establishing an obligation to the State Parties to take appropriate measures “to ensure persons with disabilities access, on an equal basis with others,(...) to information and communications, including information and communications technologies and systems” (Article 9, Accessibility).

Hence, the UN recognised the fact that accessible technology can be used by persons with disabilities to overcome certain barriers in order to live independently and enhance their participation in the society. Consequently, in the framework of the DISCIT project Work Package 7 (WP7), the study team undertook an in-depth comparative analysis on the regulatory forces and social and market factors that facilitate or hinder an Active Citizenship by persons with disabilities through the use of new technologies, and complemented it with personal experiences of persons with disabilities of three generations living in the nine DISCIT countries.

EVIDENCE AND ANALYSIS

There are studies that show that investment in new technologies might reduce the cost of the assistance for persons with disabilities. The interaction of persons with disabilities demanding technologies and the producers is mediated by different **Service Delivery Models** in all the countries studied, and especially with regard to assistive technologies (AT), which had a market value of €30 billion in the EU in 2010, and is dominated by SMEs (with the exception of hearing aids).

In the case of accessible technology, despite some good practices, a universal design approach is not sufficiently incorporated in the ICT industry market yet, which is very diversified and fragmented in

this field. Thus, the availability and affordability of accessible new technology depends on different factors: the legal framework (which generally includes binding accessibility provisions), standards, competition law, State research and production of accessible technology, and the schemes to assist persons with disabilities to access the technology they need. Furthermore, some difficulties still remain in the market such as cost, access to services like Internet, or language (80 % of assistive software is available only in English).

Accessible technology, understood as both AT and universally designed ICT products and services, increases autonomy and participation. Therefore, laws and policies affecting technologies for persons with disabilities can be a “conversion factor” that can eliminate certain budget constraints and foster the access to a certain goods and services thanks to public intervention. In the comparative legal analysis, the study team looked at:

- The **market** itself: regarding the incentives to the supply side, there is need for research and development, and subsidies to actual production of accessible technologies. In the EU, the State aid (also to this aim) is prohibited unless the Commission has been notified and has approved it. On the demand side, with regards to AT, the situation in the DISCIT countries is quite patchy, and AT are either not taxed, or provided through the health system.
- **Regulatory choices**: the study team studied the role of non-discrimination and accessibility legislation at EU level and national level in the countries studied by DISCIT.
- The role of **standards**: both accessibility standards, and interoperability standards.

Additionally, the life-course interviews with persons with disabilities shed more light on the importance of accessible technology and how this can enhance social and economic inclusion for persons with disabilities, both in short-term (inclusion in the labour market, education and social participation), and long-term (economic independence and social inclusion). For many people with disabilities interviewed, accessible technology enhances living in the community, as well as their free mobility and communication with others. However, differences in access and use of accessible technology exist depending on the disability type, being physical and visual disabilities the ones using accessible technology the most, and by contrast, the ones not using a mobile phone, computer or Internet were mainly persons with intellectual disabilities

When persons with disability look for accessible technology, apart from the common criteria of value, customer service, price and convenience, they typically gain access through an intermediary, informally (family/friends) or formally (an organisation). These **mediators**, or gatekeepers, can be both public sector (public agencies) and public sector service providers (insurance providers), which mostly rely on an eligibility determination based on health care and insurance providers, sometimes on the person’s income too.

- **Public Agency Model** (Ireland, Italy, Norway, Serbia, Sweden and the UK): health care providers or other governmental organisations authorised to distribute or finance accessible technology, in most of the cases both AT and ICT. In some countries (Ireland, Serbia and the UK), educational institutions also provide AT. Moreover, interest organisations, meaning non-profit or for-profit organisations engaged in supporting access to accessible technology, may also provide accessible technology, information about it or training and education support to these public agencies. This is the case of Ireland, Italy and Serbia, in which these organisations provide AT and ICT, or in Sweden, where these organisations cooperate with health care providers to determine eligibility to AT.
- **Insurance Provider Model** (Switzerland and Germany): these providers cooperate with public agencies, including health care providers in determining eligibility and providing accessible technology, and interest organisations also supplement the provision. Insurance providers also control access to financial resources, often in collaboration with public agencies and health care providers.

The study illustrated that **information, education and training** are useful resources for gaining access to accessible technology, which can come from public agencies, health care providers or interest organisations. Nevertheless, there are some conflicts between persons with disabilities and these gatekeepers such as: the selection of accessible technology, the need for more customizable devices, lack of consideration for the users' experience, lack of information, difficult procedure and eligibility criteria, etc. Gatekeepers typically determine the eligibility criteria, and there is the risk that technology providers may have a greater incentive to meet the demands of the gatekeepers than the users.

In a nutshell, these were the **barriers** identified:

- Availability barriers, a limited list of options to meet their needs.
- Technology barriers, meaning a limited usability of certain goods and services.
- Informational barriers, for the person to choose which technology suits him/her better.
- Procedural barriers, which limit an efficient procurement of accessible technology and create conflict over eligibility between persons with disabilities and the gatekeepers, i.e. the public agencies and insurance providers.
- Financial barriers, which also limit the person's choice.

POLICY IMPLICATIONS AND RECOMMENDATIONS

Many of the current systems of the provision of assistive technology across Europe appear to create barriers of access to accessible technology for people with disabilities. For information and communication technology cost and informational barriers were the most cited issue. This indicates a need to perhaps create subsidies or cost reductions to increase access to mainstreamed ICT for people with disabilities as well as ensuring that accessible information about accessible technologies exists and is effectively distributed to people with disabilities.

For assistive technology procedural barriers were an issue across the different systems of provision indicating that systems of provisions should be better evaluated on their ability to best serve the users with disabilities. In some cases it was clear that the personal preferences, experiences and opinions of the individuals with disabilities who would be using the assistive technology device are not taken into consideration in the provision process. Training of personnel may also be an issue as was illustrated with a comparison of interviews from Ireland and Sweden. Both systems involve the use of medical professionals to determine what types of assistive technology are needed but people with disabilities in Ireland were much more likely to complain about such interactions than people with disabilities in Sweden.

Another issue is the apparent lack of use and provision of assistive technology for people with intellectual and psychosocial disabilities. Despite the existence of such technologies many countries' accessible technology schemes either do not provide accessible technology to people with intellectual and psychosocial disabilities or are not actively publicising the availability of such technologies.

Thus, the policy recommendations would be:

1. Include people with intellectual disabilities and people with psychosocial disabilities in assistive technology provision schemes.
2. Creation of accessible information on available and accessible technologies Europe-wide for all people with disabilities.
3. Consideration of creating subsidies or other cost reduction methods for people with disabilities to access mainstreamed ICT.
4. Better training of AT provision personnel that emphasises the principles contained in the UN CRPD.
5. Ensure that AT provision systems include consideration of the viewpoint and preferences of the person with the disability that will be the end user of the AT device.

RESEARCH PARAMETERS

WP7 presents an analytical framework for a comparative analysis of accessible technology Law and Policy in the EU and the nine DISCIT countries (Norway, Sweden, Ireland, UK, Germany, Italy, Czech Republic, Serbia and Switzerland). After studying the interrelation between accessible technology and Active Citizenship, those regulatory forces, and the market and social factors in a review of the most recent literature on the topic, the researchers undertook a series of semi-structured interviews with persons with disabilities in those nine countries. These were life-course interviews with 204 participants from three birth cohorts and four disability types (physical, visual, intellectual and psycho-social). These interviews provided empirical evidences on the current use of accessible technology and how persons with disabilities usually access them.

Furthermore, the researchers carried out a series of interviews with experts on this field with the objective to give a comprehensive overview of the possible reforms in the assistive technology delivery system and the social regulation of the technology market to ensure that persons with disabilities have equal access to ICT and can fully exercise their active citizenship through the use of accessible technology.

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

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WEBSITE www.discit.eu

FOR MORE INFORMATION Bjørn Hvinden, Scientific Coordinator, HiOA - NOVA,
bjorn.hvinden@nova.hioa.no

Gerard Quinn, National University of Ireland
gerard.quinn@nuigalway.ie

Alejandro Moledo Del Rio, European Disability Forum,
alejandro.moledo@edf-feph.org

FURTHER READING Working Paper '*Analytical Framework for a Comparative Analysis of Accessible Technology Law and Policy*', January 2014

Working Paper '*Active citizenship through the use of new technologies – the experiences of three generations of persons with disabilities*', October 2014

Working Paper '*Best Practice in Producing Accessible Technology in Europe*', Forthcoming (October 2015)



EUROPEAN POLICY BRIEF



MAKING PERSONS WITH DISABILITIES FULL CITIZENS
ACTIVE CITIZENSHIP BY FISCAL INNOVATION

September 2015

INTRODUCTION

Securing economic independence is a key factor for persons with disabilities to achieve independent living and an Active Citizenship. Persons with disabilities may not be in a position to generate sustainable income from employment in the open labour market, making some kind of model of capital or asset accumulation absolutely necessary. DISCIT Work Package 8 (WP8) looked at the poverty traps and barriers in the existing redistributive systems for cash transfer throughout Europe.

The researchers reviewed the European Social Model and discussed possible ways to redefine this model and the role of the EU in supporting economic empowerment of persons with disabilities given that disability policy is one of the key areas that has been targeted for reform and recognised as being in need of further reform.

EVIDENCE AND ANALYSIS

Social protection, understood as the transfer of cash through social insurance and social assistance, is concerned with preventing, managing, and overcoming situations that adversely affect people's well-being. This encompasses three objectives: the maintenance of living standards in the event of social risks such as unemployment, sickness, disability or old age, combat poverty by guaranteeing a minimum income, and to cultivate social inclusion. The administration of this social protection can happen through different mechanism:

- by universal or contingency benefits, that are not related to income or employment status but to all individuals in a certain social category,
- by social insurance benefits, which are directly related to employment status and contributions paid into the social insurance scheme, and
- by income-related or means-tested benefits which depends on the current or recent resources of the beneficiary.

The **means-tested benefit system** takes into consideration not only income, but also the capital and assets of the person, and it can be aimed at providing a minimum income (poverty-tested benefits) or be withdrawn at a higher income level (general means-tested benefits). Furthermore, apart from the distinction between the schemes open to all or to certain groups, such as older people or persons with disabilities, there is also the distinction between cash and tied benefits, the latter entitling the beneficiary to a free or subsidised use of a specific service, such as housing. Targeting the beneficiaries is considered as the most efficient option, however it may also create problems in terms of intrusive enquiry, stigma, social divisiveness, low take-up, high administrative cost, and most importantly, poverty traps.

Generally, **disability related benefits** fall into one of these categories: social protection and income, transport, support for independent living, employment, education and training, housing, health care, information and communication, and access to leisure and cultural services. In these areas, the eligibility criteria are determined by the Member States (as disability is classified differently), and the EU law has not impacted on them. Consequently, given the diversity in terms of kinds of disability benefits provided, and the disability assessment and eligibility criteria, there is no mutual recognition of disability status across Member States.

Working-age persons with disabilities are much more likely to be unemployed and live in poverty, and many disability policies create **poverty traps** by failing in recognising this and devaluing their ability to contribute to their own support through work, since they are often developed on the presumption that they cannot work. These poverty traps are:

- **Unemployment** (double the rate of people without disabilities), which also limits social relationships and the generation of social capital.
- **Determination of eligibility for social protection disability programs** that rather encourages persons with disabilities to remain unemployed, given that to apply for these benefits people must demonstrate that they cannot work, whereas a significant number may actually be able to work.
- **Loss of benefits.** Some Member States sharply reduce benefits as the earnings of a beneficiary increase. Beneficiaries trying to augment their incomes through earnings will only do so to a limited extent.
- **Poor coordination systems for persons with disabilities.** The many in-kind supports available are administrated by a variety of agencies and private organisations with their own rules, which are usually complex, so many do not try something new, believing that they cannot rely on the system.
- **Expenditure on health care**, which can be up to 48% of the income of a household with a member with a severe disability.
- **Lack of exportability of disability related benefits** preventing persons with disabilities to move freely from one Member State to another, and in case they move, it will take time to receive a certain benefit, in particular social assistance benefits.

Additionally, the impact of the economic crisis and the budgetary stability measures affected the social protection programs of many countries. The latest data shows that more than one out of every five persons with a disability (21,1%) are at risk of poverty in the EU compared to people without a disability, and living in poverty can also increase the risk of disability.

Having highlighted this, there are differences among European countries in the way they focus on different aspects of the **European Social Model**. The researcher distinguished five models: Nordic, Anglo-Saxon, Continental, Mediterranean, and Central/Eastern European, and categorised according to two criteria: efficiency (if it provides sufficient incentive to work and generates relatively high employment rates) and equitable (if they keep the risk of poverty relatively low). The Nordic countries are both efficient and equitable and the continental and Mediterranean are described as inefficient and unsustainable. Nordic countries are high spenders, both on income maintenance and on active measures to assist persons with disabilities at work.

A more efficient social protection system would provide support to persons with disabilities to enter the open labour market and become active economic actors. This includes stimulating waged employment by developing active labour market policies, making workplaces more accessible and developing services for job placement, and on-going support.

By providing sufficient **support** to ensure that those who are working will achieve a higher standard of living with actions such as:

- Taking advantage of the advances in medicine, technology, training and workplace modification.
- Increasing public support for disability programs.
- Empowering persons with disabilities to participate in the economic mainstream.
- Addressing the unrealistically low societal expectations about the work capacity of persons with disabilities, and fighting against negative prejudices and stereotypes.

It is important to give those individuals who fall below the poverty line sufficient support to acquire the critical mass of capital necessary to raise themselves out of poverty, otherwise they will remain dependent on the social protection system, without having a chance to work. Therefore, to complement social protection policies an **asset building policy** is needed, as this has been shown to have positive outcomes on the lives of persons with disabilities (increased income flows, intergenerational transfers of wealth, increased political and civic participation, life satisfaction, self-efficiency, greater orientation towards the future and increased community involvement). Policies and programs that encourage and enable savings and asset accumulation are equally important.

Finally, incentives that make work pay would be a key component of any reforms of social protection systems.

As for the way to **redefine the European Social Model** as well as the role of the EU institutions on it, these are the recommendations:

- The European Commission to provide guidance to Member States on how to improve the administration of welfare policies.
- Promote transparency in social policy expenditure accounts for each Member State.
- Facilitate access to support and public services of the country citizens may choose to move.
- Ensure that all EU citizens are treated equally in each EU country with regard to recognition of disability, support and assistance, etc.

In regards to the **disability protection systems**:

- Those Member States where policies are not developed have a better chance to achieve convergence with other Member States if collaboration among them is improved.
- Countries should assist persons with disabilities to enter the labour market
- Achieve an effective and strategic mainstreaming of disability issues in national policy development.
- Allow exportability of social security systems, including social assistance benefits when moving within EU countries.
- Involve persons with disabilities in the discussions on developing and implementing actions affecting them.
- Apart from the High Level Group on Disability, the EU could use the Open Method of Coordination as a suitable governance tool for disability policy in the sense that it could contribute to the intervention of the EU in national disability policy and set up common objectives. This could also be a vehicle to introduce discussions regarding wealth accumulation models.

RESEARCH PARAMETERS

The study team focused on the design of redistributive cash transfer systems in Europe and how these create poverty traps and do not encourage persons with disabilities to be independent from the social protection systems. In addition to this, WP8 reviewed recent literature on the European Social Model and how this can be reformed in support of an economic empowerment of persons with disabilities, necessary to achieve an independent living and an Active Citizenship. To do so, an important aspect to study is the different proposals for asset-building models for persons with disabilities, distinguishing their weaknesses and strengths.

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FOR MORE INFORMATION Bjørn Hvinden, Scientific Coordinator, HiOA - NOVA,
bjorn.hvinden@nova.hioa.no

Gerard Quinn, National University of Ireland
gerard.quinn@nuigalway.ie

Alejandro Moledo Del Rio, European Disability Forum,
alejandro.moledo@edf-feph.org

FURTHER READING Working Paper *'How Redistributive Cash Transfer Systems in Europe
create Poverty Traps for Persons with Disabilities'*, July 2014

Working Paper *'EU's Role as a Party to the UN CRPD, Social Dialogue
Mechanisms at European Level and a Renewed European Social Model'*,
January 2015

Working Paper *'Asset-Building Mechanisms for Persons with Disabilities
in Europe with Recommendations for Reform'*, forthcoming (October
2015)



EUROPEAN POLICY BRIEF



ACTIVE CITIZENSHIP AS POLITICAL PARTICIPATION

September 2015

INTRODUCTION

Participation in political and public life is a crucial aspect of Active Citizenship. Political participation by organisations representing persons with disabilities is an important part of civil society in European countries. The conditions for and practices of civil society engagement differ among countries, and disability rights advocacy with its peculiarities has not been an exception.

The DISCIT Work Package 9 (WP9) studied the international and national structures of and for persons with disabilities to influence European and national policies, and how these organisations make actual use of existing frameworks. It also explored how the UN Convention on the Rights of Persons with Disabilities (UN CRPD) has affected those frameworks, both at international as well as national level, as a new legal and political opportunity structure for disability rights advocacy to realise the disability movement's motto of "Nothing about us without us" enshrined in the CRPD.

The CRPD recognises the right of individual political participation as well as "forming and joining organizations of persons with disabilities [...] at international, national, regional and local levels" (Article 29 CRPD). Further, it emphasises the role representative organisations of persons with disabilities are to play in "the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating to persons with disabilities" (Article 4.3 CRPD) including full involvement and participation in the monitoring process (Article 33.3 CRPD).

EVIDENCE AND ANALYSIS

In DISCIT's framework concept of Active Citizenship, social security is the precondition to personal autonomy, while both are required to claim and achieve political influence. Vice versa, political influence is a necessary condition to ensure security as well as autonomy.

However, political citizenship of persons with disabilities has not yet been widely covered by previous research. One of the findings of the literature review carried out by the DISCIT researchers proved that both **human rights and civil rights discourses** are essential to guarantee the full participation of persons with disabilities. The human rights discourse provides opportunities to universally claim full citizenship and equal rights, without any condition, while the citizenship approach is necessary to ensure the implementation of guaranteed rights in exchange for duties of the citizen. Basic political rights are twofold: They include individual and collective rights.

Regarding **individual political participation**, WP9 identified identity, general interest in politics, voting rights and enabling/hindering factors (such as identity politics, accessibility, social inclusion, social recognition, individual resources, etc.) as important aspects for individual political engagement. These factors are also essential for collective political participation. At this point, the study team highlighted that many persons with intellectual or psycho-social disabilities are disadvantaged due to denial of their legal capacity, which was emphasised by the DISCIT teams of the Czech Republic and Serbia. In general, we found these groups tend to be underrepresented and more vulnerable to discrimination than other groups of disabled persons.

Concerning **collective political action**, the researchers studied, as first step, **democratic cultures and governance environments** at the national level. According to international surveys, it appears that the best conditions for civil society engagement are provided in the countries of the social-democratic welfare regime (Norway and Sweden) plus Switzerland, followed by the liberal welfare regime (UK, Ireland), followed by Germany and Czech Republic, and finally by Italy and Serbia with the least favourable conditions. Additionally, with regard to the **actual engagement** in political parties and action groups among DISCIT countries, citizens in Norway and Switzerland seem the most committed, whereas the least are in the UK and Czech Republic. All countries ensure the free foundation of civil society organisations; restrictions remain in the case of Serbia, given the limits for people denied their legal capacity. The UK, Sweden and Switzerland seem to have less constraints for organisations in acquiring the status as legal entity, and only three countries, Italy, Norway and Sweden report on the requirement of registration to access to state subsidies.

As for the situation of disability rights advocacy and disabled persons' activism, WP9 distinguished between:

- **Disability organisations** as generic term, including all organisations of and for persons with disabilities, and national associations of same organisations, exercising influence in the interests of persons with disabilities.
- **Disability-related umbrella organisations, coalitions and networks**, as associations of different organisations of and for persons with disabilities focussing on disability rights.
- **Disabled people's organisations (DPOs)**, as organisations comprised by a majority of persons with disabilities - at least half of its membership -, governed, led and directed by persons with disabilities, in accordance with the UN CRPD Committee's understanding of representative organisations.
- **Other civil society and non-governmental organisations** that are relevant in disability rights advocacy as they engage in disability politics, but also have other activities (e.g. research, services) and / or issues (e.g. social policy, children's rights).
- **National disability councils**, as alliances of disability organisations at the national level that are also involved in supranational contexts for the purpose of achieving a common goal.
- **Disability-related advisory-committees**, set up as part of national governance, involving disability organisations (amongst them DPOs), other stakeholders and policy makers.

In general, regarding the applied welfare regime typology that the DISCIT project is using (four categories of welfare regimes: social-democratic, liberal, conservative, and post-communist), researchers found that there is not a comprehensive pattern of similarities and differences among them in regard to the disability-rights advocacy and activism.

Disabled people's organisations (DPOs) in the UK seem to have strong influence on disability policies; Germany, Italy, Norway and Sweden have a great variety of disability organisations that are also considerably influential, whereas in other countries studied by WP9 difficulties and barriers yet remain for an active and meaningful participation of persons with disabilities. There is evidence that the principle of self-representation - which is a crucial demand of the disability rights movement - has resulted in different practices at the level of **national disability assemblies**.

DISCIT countries reported differently in terms of mainstreaming disability beyond disability policies, such as the positive examples of Italy, UK, Norway and Sweden, where the influence opportunities are rather high through the disability-related advisory committees or other institutions or provisions.

With regard to the **UN CRPD** and its impact **at national level**, in all covered European countries DPOs and other disability organisations were involved in pushing for the **ratification** of the Convention. National informants and experts reported on different forms of involvement in **implementing** and **monitoring** the CRPD at national level. The DPOs' activities range from participation in advisory bodies, councils and committees or memberships in umbrella organisations to critically commenting on national implementation by conducting alternative or shadow reports. Some informants from national DPOs mentioned problems, for instance a lack of coordination in implementation processes, missing support and restricted participation on an unequal basis with official politics. Especially representatives of smaller DPOs identified funding issues and unequal participation opportunities.

Moving to the internationalisation of disability advocacy and how the CRPD has impacted activities **at supra-national level**, the researchers emphasised that the European level offers a new and differently structured venue for civil society organisations in terms of participation, in which organisations act differently than at national level. For instance, in European politics transnational networks of organisations, different advisory committees and expert groups are much more important.

The study team got the impression that the CRPD has not (yet) had such a big impact at the level of structures, since most of the opportunity structures in the European Union (EU) have already existed before the emergence of the Convention. However, its influence could be seen in the context of the Council of Europe (CoE), in which there was an impact regarding the political opportunity structures which facilitate the involvement of supra-national DPOs, through putting forward Collective Complaints or the Conference of International Non-governmental Organisations of the CoE.

At European level, the use of political and legal opportunity structures depends on further variables, such as the **internal structures and resources** of an organisation. Therefore, not all DPOs and other disability organisations considered by WP9 are making use of these opportunities, reportedly because of lack of funding and other resources. Regarding **activities**, not all organisations benefit from the same structures. While there are organisations that focus on the EU institutions and often refer to the CRPD, others work with the CoE and use the CRPD as a secondary point of reference.

The CRPD has not really changed the **issues** the disability organisations advocate for. This applies especially to DPOs, because organisations of persons with disabilities have been very involved in creating the CRPD, so there is already a match between DPOs priorities and the CRPD. The convention also has the function of providing a legal basis as well as a certain standard free of individual interpretation, an instrument to gain political legitimacy, and it frames the ways in which organisations express their claims. The CRPD also plays an important role to raise awareness on the rights of persons with disabilities among policy-makers.

Furthermore, the study team developed a theoretical typology of **strategies** based on the different degrees of consensus between stakeholders and these are collaboration, cooperation, controversy and

conflict. On one side of the spectrum, there are formalised and well-established organisations with large memberships most likely to adopt strategies of collaboration and cooperation, and on the other side, following strategies of controversy and conflict seems to be the priority of non-established, less professionalised forms of disability rights activism. Concerning strategies at international level, organisations rather tend to use strategies of collaboration and cooperation, and those of controversy and conflict are less prominent, with the exception of legal actions and alternative reports, which are written by DPOs and other (disability) organisations to the CRPD Committee reviewing the implementation of the Convention by the different State Parties. However, the reality is that a combination of strategies is probably used by all DPOs and civil society organisations.

POLICY IMPLICATIONS AND RECOMMENDATIONS

In order to realise the aims of the CRPD of full and effective participation, the European Union and its member states are recommended to create new opportunities for the effective individual and collective political participation of civil society.

Lack of accessibility has been among the most mentioned barriers to **individual political participation**. The EU should therefore stipulate higher standards to foster the implementation of the CRPD.

Most fundamentally, all member states shall recognise

- the right to legal capacity as stipulated in Article 12 CRPD to end the discrimination of persons with disabilities (in particular persons with intellectual disabilities or psycho-social problems)

As regards **collective political participation**, research findings of WP9 indicate that the EU and its Member States shall actively improve the opportunities for DPOs by

- facilitating joining and forming organisations of persons with disabilities
- ensuring that DPOs are actively involved in the monitoring and implementation of the CRPD, in particular by ensuring meaningful participation in structures established to implement and monitor the CRPD: monitoring bodies advisory bodies, committees and expert groups.

Findings have further demonstrated a correlation between resources and the quality of not only individual but also of collective political participation. While there is a lack of transparency as regards funding of civil society organisations, findings indicate that DPOs in many cases face serious financial problems preventing them from representing the interests of persons with disabilities and fulfilling the role of monitoring the CRPD implementation. The EU and its member states should therefore improve funding opportunities for organisations of persons with disabilities, especially

- to ensure the principle of self-representation within disability rights advocacy
- for smaller DPOs that are more dependent on project-based funding
- by providing funds to overcome language barriers in transnational exchange between DPOs, i.e. promoting the exchange of best-practice and mutual learning in European civil society

Further, the EU is advised to launch programmes and initiatives to stimulate media coverage on disability, human rights and political participation, disability mainstreaming and the role of civil society for realising the full and effective participation of persons with disabilities on an equal basis with others.

RESEARCH PARAMETERS

First, the study team analysed disability rights advocacy and activism at the national level. To do so, they carried out a comprehensive literature review and discovered major research gaps in the previous literature about the topic. They also distributed among the different DISCIT teams a questionnaire to shed light on the structures, practices and patterns of national disability organisations in the nine countries covered by the project. WP9 compared the reports from the nine countries keeping in mind the concept of Active Citizenship as defined by DISCIT's research framework as well as Esping-Andersen's welfare regime typology.

Second, to study the internationalisation of disability rights activism, the WP9 team generated empirical data through ten semi-structured expert interviews with members of European organisations of and for persons with disabilities, as well as internet resources, and publicly available documents.

Third, the researchers used empirical evidence gathered in the nine DISCIT countries, based on a series of interviews with experts of disability policies as well as representatives of DPOs and other disability organisations at the national level. As European countries WP9 considered the Czech Republic, Germany, Italy, Ireland, Norway, Serbia, Sweden, Switzerland and the United Kingdom.

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,
bjorn.hvinden@nova.hioa.no

Anne Waldschmidt, University of Cologne,
anne.waldschmidt@uni-koeln.de

Alejandro Moledo Del Rio, European Disability Forum,
alejandro.moledo@edf-feph.org

FURTHER READING

Working Paper '*A comparative analysis of Disability Rights Activism – with reference to the concept of Active Citizenship*', January 2014

Working Paper '*The internationalisation of Disability Politics – The new opportunity structures created by the UN CRPD*', January 2015

Working Paper '*The Involvement of DPOs in the Implementation of the CRPD – a cross-national comparative study*', October 2015 (forthcoming)