Making Persons with Disabilities Full Citizens - New Knowledge for an Inclusive and Sustainable European Social Model

Reporting

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DISCIT

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

Executive Summary:

The FP7 project DISCIT provides new knowledge about the diversity in disability policy in European countries and emerging possibilities for policy learning and innovation across Europe. This knowledge shows what steps policymakers and stakeholders need to take to enable persons with disabilities to exercise Active Citizenship and participate fully in society on an equal basis with others.

In DISCIT, 10 organisations (six universities, two research institutes and two Civil Society Organisations) from 10 different countries (Belgium, Czech Republic, Germany, Ireland, Italy, Norway, Serbia, Sweden, Switzerland and UK) worked intensively together over a period of three years (February 2013 – January 2016). Through the involvement of the European Disability Forum (EDF, Belgium) as one of the 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 during the lifetime of the project.

When examining how policymakers and stakeholders discuss disability policy and put it into practice, DISCIT has taken into account the different levels of governance involved and their interrelationships. First, international policy and law (notably the UN Convention on the Rights of Persons with Disabilities). Second, regional policy and law (EU legislation, strategies, Social Fund grants, etc.). Third, national policies (policy and law on cash transfer, services delivery and social regulation). Finally, subnational/local policies (systems of provisions and regulations). A major issue has been whether the decisions-makers succeed in coordinating actions taken at these different levels of disability policy governance and make these actions mutually supporting.

DISCIT collected and analysed data in three steps: First, the team started by synthesising policy documents and existing statistics and findings from earlier research. The purpose of this step, which the team mainly carried out in 2013, was to map and analyse the overall structures of national policy systems and developments in the situation of persons with disabilities over time. Second, during 2014, the team conducted 217 life course interviews with an almost equal number of women and men, with four main types of disabilities, from three birth cohorts (born around 1950, 1970 and 1990) and in nine countries (Czech Republic, Germany, Ireland, Italy, Norway, Serbia, Sweden, Switzerland and UK). The interviews provided new knowledge about the experiences and perceptions of persons with disabilities, and change and continuity within and across countries. Third and finally, in 2015, the team conducted 85 interviews with other informants (experts) in the nine countries to assess the actual development in disability policy and the degree of coordination between levels of policy governance in practice.

All this work led to eight Policy Briefs in different European languages, 60 varying dissemination activities (including conferences, press releases and videos) and 25 scientific Deliverables, of which DISCIT has published 22 as working papers on its website. The international publisher Routledge has agreed to publish the two main joint scientific publications from DISCIT - two edited volumes – by the end of 2016 or early 2017. Furthermore, four colleagues involved in DISCIT are currently working with their doctoral theses partly based on DISCIT findings. By 2017, DISCIT Consortium Members will have published at least 10 peer-reviewed scientific articles.

Project Context and Objectives:
Why has DISCIT focused on Active Citizenship? Internationally we have seen a growing interest in the

meanings of Active Citizenship, and particularly in how one can achieve that persons participate as active subjects in society rather than as passive objects of welfare benefits. In both the OECD and the EU, a prevalent perception has been that many people have become passive citizens: e.g. recipients of social security benefits rather than participants in the labour market, and inactive consumers rather than active co-producers of the services provided by public agencies or civil society organisations. According to these supranational actors, governments have to take actions to ensure that people are actively involved in the community and co-responsible for contributing to economic growth and their own wellbeing and social security through paid work.

With regard to persons with disabilities, a key concern has been that social protection systems have made beneficiaries of disability benefits and other social services in cash and in kind mere passive objects of other people’s help and concern. As a result, many observers claim that social protections systems are effectively excluding many persons with disabilities from opportunities to participate in the market, in civil society and in deliberation of public policy on an equal basis with others.

Organisations of persons with disabilities have for a long time demanded to be involved in policy-making and other decision-making of concern to themselves. The adoption of the UN Convention on the Rights of Persons with Disabilities (CRPD) has given an impetus for focusing on the opportunities for “full and effective participation in society”.

Altogether the various demands and expectations about involvement, co-responsibility and participation from national governments and transnational and supranational organisations (“from above”), as well as from the organisations of persons with disabilities (“from below”), have given reasons to ask what enables or prevents persons with disabilities in exercising Active Citizenship. In other words, what are the conditions for full and effective participation in society of persons with disabilities on an equal basis with others? Drawing upon existing conceptualisations of social citizenship, the team has examined three dimensions of citizenship: the security dimension, the autonomy dimension and the influence dimension.

The security dimension refers to whether persons with disabilities are able to avoid major uncertainties or the need for individual risk-taking (for instance in relation to financial matters), avoid constant worries about the future, and enjoy social protection against major life risks (such as illness, poverty, violence etc.). The autonomy dimension refers to whether persons with disabilities are able to avoid dependence or interference from, others, and able to live independently, exercise freedom and live the life they have reasons to want to live. The influence dimension refers to whether persons with disabilities have real opportunities to participate in public deliberation and decision making processes setting the framework for their own life as well as decisions aiming at the promotion of the common good. An underlying assumption is that three dimensions serve as mutual conditions for each other.

DISCIT has not only examined how things work today but also asked what needs to change to improve the conditions for persons with disabilities to exercise Active Citizenship in the future. For this purpose, the team has developed a threefold theoretical framework for analysing under which conditions one is more likely to achieve Active Citizenship for persons with disabilities:

1) A SET OF INTERRELATED INITIAL STRUCTURES serving as preconditions for decisions or actions

that may promote or hinder Active Citizenship. These structures include characteristics or dispositions at three levels:
- The disability policy system (macro)
- Business organisations, civil society, local community, family and kin (meso)
- The individual with a disability (micro)

2) A SET OF INTERACTING PROCESSES linking initial conditions and outcomes:
- Policies as governments implement and coordinate them in practice
- The diverse practices of employers, civil society and families
- The active agency of person(s) with disabilities

3) OUTCOMES
- The extent to which persons with disabilities exercise Active Citizenship to a greater extent than before – collectively and individually
- Whether a possible increased exercise of Active Citizenship by persons with disabilities includes ‘feedback’ mechanisms modifying the next iteration’s initial structures.

In this way, DISCIT has not only examined the initial conditions for participation but also identified the mediating mechanisms and processes that are influencing the extent to which persons with disabilities are able to exercise greater degrees of Active Citizenship than before. One important precondition for change is the national and supranational system of disability policy. By ‘disability policy system’, we refer to the totality of policy measures, with intended or unintended consequences, for the welfare, living conditions, autonomy, participation and dignity of persons with disabilities. By comparing the systems of disability policies in nine European countries and at EU level, DISCIT has examined the strengths and weaknesses of existing approaches and the scope for policy learning, improvement and innovation. For this purpose, DISCIT has distinguished between three subsystems of disability policy intended to meet the needs and risks of persons with disabilities:

- The cash transfer subsystem aims at providing income security for people out of paid work, at redistributing monetary resources, and compensating for higher expenses (e.g. for diet, transportation, heating).

- The social delivery subsystem aims at providing benefits in kind to compensate for disabilities and offering social services for medical assistance and rehabilitation, education and vocational training, assistive technology, personal assistance, and others which all mean to improve the independence and social participation of persons with disabilities.

- The social regulative subsystem involves government efforts at influencing the functioning of markets and the behaviour of non-governmental actors with the aim of promoting social policy objectives.

Both the cash transfer and services delivery subsystems aim at redistributing resources among differing population groups and equalizing life chances. The provisions seek to provide individuals with resources compensating them for disadvantages and enabling them to participate fully in the labour market and other sectors of society. General taxes or contributions from the protected person and employers are often financing the provisions. By contrast, social regulative policies aim at remedying market failures. Governments seek to influence the markets and their functioning as well as the behaviour of non-governmental actors, e.g. by setting legal standards for health, security and labour protection or by stimulating the development of industry standards for the accessibility and usability of products and services.

DISCIT has examined whether nine European countries (Czech Republic, Germany, Ireland, Italy, Norway, Serbia, Sweden, Switzerland and UK) have the right balance between the three subsystems and whether there are reasons to rebalance the subsystems. Although it has not been possible to examine the policies of all countries to the same extent and every detail, DISCIT has provided new knowledge about the diversity in disability policy in European countries and new possibilities for policy learning and innovation across Europe.

When examining the deliberation behind and the actual implementation of the disability policy, DISCIT has taken into account the different levels of governance involved and their interrelationships. First, international policy and law (notably the UN Convention on the Rights of Persons with Disabilities). Second, regional policy and law (EU legislation, strategies, Social Fund grants, etc.). Third, national policies (policy and law on cash transfer, services delivery and social regulation). Finally, subnational/local policies (systems of provisions and regulations). A major issue is whether the decisions-makers succeed in coordinating actions taken at these different levels of disability policy governance and make them mutually supporting.

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Third and finally, in 2015, the team has conducted 85 interviews with other informants (experts) in the nine countries to assess the actual development in disability policy and degree of coordination between levels of policy governance in practice.

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Project Results:

1. Introduction

The main scientific results of DISCIT relate to the following overarching issues and area-specific issues:

Overarching issues

a) How are the possibilities of persons with disabilities in nine European countries (Czech Republic, Germany, Ireland, Italy, Norway, Serbia, Sweden, Switzerland and UK) to exercise Active Citizenship? How have these possibilities developed over time, and more specifically; developed since the beginning of the millennium?

b) What are the main factors enabling and constraining people with disabilities in exercising Active Citizenship and participating fully and effectively in society? What roles do public provisions (cash transfers, services and regulations) play as enablers?

c) To what extent are some groups of persons with disabilities likely to face greater hindrances and barriers in exercising Active Citizenship than other groups?

d) Is it possible to construct a cross-national typology linking types of institutional arrangements (disability policy designs) and the prospects for persons with disabilities being able to exercise Active Citizenship?

Area-specific issues

e) How have the possibilities for community living developed over time in the nine European countries? What are the main factors enabling and constraining persons with disabilities in achieving community living?

f) How have the possibilities for employment for persons with disabilities developed over time? What are the main factors enabling and constraining persons with disabilities in participating in the labour market and achieving economic independence?

g) How have the possibilities for persons with disabilities for exercising influence by participating in organisations and political affairs developed over time? What are the main factors enabling and constraining persons with disabilities in exercising influence?

h) How have the roles of information, communication and other technologies as conditions for exercising Active Citizenship developed over time? What are the main factors influencing the accessibility, usability and availability of such technologies?

i) How has the possibilities for exercising Active Citizenship by persons with psychosocial disabilities developed over time? What are the main factors of enabling and constraining nature experienced by persons with disabilities? What role do social services in a broad sense play as enabling factor?

j) How can redesign of redistributive provisions promote asset-building, stable economic well-being and freedom of mobility among persons with disabilities? What lessons can European policymakers draw from innovative redesign in other parts of the world?

k) What kind of systematic knowledge do European policymakers need to assess the effectiveness of policies to strengthen the possibilities of persons with disabilities to exercise Active Citizenship? How can relevant authorities take steps to make European surveys and regular statistical registrations of relevance for the situation of persons with disabilities and disability-related policy efforts more truly cross-national comparative?

In the rest of this part of the Final Report, we start with the area-specific issues and deal with the overarching issues in the final section.

2. Area-specific issues related to achieving Active Citizenship for persons with disabilities

2.1 Active Citizenship through community and independent living

Issues:
o How have the possibilities for community and independent living developed over time in the nine European countries?
o What are the main factors enabling and constraining persons with disabilities in achieving community living?

The UN CRPD, Article 19, states that supporting disabled people to live in the community as equal citizens is an issue of human rights. The segregation of disabled people in institutions is a human rights violation in itself. More specifically, living in the community is a key pre-requisite for Active Citizenship.

Overall, the nine DISCIT countries - Czech Republic, Germany, Ireland, Italy, Norway, Serbia, Sweden, Switzerland and the UK – have seen considerable developments in the last decade towards community based support for people with disabilities. Yet, one still needs to make substantial progress. In some countries, institutional provision is still the main form of provision, especially for those with more severe disabilities. In all countries, services for more than 30 people on one site still exist. In Norway, however, this is only the case for a very few people with multiple and profound physical disabilities (e.g. following an accident). In Sweden, such services exist only in the form of acute services for people with mental health problems. Even in countries where the process of closing the older hospitals has completed, observers report a trend towards re-institutionalisation. In terms of Active Citizenship, people with disabilities (especially those with more severe disabilities and in particular those with intellectual disability) have little choice over where they live, with whom they live and who supports them. They experience lack of freedom even within their own homes and lives and often do not receive the support needed to support their inclusion in their local communities. People with disabilities still face disadvantages in terms of employment and access to community facilities, despite policies that exist to ensure equal opportunities and access.

Challenges to Active Citizenship for people with intellectual disabilities include issues such as mistranslations of the UN CRPD, the state of nations financially and politically, associated limitations in spending on social services. Moreover, there is a lack of progressive mental capacity legislation and attitudinal barriers. The introduction of direct payments, personal budgets or personal assistance facilitate Active Citizenship but have not always resulted in any significant improvement and, contrary to expectations, do not always result in a decline in the number of people requesting places in institutional services. In addition, in most countries, even in Norway and Sweden, these systems are only really an option for those with less severe disabilities. Only in the UK are people with more severe disabilities able to access personal budgets and personal assistance on a regular basis. A key factor in determining the quality of people’s lives is the approach and skills of staff who are supporting them. This has important implications for the training of staff who are supporting people to live in the community.

2.2 Active Citizenship through employment and economic independence

Issues:
o How have the possibilities for paid employment for persons with disabilities developed over time?
o What are the main factors enabling and constraining persons with disabilities in participating in the labour market and achieving economic independence?

All available statistical data on labour market participation indicate that persons with disabilities tend to have lower employment rates than persons without disabilities. Even if one takes the necessary reservations for possible shortcomings of available cross-national data in terms of validity and reliability, there is no reason to doubt that there has been an enduring gap in employment in all the nine DISCIT countries. This gap has persisted despite the policy efforts of national governments, supported by the OECD and the EU Employment Strategy over two decades, as well as by the 2000 EU Employment Equality Directive and the Europe 2020 Strategy. In those countries where the employment gap did diminish (particularly from 2008) this tended not to be because more disabled people entered employment, but because employment rates among non-disabled people decreased. Moreover, in most countries, women with disabilities have lower participation rates than men with disabilities. Similarly, increasing age is typically associated with lower employment rates. Severity of disability is largely consequential for levels of employment, as well as for how people interact with the labour market (for instance, whether they go into sheltered or supported employment). The higher level of education, the more likely also persons with disabilities are to be in employment. Finally, people with psychosocial and intellectual disabilities are, to varying degree, more disadvantaged in the labour market than people with physical disabilities are. There is still a need for research to understand the underlying mechanisms generating these differences in the employment chances of subgroups of persons with disabilities.

By looking at the disability policy systems in each country it is possible to identify a range of provisions that the nine DISCIT are using to different degrees and in different combinations:

From the social services sub-system, nearly all the countries use supported employment or employment programmes (these include work experience programmes, internships and integration procedures). These interact with the open labour market and aim to equip people with skills and capacities necessary for them to work towards gaining employment. Governments use these in different ways, with some being more structured than others are. In many countries, there is a clear focus on increasing the number of supported work positions available or on encouraging entry onto employment programmes. Often the motivation is integration or inclusion into ‘ordinary’ places of work. For instance, governments claim that integration is a guiding philosophy. However, in many cases, the reality may be more complex, with integration occurring for some, whilst others, notably with severe learning disabilities, end up in sheltered employment outside the regular labour market. Sheltered workshops (social cooperatives in Italy) provide an alternative to the open labour market. People who have learning or psychosocial disabilities, as well as other categories of people who are disadvantaged in the labour market, often populate these workshops. They usually offer participants a nominal payment for their labour, or are on benefits. In some countries sheltered workshops are supposed to be temporary (as in Germany and Sweden, for instance) and services operate to move people out of them. Data suggests however that some people may stay in them for considerable amounts of time.

From the social regulation sub-system, we find attempts in each country to influence the operation of the open labour market by clarifying companies’ responsibilities in relation to the employment of people with disabilities. Quotas and anti-discrimination legislation aim to help disabled people into work by obliging their employment or prohibiting discrimination against them. Some countries, like Germany and Serbia, use both. Employment obligations are in place in central or Southern Europe (Germany, Italy, the Czech Republic and Serbia). In Northern Europe (Sweden, Norway, Ireland, UK), anti-discrimination and work environment laws and social services are meant to encourage the employment of people with disabilities (Switzerland also falls into this second category). These provisions involve a range of differences in the extent to which private employers are obliged to employ people with disabilities, or in the degree to which they actually are preventing the discrimination of job seekers with disabilities in recruitment practices, when compared to the situation in the public sector. There is also a number of financial incentives for employers to modify their behaviour. For instance, tax relief, wage subsidies, contributions towards the cost of reasonable adjustments, and access to technologies and equipment aim to compensate for any cost to employers that come with employing people with disabilities.

Finally, many countries use income maintenance measures. Typically, countries with highly developed welfare systems used incapacity benefits, sickness benefits, or disability pensions for people assessed to have very limited or no working capacity. Increasingly, governments make cash benefits temporary or provisional, linking them to the two other sub-systems through conditions, which require engagement with them.

For most of the DISCIT countries, the UN CRPD arrived at a time when there were well-established ways of managing participation in the labour market for people with disabilities. The majority of policy systems have a long history (for example, Switzerland’s system of insurance and Italy’s quota system). Consequently, for the most part, the UN CRPD has, not informed the creation of disability policy systems but stimulated modifications of these, for instance by introducing anti-discrimination legislation and notions of reasonable accommodation, which had not already existed or only weakly defined before. The transposition of the 2000 EU Employment Equality Directive may also have stimulated or shaped such modifications.

In sum, the conclusion is that policy interventions aimed at increasing the employment rates of disabled people have had limited impact. Furthermore, some groups within the disabled population such as people with mental health conditions or with learning disabilities continue to fare poorly. Whilst exceptions of apparently successful provisions exist, it is more common that impacts have either been small or that we do not have the evidence to suggest either success or failure. In particular, there are few robust evaluations of policy interventions on which to draw. Even when researchers have used randomised control trials or quasi-experimental methods of evaluation, they have struggled to capture small effects. Still there is immense scope for improvement in existing policy measures and for developing new policy ideas. Yet, a general constraining factor in this context is that employers in the private sector make their decisions to hire or not based on their risk perception and on what they see as being in the best interest of their company.

2.3 Active Citizenship through exercising influence on decision-making

Issues:
o How have the possibilities for persons with disabilities for exercising influence by participating in organisations and political affairs developed over time?
o What are the main factors enabling and constraining persons with disabilities in exercising influence?

Disability rights activism as a type of organised civil society has been and continues to be vital in campaigning for and implementing social and political change in European societies. Yet, the conditions for and practises of civil society engagement of persons with disabilities differ among the nine DISCIT countries. Moreover, we find a complex situation in Europe regarding the conditions for the establishment of civil society organisations, the freedom of forming associations, registration procedures, the importance of formal registration for the status as a legal entity, access to state subsidies, and finally yet importantly, funding opportunities. There is a great variety of disability-related associations: organisations of and for persons with disabilities ('DPOs' in a strict sense), diverse umbrella organisations, national disability councils and other relevant organisations. Most state authorities have established all-encompassing advisory committees. DPOs in the UK, Italy, Norway and Sweden seem to have relatively high influence on disability politics. There are indications of a significant impact of the UN CRPD as well. Concerning national disability councils, admission requirements for membership range from very liberal approaches to strict quota-determination in our country sample.

An analysis of the life-course interviews from the Czech Republic, Germany, Ireland and Sweden revealed a number of barriers in relation to political or organisational engagement and the use of participatory opportunities. These factors included – ordered according to how often interviewees mentioned them:

o Inaccessibility: refers mainly to spatial or physical inaccessibility, e.g. when a building, where meetings take place, is inaccessible, but also includes mobility issues, when it proves difficult to get to meetings (due to inadequate public transport etc.). Persons with mobility impairments mentioned inaccessibility more often than persons with other kinds of impairments did. Persons with intellectual impairments report on difficulties with public transport (also linked to questions of resources). Interviewees from the Czech Republic and Sweden mentioned inaccessibility less frequently than interviewees from Germany and

Ireland did.

o Lack of Resources: refers to three basic forms of lack of resources: restrictions of time, lack of financial resources and reduced energy or capacity related to the person’s health condition.

o The impairment itself: refers to experiencing it as limiting in the sense of resources or involving ‘motivational’ limits, the latter mostly related to psychosocial problems.

o Complexity: refers to the perceived high complexity of politics, making it difficult to understand. Persons with intellectual impairments mentioned complexity most often, emphasising other indications that persons with intellectual impairments are among those mostly excluded from participation in politics.

o Lack of information: refers to the need to have access to basic information to be able to participate, like for example the knowledge that a specific self-help group exists, before he or she can become engaged. Persons with intellectual impairments or psychosocial difficulties, especially younger persons, mention lack of information most frequently.

o Prejudices and attitudes of other people: refers to experiencing that other deny them recognition for their abilities or reject them as possible candidates of political parties. Persons with mobility impairments and psychosocial difficulties refer most frequently to this barrier.

o Organisational structures: Only few of the interviewees mention organisational structures as a possible barrier for involvement. One aspect is the age structure of an organisation.

o Fear of stigma: refers to interviewees' fear of stigma if they became active in a disability organisation. This barrier is in particular linked up with engagement in disability organisations as one has to self-identify and 'come out' as a disabled person when becoming a member or acting as representative of such an association. However, the perceived risk of stigma may also relate to the general image of disability in society and to one’s own perspective on disability.

In short, this analysis confirms that individual lack of resources directly affects a person’s opportunity or likelihood to become engaged in organisational and political activity. Another general finding is that persons with learning difficulties and persons with psychosocial disabilities face profound disadvantages. Segregating and institutional settings remain a reality for these two groups affecting considerably their possibilities to exert autonomy and influence. The life-course perspective emphasises that they are not only excluded from community living, but also less likely to engage in organisational and political participation.

Another part of the analysis of the scope for influence shows that the CRPD has an impact on political opportunity structures for exercising influence. This in turn facilitates the involvement of supra-national DPOs to have an impact on the implementation and use of the CRPD. The actual use of the available opportunity structures, however, depended on various factors such as individual dispositions and resources (‘internal structures’) and the funding and resources available for organisations. Therefore, not all DPOs included in the analysis were equally capable to make use of the new opportunities.

2.4 Active Citizenship through the use of new technologies

Issues:
o How have the roles of information, communication and other technologies as conditions for exercising Active Citizenship developed over time?
o What are the main factors influencing the accessibility, usability and availability of such technologies?

Overall, the results demonstrate a positive impact of accessible technology in supporting both short-term and long-term changes in the life courses of persons with disabilities and expanding the individual’s imagination about a life they can aspire to lead. The findings about changes in the lived experiences of persons with disabilities show how Europe can use the new technologies to achieve more inclusivity and higher levels of Active Citizenship. Access to and use of accessible technology contributes to both short-term changes in the daily functions of life and long-term fundamental changes in the life course and contributes to the effective exercise of Active Citizenship among persons with disabilities. At the same time, the findings also clarify barriers to accessing and using accessible technology:

1) Differences in access to and use of accessible technology among persons with different disability types may constrain efforts for enhancing Active Citizenship, particularly among persons with intellectual disabilities,

2) Gatekeepers, including public agencies and insurance providers, control access to physical and financial resources for procuring accessible technology and through the ways they carry out this control, they can inhibit access to accessible technology,

3) Accessible technology influences changes in an individual’s life course, including short-term transitions in education, employment and community living and long-term fundamental changes that improve economic independence and social inclusion,

4) 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 short, while differences in disability type relate to characteristics of use, country differences determine how individuals are able to procure accessible technology. In the life-course interviews, the people who spoke about using assistive technology were most likely people with mobility disabilities or people with visual disabilities. People with intellectual disabilities and people with psychosocial disabilities who did not use assistive devices attributed non-use to a variety of factors: lack of need, lack of information, and lack of interest in use. Some of the cross-national differences in use of assistive technology reflected that use of certain types of assistive devices (i.e. TYFLOSET, DAISY Players and Swiss Trac) were specific to certain countries. Gender differences in use of assistive technology existed in two areas: women with disabilities were more likely to mention tablet use and women with disabilities were more likely to discuss how their assistive technology (cane, guide dog, mobile phone) made them feel safer.

People with disabilities procured technology through a variety of systems both private and public. There were two general categories of systems: 1) Public Provision Systems, where a government agency provided the assistive technology through some system, and 2) the Insurance Provider System, where a nationally funded health system provided the assistive technology through the insurance scheme. In addition to these systems, there were also disability organisations or other NGOs that provided technology. Virtually all the provision systems as described in the interviews had gatekeepers that controlled and mediated access to the technology. Several people interviewed spoke of preference for accessing assistive technology through the private market because of dissatisfaction with the public provision system. In some cases, these gatekeepers created procedural barriers to access.

There were five main barriers to accessing assistive technology: Procedural, Financial, Availability, Informational and Technological. Procedural barriers encompassed rejections by insurance companies, difficulties with the organization responsible for providing the assistive technology and lengthy waits to receive the technology because of the procedures involved. Availability barriers referred to a lack of choice available to the person, usually in insurance schemes where the person would only have one choice of an assistive technology device regardless of what the person's needs were. Technological barriers meant that the assistive technology, which the person needed, did not exist or what existed did not work for them. Informational barriers indicate that the person did not have enough information to find the assistive technology they wanted or needed. Overall, procedural and financial barriers were the most commonly cited barriers to accessing technology. Women with disabilities were more likely to encounter procedural, technological and availability barriers.

All DISCIT countries have at least one national law that mandates some level of public sector website accessibility. Informant interviews from the different DISCIT countries indicated that despite this, one had not fully achieved actual accessibility of public sector websites at all levels of the DISCIT states. The informants cited lack of monitoring, awareness and enforcement of the laws on public website accessibility as reasons for the lack of full compliance with the website accessibility laws of the different countries. Issues included the exact meaning of web accessibility and the ways in which certain groups of people with disabilities. For instance, one often does not consider the needs of people with autism or intellectual disabilities in the definitions of web accessibility.

Some key informants discussed the existence or non-existence of formal ties between assistive technology providers and developers and people with disabilities. Although some countries had networks of cooperation between assistive technology providers and DPOs, other countries found such cooperation completely absent or actively hindered. Informants also discussed what constitutes representation and the logistics of representing all people with disabilities. They noted that in some countries DPOs are organised around disability, which makes it difficult to coordinate complete representation of people with disabilities, as it would involve many different organisations. In some cases, there may just be room for one DPO in a system of cooperation resulting in a DPO representing only a small subsection of people with disabilities.

Moreover, in some countries, the public systems of provision of assistive technology do not adequately allow for hearing the voice or opinion of the person with a disability or the person face other high transaction costs. As a result, people with disabilities, including people with disabilities on fixed incomes, buy assistive technology on the private market in order to avoid the hassle and indignity of the public provision system. Informants also pointed to the changing national definitions or focus of universal design and the challenge of incorporating all groups of people with disabilities into the definition. The lack of focus on universal design for people with intellectual disabilities and psychosocial disabilities in countries that otherwise had strong universal design policies was mentioned. There were also discussions around how to ensure adequate accessibility for all groups and how increasing accessibility for one group can sometimes make it inaccessible for another.

Many of the life course interviews showed how increases in ICT accessibility, advances in technology and relatively lower prices are resulting in everyday ICT (such as smart phones, other mobile devices and “apps”) being used as a substitute for freestanding assistive devices. Despite this change, few of the interviewees would be able to get access to these devices through assistive technology public provision systems. Key informants discussed the legal roadblocks that exist to restrict the ability of states to fulfil this obligation. In some cases the laws on assistive technology are old (and perhaps inflexible), so new technologies are not covered. In other cases, governments are slow to take on successful pilot programs that rely on new technologies.

2.5 Active Citizenship for persons with psychosocial disabilities - social services as enablers

Issues:
o How has the possibilities for exercising Active Citizenship by persons with psychosocial disabilities developed over time?
o What are the main factors of enabling and constraining nature experienced by persons with disabilities? What role do social services in a broad sense play as enabling factors?

The findings from the life-course interviews with persons with psychosocial difficulties showed that although the participants’ life trajectories have been characterised by a variety of experiences and events, they also have striking similarities in the sense that mental ill-health had started early in life (in childhood or in youth) and had left clear marks on their lives. Periods of mental ill-health had alternated with periods of good health. Both the demands of the environment and the individual’s capacity to increase his/her level of personal potential, alone or with help of family, friends, professionals or other actors, had significance. Timely and adequate measures of care and recovery played a crucial role in restoring the conditions for health. Many informants are able to be full-fledged citizens if they have access to the necessary conditions, both at personal level, interpersonal level and at societal level. In relation to life areas like access to mainstream education, job and occupation, and contacts with public and private welfare providers, informants reported that support from parents, teachers, employers and other persons was crucial.

Situations of mental ill-health were more likely to happen during moments of ‘transition’, e.g. when individuals had to face increased demands of the environment due to changes in the workplace or in the family. Therefore, social services have a major role to play, not only to prevent the recurring apparition 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 various needs of the individual.

Findings indicate that perspectives on psychosocial disabilities varied in terms of definitions and organisation of services. All the interviewed experts stated that psychosocial difficulties were associated with stigma, discrimination and that there was a general lack of knowledge about psychosocial disabilities. In some countries, a medical model of psychosocial disabilities was still salient. This meant that services to persons with psychosocial disabilities were assessed and provided within the framework of a mental health care system. In other countries, we can see the contours of an emerging social approach to psychosocial disabilities emphasizing community mental health services and life in the community.

Cash benefits available for persons with psychosocial disabilities varied between the nine countries. Encompassing systems of benefits designed to protect against major life risks and economic uncertainties dominated in the Scandinavian countries (Norway and Sweden) in terms of universal social insurance coverage (supplemented by means-tested social assistance). Systems with different mixes of modest universal transfers, means-tested social assistance and social insurance plans existed in other countries (United Kingdom, Ireland and Germany). In Italy, providing for persons with psychosocial disabilities largely depended on family resources according to principles of subsidiarity. Experts in the post-communist countries (Serbia and the Czech Republic), gave evidence that as these countries were turning away from relatively generous social benefits during the Socialist era, these were replaced on the one hand with strict needs-test in the emerging social benefit programs, and on the other hand to get away from lenient practices regarding early retirement.

When it comes to social services of relevance for persons with psychosocial disabilities, some countries had made significant achievements through early deinstitutionalisation of mental health services (i.e. the closing down of mental hospitals in Norway, Sweden, Italy, United Kingdom). Others found themselves in the beginning of this process (Serbia, the Czech Republic) and others had reached “halfway” (Germany, Switzerland, Ireland). However, evidence in all the countries indicated that policymakers had not established community mental health services to an acceptable degree. In addition, the public-private mix in services to persons with psychosocial disabilities varied. The Scandinavian countries have permitted private providers to take on outsourced, but publicly financed, services. The UK and Ireland have longer traditions of private providers. In Ireland, NGOs and Churches also play a significant role, and in Italy the family, NGOs and Social Cooperatives are crucial components in the public-private mix of services. Germany and Switzerland, with strong traditions of insurance companies (public, private) financing and providing for social services, form a special group. These two countries also display large differences within in each respective country because of the relatively high autonomy ascribed to the Länder respectively Cantons. We could also observe regional differences regarding mental health services in other countries due to the autonomy of local authorities or semi-autonomous municipalities.

Social provisions for persons with psychosocial disabilities in the nine countries are the outcomes of different national policy designs. In some countries, also intra-country variation was significant. One can only understand national policies in the context of nation-specific historical legacies. Yet, the findings do not point to coherent national models at all. However, we could discern three dimensions of change in terms of Active Citizenship. First, the spending on cash benefits and social services has travelled from the family (or segregated institutions) towards public or public-private-NGO configurations of service provision. Secondly, entitlement to publicly financed services increasingly builds on individual citizenship (with various consequences in terms of Active Citizenship). Third, as persons with psychosocial disabilities are increasingly dispersed and visible in the community, there is a growing need to deal more systematically with the interrelated issues of strengthening community-based services and user-influence.

2.6 Active Citizenship through redesign of redistributive systems – promoting asset-building and freedom of mobility for persons with disabilities

Issues:
o How can redesign of redistributive provisions promote asset-building, stable economic well-being and freedom of mobility among persons with disabilities?
o What lessons can European policymakers draw from innovative redesign in other parts of the world?

Many disability-related provisions create poverty or welfare traps by failing to recognise that persons with disabilities are capable of participating in the workforce and consequently devalue the considerable ability of people with disabilities to contribute to their own support through work and by encouraging people with disabilities to retire early even when they still have some work capacity. Support programmes and other policies that assume that people with certain physical or mental conditions cannot work create a poverty trap for many people with disabilities. Instead of helping and encouraging people with disabilities to use their own abilities to stay out of, or escape from, poverty, they build on the presumption that people with disabilities cannot work, and so they provide most of them with low levels of benefits. Today’s policies do little to help people with disabilities overcome poverty or protect themselves from poverty in the first place using their own abilities. There is clearly a need to enhance income security programs, in terms of eligibility, adequacy and efficiency, to reduce the high rate of poverty among persons with disabilities and to help offset their associated additional costs.

Economic well-being does not come solely from income, spending, and consumption, but also requires savings, investment, and accumulation of assets, because assets can improve economic independence and stability, connect individuals within viable and hopeful future, stimulate development of human and other capital, and enhance the welfare of offsprings. If persons with disabilities become more powerful economically, decision makers and policy makers will need to take them more seriously.

For these reasons, this part of DISCIT examined various asset-building mechanisms for persons with disabilities across the world. Specifically, it shows how asset-building and wealth accumulation mechanisms are means of securing Active Citizenship for persons with disabilities. Assets are a key factor in opening doors for the disability community. With assets, the purchase of a home, postsecondary 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 futures, but they provide a psychological orientation toward the future.

Examples of asset-building systems include the National Disability Insurance Scheme (NDIS) Act 2013, a healthcare program that provides individualised support for eligible people with disabilities, their families and carers in Australia. In the United States, Individualised Development Accounts (IDAs), match savings accounts designed to enable low-income families to save towards a targeted amount. Still in its infancy, the Achieving a Better Life Experience (ABLE) Act in the United States amends the federal tax code to allow Section 525A tax-exempt saving accounts for disability-related expenses. This allows federal law to disregard ABLE account funds for means-tested federal programs such as Supplemental Security Income (SSI) and Medicaid (the US national healthcare system). The highly successful Registered Disability Savings Plan in Canada is a long-term savings plan designed to enable individuals with disabilities and their families to save for their future financial security. The first of its kind in the world, the program consists of the Canada Disability Savings Grant, that matches personal contributions and the Canada Disability Savings Bond that provides funding to RDSPs of people with low and moderate incomes.

This examination has identified savings plans that have great potential to diminish poverty, not just for people with disabilities but all of those that fall below the line of poverty. They offer people with disabilities the chance to accumulate savings and to use them without fear of claw backs by income assistance programmes. Without these types of accounts, many people with disabilities have very limited avenues to save and allow for further independence. Though these plans are exciting new tools that will go a long way towards improving future financial security, there is still a need to look at the full range of planning options available including wills and estates, trusts, supported decision-making and home ownership. Financial security for persons with disabilities requires a more creative approach than just asset accumulation models. Person with disabilities have only achieved financial security when they can get a paid job without losing their social benefits, continue to build assets and accumulate assets and wealth from wills, estates, gifts etc.

2.7 Active Citizenship through regularly up-dated and systematic knowledge for policymaking – more relevant indicators and frequent measurement of progress towards Active Citizenship and the impact of policies

Issues:
o What kind of systematic knowledge do European policymakers need to assess the effectiveness of policies to strengthen the possibilities of persons with disabilities to exercise Active Citizenship?
o How can relevant authorities make European surveys and regular statistical registrations of relevance to the situation of persons with disabilities and disability-related policy efforts more truly cross-national comparative?

If the EU and governments of member states are to make progress towards increased Active Citizenship for persons with disabilities there is a strong need for the development of a sound methodology and valid and reliable data that are suitable for this purpose. One need to have access to or create data that enable the EU and national governments to measure whether one had made progress on each of the three dimensions of Active Citizenship (security, autonomy and influence). Moreover, one requires systematic indicators of the barriers and enablers of Active Citizenship. To the extent that one would like to benchmark and identify which country that succeeds best and on the basis of what policy instruments and other conditions, one also needs to ensure that data are truly cross-nationally comparative, that is, , that one measures the same thing in the same way in all countries to be compared. Altogether, this could serve as a step towards more effective multilevel policies to remove barriers and strengthen enablers for Active Citizenship. Finally, it would enhance the likelihood of actual use of the indicators related to Active Citizenship if one was able to harmonise these with the indicators required in the monitoring and assessing of the implementation of the UN CRPD in member states.

As a first step, DISCIT sought to find appropriate ways to empirically specify and operationalize the concept of Active Citizenship and its three dimensions. As a second step, DISCIT translated these operationalisations into a proposal for 47 indicators of Active Citizenship (see Table 1). The strategy adopted involves the distinction between indicators more suitable for quantitative data on socio-economic conditions, and indicators more relevant to the rich, subjective information collected by the Life Course interviews. As a third step, DISCIT asked whether it is possible to harmonise these indicators with a great number of (if not all) indicators required for monitoring and assessing the implementation of the UN CRPD. Relying on the received model for human rights indicators, produced by the Office of the High Commission for Human Rights in 2008, and learning from the challenges identified during the implementation of the DISCIT project, DISCIT presents a detailed proposal of how one can map DISCIT indicators for Active Citizenship onto the Articles and provisions of the UN CRPD. The harmonisation exercise yields a potential set of Structure, Process and Outcome human rights indicators that are applicable to task of monitoring the implementation of the Un CRPD (as mandated by CRPD Articles 31 and 33). Although the scope of DISCIT Active Citizenship indicators is surprisingly broad, in terms of coverage of CRPD Articles and provisions, there are inevitably some UN CRPD provisions for which there are no relevant DISCIT indicators. At the same time, it is clear that all of the proposed DISCIT indicators are relevant to the UN CRPD.

Table 1: Proposal for 47 indicators of Active Citizenship for persons with disabilities

SOCIOECONOMIC INDICATORS (Social Practices and External Outcomes)
1. Annual Spending on cash and in kind benefits programmes
2. Rate of non-take-up of benefits in cash and kind
3. Rate of poverty before and after transfers
4. Prevalence difference between disposable income for persons with disabilities
5. Prevalence of severe material deprivation
6. Rate of use of different living arrangements
7. Rate of use of in-home, residential or community support services
8. Rate of use of personal mobility and communication supports,
9. Rates of distinct employment patterns
10. Rates of participation in organisations and campaigns
11. Rates of participation in conventional politics
12. Prevalence of discrimination

CONTEXTUAL INDICATORS (External Structures)
13. Structure of social benefit system
14. Structure of social services system
15. Structure of social regulation system
16. Structure of legal and practical provisions for effective and full participation in public, political and organizational life
17. Structure for co-determination in personalised services
18. Accessibility system
19. Anti-discrimination system

EXPERIENCE INDICATORS (Internal Structures, Practices and Outcomes)
20. Health condition and coping styles
21. Dispositions
22. Perceptions and judgments of self and others
23. Knowledge
24. Reaction
25. Critical awareness
26. Accessibility
27. Discrimination
28. Availability, adequacy and relevance of benefits
29. Participation in efforts to achieve security improvements
30. Social accept or stigma
31. Poverty traps
32. Conditions for receiving cash or services
33. Change in benefits
34. Change in standard of living
35. Degree of economic freedom
36. Previous and current living arrangements
37. Participation in efforts to achieve autonomy improvements
38. Stigma related to living arrangements
39. Accessibility, availability, adequacy, quality of supports
40. Shift towards independent living
41. Accessibility, availability, quality of in-home, personal mobility, communication supports
42. Employment prospects, related supports
43. Participation in campaigns, advocacy groups, organisations (DPOs and others)
44. Participation in conventional politics
45. Participation in provider discussions, organisations, campaigns and conventional politics
46. Effective influence (or co-influence) at individual level and collective level
47. Participation in discussion with service providers

Source: DISCIT Deliverable 3.4 Harmonization of indicators for Active Citizenship and proposed indicators for monitoring the implementation of CRPD in Europe (author: Jerome Bickenbach), pages 10-11 https://blogg.hioa.no/discit/publications/.

A second part of the DISCIT work in the area of data and indicators deals more specifically with the issue of how to translate general notions about 'disability' into measurement for use in surveys or censuses. Such translation or 'operationalisation' is essential when we seek overviews of how many people have a disability and how the situation of people with disabilities differs from the situation of people without disabilities, for instance related to exercising Active Citizenship. However, such operationalisation involves diverse challenges when we would like to compare the situation of persons with disabilities across countries or over time. Unfortunately, neither researchers nor agencies producing national or European statistics have so far paid sufficient attention to these issues:

1) Different operationalisations: Statistical agencies and researchers have adopted a variety of measurements to identify disabled people and this may affect research results. In order to rule out variation due to language or cultural differences, we ask how different operationalisations “behave” when controlled for time and space, that is, within countries and a short time span.

2) How to compare across countries: We ask whether the same or seemingly same operational definitions are likely to identify the same or similar groups in different countries. Do current operational definitions permit reliable comparisons across space?

3) How to compare over time: Similarly, we ask whether similar or identical operationalisations “behave” the same way over time within a country. Do current operational definitions permit reliable comparisons across time?

4) Robustness of findings: Is it the case that we – despite problems of consistency in operationalisations and instability in the behaviour seemingly similar operationalisations across space and time – still can get research findings of some robustness?

The main conclusion of this work is that the current basis for comparative survey research on disability and disability policies is weak. In most cases, one cannot draw any conclusions based on this research without strong reservations. Different empirical or operational definitions are likely to return clearly different prevalence rates. One cannot rule out that this also has an impact on policy aims variables as well. Similarly, one cannot take it for granted that seemingly similar subjective definitions in different countries, languages and cultures in practice lead to truly comparative data. However, the potential for comparison over time within one country is better, if researchers or statistical agencies stick strictly to the same operationalisations over time. To the extent that operationalisations are changing over time, the result is inconsistency that undermine time series and the basis for comparisons over time (see for instance the changes in questions between the ad hoc disability modules of the 2002 and the 2011 European Labour Force Surveys). Overall, the concept of disability appears to be unexpectedly sensitive to subtle nuances in questions when it comes to empirical definitions. It is therefore of the greatest significance that European and national statistical agencies fund (or themselves carry out) more thorough development, testing and piloting of all interview or questionnaire instruments related to disability. Finally, it is essential that European and national decision-makers see the usefulness and value of consistent time series of disability data with more frequent measure points (e.g. yearly, as has with the disability module to the Norwegian Labour Force Survey since 2002).

Finally, anticipating the future availability of more reliable, valid and truly comparative cross-national data relating to Active Citizenship for persons with disabilities and the barriers and enablers for achieving such Active Citizenship, DISCIT has developed a causal model of Active Citizenship impacts and outcomes. This work builds on the general literature on impact evaluation and provides a proposal for an overall causal model of Active Citizenship impacts and outcomes. It includes a qualitative analysis of the potential impacts of the model based on analogical reasoning and interpretation of case studies, a draft methodology to carry out an ex ante simulation modelling of potential impact of the model, regarding in particular the kind of data and software to be needed. Finally, it describes how to use dynamic simulation modelling to overcome the problem of having long time series and high quality datasets to develop simulation models. This is in the majority of the cases, and according to experience, one of the most critical part of socio-policy research.

Several results are relevant for the development of a dynamic simulation model. First, they allow justifying the use of a hybrid approach that combines Agent Based Modelling and System Dynamics for the dynamic simulation of policy interventions' impacts. Second, they provide an extensive list of dynamic simulation applications developed and applied for the simulation of social problems in the last few decades. Both results build on a sound literature review. Third, this work has produced a methodological framework that will support a simpler, effective, participative design, at minimum cost, for dynamic simulation of the impacts of policy intervention on Active Citizenship of persons with disabilities. Finally, it provides a preliminary a simulation model, in the form of a Causal Loop Diagram.

3. Overarching issues related to achieving Active Citizenship for persons with disabilities

3.1 To what extent are some groups of persons with disabilities facing greater hindrances and barriers in exercising Active Citizenship than other groups are?

Community living: A key finding of the life-course interviews was the variation between disability groups. In all countries, those with intellectual disabilities had the most limited experiences in terms of living situation - they tended to have experienced, in particular those who were older, more segregated settings and more separation-based trajectories. They also reported less choice about where to live, whom to live with, and even how they spent their time. They participated less in employment, in voluntary activities, in political activities, and even in social and leisure activities in their community. In many countries, this was down to limited support to access out of home activities.

Researchers also identified the nature of support available as an issue – especially for those with psychosocial disabilities who needed support that varied with their health. All groups complained about lack of choice over and flexibility of the support they received – how, when and from whom they received it. The most common difficulties experienced in terms of living in the community, were difficulties with physical accessibility of buildings, transport etc. and the attitudes of other people towards them and towards people with disabilities more generally.

In interpreting these findings, one need to bear in mind that the life-course interviews did not involve a representative sample of people with disabilities. They did not include people with more complex disabilities, in particular those with more severe communication impairments. However, given that even this relatively able, well-resourced and, in many cases, politically active group still experienced difficulties and barriers to their ability to live full lives in the community, it is reasonable to assume that those with more severe and complex needs will experience even greater difficulties in this respect. In this situation, the quality of the support they receive will be critical to their successful role as an active citizen. For those with intellectual disabilities, families were often powerful allies (although sometimes this was not the case). However, as people grew older or when they had lost contact with families due to long periods in institutions, the role and attitudes of paid support staff were critical.

Employment: As already suggested, the life-course interviews highlighted the diversity in education and employment experienced by persons with disabilities. People’s trajectories into and through the labour market were shaped by gender, impairment, and age and generation, as well as by national policy instruments, structuring the schooling people had and the work they did. Similarly, the life-course interviews confirmed the differences in employment prospects between men and women, between the four impairment groups, and between the three age cohorts. It shows how men and women, whilst having similar schooling often diverged in the routes they took into work and the experiences they had in it, with many women spending less time in the labour market than men.

Across the impairment groups, the findings show the variations in the experiences of people with intellectual, mobility, visual and psychosocial impairments, including how schooling was connected to form and severity of impairments, and in the forms of accommodation offered or made available to people in need to help integrate them into mainstream schools and workplaces. Differences over the impairment categories suggest different needs and levels of accommodation. Finally, variations across the age cohorts and nine countries show how policy structures and social attitudes have informed the extent to which persons with disabilities have found work in the open labour market, or activities outside of it.

Political influence through DPOs: In several DISCIT countries, especially in the Czech Republic and Serbia, informants commented on the underrepresentation of persons with mental or intellectual disabilities in terms of opportunities for political partici¬pation. We assume that this indicates a general problem, as these persons already face more discrimination – particularly those persons lacking legal capacity – as already reported by the European Union Agency for Fundamental Rights with regard to voting rights. Hence, we conclude that this group should be the touchstone to qualify the participation opportunities, including influence and self-representation, for all. According to Article 29 of the CRPD every human being, regardless of ascribed disability, shall have the “political rights and the opportunity to enjoy them on an equal basis with others”.

The use of accessible technologies: We have seen that the use of accessible technologies appeared to play a more important role in the lives of persons with mobility or visual disabilities than in the lives of persons with intellectual or psychosocial disabilities. At the same time, it is doubtful whether the needs and requirements of persons with intellectual disabilities are sufficiently incorporated in the processes of designing and supporting access to new technologies.

3.2 Enabling and constraining factors in Active Citizenship

Issues:
o What are the main factors enabling and constraining people with disabilities in exercising Active Citizenship and participating fully and effectively in society?
o What roles do public provisions (cash transfers, services and regulations) play as enablers?

The findings from DISCIT indicate that there is a range of enabling as well as constraining factors that persons with disabilities face in exercising Active Citizenship. Many of these factors reflect broad societal processes, divisions and interactions far beyond what is directly under the remit of public authorities, policies or provisions. In all nine DISCIT countries, we see the impact of historical legacies of how dominant understandings and societal actors have tended to define or perceive persons with disabilities and particular groups of persons with disabilities. For instance, there are many kinds of stereotypes and untested attributions about what persons with disabilities are able to do or achieve. In general, the surrounding society tends to underestimate the potentials, knowledge, skills and capacities of persons with disabilities. Similarly, there is a broad tendency to not see or be aware of how the practical impact of a particular kind of disability depends strongly on how one has designed the physical, social and organisation structures in which we all operate, or on ways in which the characteristics of these structures may interact with different kinds of impairments.

Consequently, many people with disabilities face attitudinal barriers, for instance when they apply to study a particular subject, train for particular occupations or for getting a particular job. An even more fundamental consequence of the underestimation of how persons with disabilities can contribute positively to society is the tendency to neglect or failing to take into consideration persons with disabilities in the recruitment to political positions, to membership of boards or decision-making bodies or standing as a candidate in public elections. Such exclusion does not only contribute to making persons with disabilities ‘invisible’ in organisational and political processes; it is also likely that it adds to frequent omission or neglect of the situation, well-being and interests of people with disabilities when political bodies make their decisions.

Moreover, the inaccessible physical, organisational and social structures that many people with disabilities face, are evidently forceful barriers for exercising Active Citizenship, as also this report has illustrated several times. In general, a combination of universal design and full and encompassing accessibility, complemented by appropriate accommodation to special requirements, is essential.

A general insight in social science is that the attitudes and perceptions held by the majority in a community or society in general about a group of people with particular characteristics, may affect adversely how members of the group see themselves and each other. The negative labelling by others may to varying degree be influencing the person’s self-conception and identity. To the extent that persons with disabilities internalise others’ negative perceptions, this may also function as a barrier to Active Citizenship.
Active support and backing from one’s family is an important enabling factor for Active Citizenship that we have only to a limited extent touched upon earlier in this report, but one that the forthcoming edited volumes from DISCIT will analyse and discuss. Similarly, support from social networks, friends of the family, other acquaintances or contacts made in neighbourhoods and civil society have generally proved to be important for getting a job, and this is also the case for persons with disabilities.

Turning to public provisions, access to free, relevant and high-quality education is an important enabling factor for Active Citizenship. There is a solid body of research showing that especially somewhat having a higher education has a strong impact on the employment prospects of persons with disabilities. Among the DISCIT countries, some are to greater extent than others offering free education beyond upper secondary level. However, all educational institutions need to build on universal design, full accessibility and necessary reasonable accommodation in order to be inclusive and prevent dropout from students with disabilities.

We have seen that the availability of accessible technology is of great importance. This availability is safer to the extent that countries have introduced and enforced social regulations on access to accessible technologies. In addition, we have touched upon the roles of public cash transfers and social services to make such availability a reality, although in some countries also non-governmental organisations have a role in such provision.

Equal treatment, non-discrimination, accessibility legislation and other forms of social regulation are important for the employment opportunities of persons with disabilities, if governments ensure that employers are fully aware of such regulations and that there are low-barrier channels for filing complaints about employers' failure to comply with the regulations.

Income transfers linked with relevant social (or employment) services can enhance the employment prospects of persons with disabilities, for instance, by securing work practice and temporary job placement and training for improving job skills and navigating in the labour market.

Finally, earlier in this report we have commented on the role of public cash transfers in protecting persons with disabilities from poverty and material deprivation but also stressed the risk that badly designed systems for cash transfers can 'lock in' recipients through poverty or benefit traps, rather than strengthening the recipient's capacity for entering or returning to employment. Many countries might adopt the EU Active Inclusion Approach of combing adequate income support, relevant and timely employment services and access to high quality other services (health, childcare, etc.) to enhance the employment prospects of persons with disabilities who have limited prior experience from the labour market.

3.3 What is the main picture regarding Active Citizenship?

Issues:
o Overall, how are the possibilities of persons with disabilities in the nine European countries (CH, CZ, DE, IE, IT, NO, RS, SE and UK) to exercise Active Citizenship?
o How have these possibilities developed over time, and more specifically; developed since the beginning of the millennium?

Summarising the findings we have presented in this report, it is fair to say that all the nine DISCIT countries have moved towards making Active Citizenship a reality for all inhabitants with disabilities but at somewhat different speed and emphasis on the three dimensions of Active Citizenship.

The historical deinstitutionalisation process has played a key role here. More people than before receive the necessary support (e.g. through support for accommodation (housing) costs, access to personal assistants, personal budgets, or at least, home helps) to live their lives independently of institutional care or parents. At least in most of the countries the longer trend has been towards greater economic and material well-being based on some mix of public cash transfers and income from work. However, there is no clear and consistent trend toward higher employment rates among persons with disabilities. Some groups, for instance, persons with intellectual disabilities may even have lost the jobs or work-like activities they had previously. In general, we have noted that men with disabilities tend more often to be in paid work than women with disabilities are. Persons with physical (mobility or visual) disabilities more often than persons with intellectual or psychosocial disabilities are.

In some countries, the financial crisis, change of governments, and cuts in spending have had adverse effects on the availability of cash transfers and social services for persons with disabilities, constraining the possibilities for exercising Active Citizenship. However, among the nine DISCIT countries it is only in the UK that cuts in public spending on disability-related provisions have been so marked that it shows in aggregate figures for social protection expenditure.

Overall, the findings and conclusions from the empirical analyses in DISCIT present a rich but diverse picture of the developments towards achieving Active Citizenship for persons with disabilities in Europe. Across the nine countries examined in DISCIT, these developments have been uneven. In several respects, there are shortcomings measured against the idea that persons with disabilities should be able to exercise Active Citizenship on equal terms with non-disabled. It is a long way to go before the UN Convention’s overarching norm that persons with disabilities should be able to enjoy full and effective participation in society on an equal basis with others can be measured in practice.

For instance, some countries have made considerable progress towards ensuring the conditions for persons with disabilities exercising autonomy. Independent living has become a reality for a greater number of people through the granting of personal assistance or personal budgets, and making access to these a matter of individual rights and not administrative or professional discretion. However, while a number of countries over some time had seen a process of deinstitutionalisation and trend toward community living, although with somewhat different speed and timing, this process has stopped and to some extent even been reversed more recently. Despite a strong emphasis, both from the EU and national governments, on enhancing employment and economic independence among persons with disabilities, it is difficult to find evidence for a consistent and clear trend in this direction. Especially some groups of persons with disabilities have great difficulties in finding a suitable and accessible job in the mainstream labour market. The crisis may have limited progress towards economic inclusion but even in countries where the crisis had limited overall impact, there has hardly been any notable improvement.

Similarly, we find a very diverse picture in what proportion of their public budgets the nine countries spend on disability-related cash transfers and services (benefits in kind). Some countries have cut their spending per inhabitant, especially on cash transfers, suggesting that reduced benefit levels or numbers of people qualifying for benefits have affected negatively on the security dimension of Active Citizenship. However, other countries have increased their spending on disability-related benefits or shifted their expenditures towards services.

While most countries have strengthened their social regulative provisions to promote equal treatment and full accessibility, the main practical improvements appear to be in the regulation of new information and communication technologies. However, when accessible, affordable and available, such technologies can be important instruments to strengthen the conditions for exercising Active Citizenship, and in particular for the autonomy and influence dimensions.

3.4 Are we likely to see a convergence or continuing divergence in the policy designs to promote Active Citizenship for persons with disabilities in Europe?

Issue:

o Is it possible to construct a cross-national typology linking types of institutional arrangements (disability policy designs) and the prospects for persons with disabilities being able to exercise Active Citizenship?

The further process of implementing the UN CRPD in the EU will offer enhanced opportunities for persons with disabilities and their organisations to influence the development towards Active Citizenship and push for the necessary reforms at European as well as national levels. Yet, for several reasons it is unlikely that this implementation will involve any clear trend towards convergence in this area. In near future, we are likely to see notable and stable contrasts between the different combinations of strategies, policies and instruments that European governments pursue albeit with variable success.

In terms of the analytical framework of DISCIT and available statistical indicators, it is possible to sketch a simple typology of national disability policy systems, depending on whether
A) Cash transfers play a comparatively great role or a comparatively more limited role in the country's disability-related public provisions

B) Means-testing has a comparatively limited role or a comparatively greater role in the country's disability-related public provisions

C) Services provisions play a comparatively great role or a comparatively more limited role in the country's disability-related public provisions

Similarly, it would be desirable to be able classifying countries based on whether social regulations (e.g. expressed in equal treatment, non-discrimination and accessibility legislation, quota systems or the use of financial incentives) play a comparatively great role or a comparatively more limited role in the country's disability-related public policy. However, for the time being we do not have access to indicators – neither quantitative nor qualitative - that systematically summarise the designated roles of social regulations of direct relevance for the Active Citizenship of persons with disabilities. An important task for future disability research is to contribute to developing and testing indicators about types of social regulations, cf. the earlier discussion of need for indicator development in this report. Such indicators would serve to balance and complement the picture we get by relying solely on indicators A, B and C.

Based on indicators A, B and C and the 2013 Eurostat figures for countries' profiles on spending on disability-related social protection, the nine DISCIT countries spread themselves in the following way:

I) Comparatively high levels of spending on cash transfers and services provisions, and comparatively low degree of means-testing: Sweden, Norway

II) Comparatively high levels of spending on cash transfers and services provisions and a comparatively high degree of means-testing: Germany, Switzerland

III) Comparatively high level of spending on cash transfers, comparatively low level of spending on services provisions and comparatively low degree of means-testing: Italy

IV) Comparatively low levels of spending on cash transfers, comparatively high level of spending on services provisions, and comparatively high degree of means-testing: United Kingdom

V) Comparatively low levels of spending on cash transfers and services provisions and comparatively low degree of means-testing: Czech Republic, Serbia

VI) Comparatively low levels of spending on cash transfers and services provisions and comparatively high degree of means testing: Ireland.

In the future, when we have available indicators that systematically summarise the designated roles of social regulations of direct relevance for the Active Citizenship of persons with disabilities, we are likely to get a different and more balanced typology of European countries.

Potential Impact:
DISCIT is providing new knowledge for different target groups: for the scientific community, teaching environments, the policy level (including the European Commission), private companies (e.g. employing persons with disabilities) and for persons with disabilities, their social environments, spokespersons and organisations, as well as for mass media and the general public.

DISCIT will achieve its main scientific impact by publishing two volumes at the end of 2016, beginning of 2017. Already by the end of January 2016, 22 working papers (public Deliverables from scientific Work Packages) were available on the DISCIT website.

By January 2016, DISCIT Consortium Members (CMs) had published four peer-reviewed articles and more were planned and accepted for publication. It has to be noted that publications need to be based on DISCIT findings and will therefore be published after the end of DISCIT. In addition, four members of the DISCIT team are working with their theses, based on DISCIT research, which will be defended in 2017 and 2018.

All CMs contributed to dissemination activities, the list included in the Final Report shows 60 different activities, from interviews till presentations at scientific and public events. It appears, that CMs, who employed early stage researchers, who worked mainly with DISCIT, for example colleagues in Germany, Ireland and Sweden, where more involved in dissemination activities than others. Furthermore, the National University of Ireland in Galway used their large scale international Summer School (June 2015) to present DISCIT and its findings and to involve third-level students in discussions on these findings and all CMs presented DISCIT at several conferences and seminars organised by their home organisations.

DISCIT worked together with colleagues at other universities and research organisations, e.g. through close collaboration with the members of the Scientific Advisory Committee (SAC) and participation in conferences from academic networks and other FP7 projects.

In addition, the Coordinator encouraged CMs to participate in discussions on future research programmes, collaborated with the FP7 project IMPACT-EV and will upload DISCIT findings, described in the Final Report, to the Social Impact Open Repository (SIOR, http://www.ub.edu/sior/index.php).

Essential for DISCIT's societal impact was the involvement of Civil Society Organisations, the European Disability Forum (EDF) and the Mental Disability Rights Initiative from Serbia, as CMs as well as the close collaboration with the members from the European Stakeholder Committee (ESC) and the National Stakeholder Committees (NSCs). The Coordinator informed regularly the members of the ESC and almost all members participated in the Kick-Off, the Midterm Workshop and the Final Conference. Already on the 10th of December 2014, DISCIT presented first results at a seminar at the European Parliament, which was organised by the EDF.

All CMs met at least twice with their National Stakeholder Committees (NSCs) and the members of these Committees were invited to the Final Conference (09 -10 November 2015 in Brussels). In particular, ARCO (Action Research for CO-Development) PIN at the University of Florence, worked closely with Civil Society Organisations (CSOs) and politicians in Italy and presented and discussed DISCIT findings at five national events between March 2014 and February 2015.

At the Final Conference, members from the ESC and the NSCs and invited experts demanded

- translations of DISCIT material into national languages,
- easy to understand recommendations, which should be send to relevant stakeholders,
- different dissemination activities, also after the end of the project, at national level and special political occasions,
- development of education material based on DISCIT findings,
- even closer collaboration with stakeholders at national level.

DISCIT CMs have picked up these suggestions. For example, colleagues at the University of Cologne organised a seminar in January 2016, involving colleagues from the University of York, and published a press release on DISCIT findings. In March 2016, the DISCIT team drafted a final Policy Brief, which will be used for future dissemination activities.

The DISCIT videos produced for the Final Conference are especially valuable for DISCIT's future dissemination activities. A CSO from Sweden has been interested to translate the text in the EDF DISCIT video to Swedish and following this demand the EDF made a version available which allows translating the text into different languages.

During the lifetime of the project, DISCIT published eight Policy Briefs and a Report proposing options for a policy position by the EU to promote Active Citizenship in Europe. These papers are all available on the DISCIT website. The two general Policy Briefs (D10.5 and D10.7) are available in several languages (Czech, English, German, Italian, Norwegian, Serbian and Swedish).

HiOA NOVA subcontracted two briefing notes: 'Identifying options for developing new EU policies to promote Active Citizenship for persons with disabilities – a European stakeholder perspective' (September 2014, updated January 2015) and 'Exploring the possibilities for developing European Law to promote Active Citizenship for persons with disabilities' (October 2014, updated January 2015), which were presented and discussed at the Midterm Workshop in Prague (October 2014):

Jen-Luc Simon, Member of the European Stakeholder Committee and representative of ‘Disabled People’s International Europe’, presented his personal paper on ‘Identifying options for developing new EU policies to promote Active Citizenship for people with disabilities – a European stakeholder perspective’. The paper reflects on the involvement of persons with disabilities in research and policies: ‘Looking and searching on disabilities issues is far away to be neutral. As the case is in DISCIT, when the people with disabilities take an active part in the research, all stakeholders have to consider their own and personal relationship with their probable future needs of personal assistance and/or technical aids. The citizenship of people with disabilities is not only external and observable but also personal and structural.’
(Source and further reading: Jean-Luc Simon, Identifying options for developing new EU policies to promote Active Citizenship for people with disabilities – a European stakeholder perspective, January 2015, available on the DISCIT website)

Lisa Waddington, Member of the Scientific Advisory Committee, presented her study on ‘The Potential for, and Barriers to, the Exercise of Active EU Citizenship by Persons with Disabilities: The Right to Free Movement’, elaborated for DISCIT during the summer 2014. Waddington concluded with the following findings:
‘There are a variety of possibilities for persons with disabilities to exercise Active EU Citizenship through the right to free movement.
The EU definition of ‘worker’ is fairly broad; however, individuals working a very low number of hours or earning a very low income are excluded, as are, possibly, people working in sheltered or supported employment.
Non-economic migrants must not become ‘a burden on the social assistance of the host Member State’ and this can pose a barrier to free movement for persons with disabilities who require financial support, or benefits in kind.
Social security benefits paid in cash can be exported, but social assistance and ‘special non-contributory cash benefits’ cannot be exported, and this is also true for benefits in kind.
The combination of this lack of exportability, along with the absence of a right to claim equivalent benefits in the host Member State on arrival, can act as a significant disincentive to exercising Active EU Citizenship through free movement.
Persons with disabilities who are visitors to another Member State may experience problems in accessing disability-related benefits, such as concessions on public transport or free admittance to museums, because they are unable to provide proof of their disability status which is accepted by national authorities.’
(Source and further reading: Lisa Waddington, The Potential for, and Barriers to, the Exercise of Active EU Citizenship by Persons with Disabilities: The Right to Free Movement, Briefing note, January 2015, available on the DISCIT website)

All these activities will contribute to a new understanding of disabilities, ‘which should help to minimise barriers to integration and maximise participation on equal terms’ (FP7, SSH, WP2012, page 30).

Following this aim, DISCIT participated in the Public consultation on the mid-term review of the European Disability Strategy 2010-2020 and submitted, in March 2016, the following comments to the EC, DG EMPL:

The DISCIT main findings and recommendations connect most directly to the actions on accessibility, employment, social protection, training and participation under the European Disability Strategy 2010-2020. These findings expand and enrich our prior knowledge about the extent to which and why persons are at greater disadvantage across these areas than persons without disabilities are.

First, given DISCIT's broader understanding of some of these themes compared to the European Disability Strategy (EDS), we take the liberty to suggest that in the next iteration of the European Disability Strategy, 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 means to achieve influence on decisions of great importance for the lives of persons with disabilities and the full implementation and systematic enforcement of their human rights in society. While the current version of the European Disability Strategy deals with several general issues of social participation, the barriers and facilitators for involvement of persons with disabilities in organisational and political activities receive too limited attention. Findings from DISCIT confirms that a strengthening of this involvement is of uttermost importance to ensure the full and effective implementation of the UN CRPD in all European countries.

Second, we would like to propose that the next iteration of the European Disability Strategy emphasises to fund further human rights based research on disability, through the lens of Active Citizenship, and using a life-course approach. The EU could achieve this under the Horizon 2020 funding streams. In the context, it is important to acknowledge that DISCIT was funded under the first ever call in FP7 for research on 'disability in evolving societies' and that no calls under Horizon 2020 to date have explicitly focused on persons with disabilities and the achievement of their human rights, or on issues of social exclusion. The EU could rectify the gap in future Horizon 2020 Work Programmes and calls, including the Work Programmes for 'Europe in a changing world – inclusive, innovative and reflective societies'. Interdisciplinary research in this field should be encouraged even more.

Third, we recommend 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 purposes). 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, and for that matter, to the UN CRPD notion of full and effective participation on an equal basis with others. Given these shortages and gaps, it is impossible to give reliable and complete overviews of the situation of persons with disabilities in Europe and member states, or the necessary knowledge basis about the effectiveness of policies and provisions meant to improve this situation (e.g. in terms of Active Citizenship and human rights). Without more precise and reliable knowledge about what measures work and for what reasons they work, it is impossible to achieve policy learning and greater effectiveness of such measures.

There is a strong need to collect data about the situation of persons with disabilities on a regular basis and more often (e.g. yearly). One must use consistent question instruments over time (e.g. to ensure that the findings from the diverse ad hoc disability modules of the European Labour Force are comparable over time). Samples in surveys must more often be stratified and of sufficient size to be able to compare the situation of different groups of persons and not only all people with disabilities lumped together. There are strong indications, also confirmed by DISCIT, that there are striking contrasts in the barriers in exercising Active Citizenship that persons with disabilities face, and that persons with intellectual and psychosocial disabilities are at the greatest advantage across a range of arenas for participation.

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 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. Statistics and data collection should be aligned 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 thus, promote empirically provable ways in which one can succeed in removing obstacles to Active Citizenship.

Furthermore, DISCIT developed and discussed, for example during its Final Conference (Brussels, 09 – 10 November 2015), the following specific recommendations for different fields of policies:

Policies for persons with psychosocial disabilities
It is evident that disability policies for persons with psychosocial disabilities in the nine countries that we explored are the outcome of different welfare designs. Also variation within each country was significant. National policies may only be understood in terms of nation-specific historical contexts. Essentially, the findings do not point to coherent models at all. However, three dimensions of change in terms of Active Citizenship were discerned: first, the spending on social benefits and services have travelled from family (or segregated institutions) towards the public or public-private-NGO configurations of service provision. Secondly, entitlement to publicly financed services has increasingly become based on individual citizenship (with various consequences in terms of Active Citizenship). Thirdly, as persons with psychosocial disabilities are increasingly dispersed and visible in the community, this highlights the need to deal with the issues of community-based services and user-influence.

Labour market participation
The aim of the DISCIT project was to consider the potential for enhancing Active Citizenship for persons with disabilities. The concept of Active Citizenship is used as a means of operationalizing the phrase ‘full and effective’ participation in society and the economy. In particular, it focuses on the rights of persons with disabilities to make choices in key areas, including around paid employment, and to be protected from major uncertainty and life risks in those areas. In the context of paid employment, this means having choices in the kinds of careers and forms of employment persons would hope or seek to go into, and to be protected from discrimination or risk of exclusion, both from the labour market in general and from preferred sectors.
Having said that, it is important to acknowledge that the notion of Active Citizenship might not be realized in the same way by all people. 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. The assumption that being an ‘active citizen’ necessarily includes having paid work within the mainstream labour market is challenged by the accounts of some of the people interviewed in the DISCIT project. 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.

Drawing on data from expert informants the Work Package on employment has highlighted the need for more critical thinking about the nature of employment and to consider how the labour market is structured, and what demands that creates for employees and people seeking work. A great deal of thought goes into improving the skills and resources of disabled persons, and efforts are made to minimise exclusion and discrimination through anti-discrimination laws, notions of reasonable adjustment and quota systems. However, there is also the issue of labour market structure, labour market demand and the nature of jobs, which might exclude and deny choice for persons with disabilities. The need is for long-term thinking about work and the kinds of work people can and hope to do. In the future rethinking work with disability in mind may contribute as much, and possibly more, to enhancing Active Citizenship for persons with disabilities through mainstream labour market participation.

Community Living

Evaluating the situation of persons with disabilities concerning community living, the DISCIT team developed the following recommendations:

1. Establish a minimum dataset related to living situation, which all States are expected to provide data for in a format that can be compared across countries and which allows the monitoring of where people are living over time and what support is available to help them to live and participate in their community as active citizens.
2. European Commission should continue to monitor how European funds are used and to set conditions on their use so that accommodation and support developed for people with disabilities are consistent with the UN CRPD and so that they have the chance of achieving Active Citizenship.

At National government level

In most countries policy already exists that allows community based services to be established. However, in some countries, involved in this project, further developments were needed in terms of useful policy. The power or importance of policy varies across countries.

3. National governments need to provide the right messages, definitions and leadership around disability issues and in particular around support and accommodation services to ensure consistency at different levels of government and across geographical locations.
4. It should be clear and transparent as to who holds primary responsibility for disability issues.
5. Governments need to ensure that funding systems are available, efficient and flexible so that people get the support they need.
6. National governments need to monitor the implementation of policy on a regular basis.
7. In establishing deinstitutionalisation programmes, national governments need to ensure that they include all people with disabilities, not just those who are more able.
8. National governments need to consult and involve people with disabilities and their representatives in any decisions that affect people with disabilities.

At local government level

Most of the recommendations made at national level also apply at local government level.

9. In particular local governments need to have a holistic and life course approach to disability and ensure a consistent and co-ordinated approach.
10. They need to work with local DPOs and consult people with disabilities in making local policies and when making decisions affecting people with disabilities.

11. The need to ensure a focus on all people with disabilities and not leave those with the most complex needs to the end of the process of deinstitutionalisation.
12. Local governments need to provide clear guidance and leadership to those providing accommodation and support to people with disabilities as to the nature of services that will be funded and what is expected of those services in terms of outcomes for those supported.
13. The systems for applying for support need to be made more transparent and support available to help people apply.

Disabled People’s organisations

14. DPOs should work collaboratively with each other and with other agencies as much as possible to help raise awareness about disability issues and the CRPD at all levels.
15. They should work together to ensure that the voices of all people with disabilities are heard at local and national government levels and also by service providers designing services etc.
16. DPOs should work collaboratively with other agencies to ensure that people with disabilities themselves (and their families and carers) have access to information about their rights and the services available to them.

Service providers/NGOs

17. All those who are providing accommodation and/or support services in any sector for people with disabilities need to be willing to work together with each other and with local government and NGOs to provide a holistic service for people with disabilities.
18. They need to be willing to find alternative ways of providing support that are consistent with national definitions of community-based services and the UNCRPD.
19. They need to consult with the people they support and their advocates to ensure they are meeting people’s needs and providing a service that is working for people.
20. They need to ensure that they provide training and support to staff to work in a way that supports people to be active members of their community and to experience choice and control in their lives.

The use of new technologies

Work Package 7 of the DISCIT project was unique in that it combines traditional legal analysis of an area of law, in this case accessible technology, with qualitative research that incorporates both the views of experts and people with disabilities. Often times these two types of research are quite separate resulting in legal analysis that does not take into account the lived experiences of those living under the law and qualitative research that does not acknowledge or examine how laws shape the documented experiences. This project allowed us to bridge this gap resulting in several interesting insights. One of the most interesting differences between the interviews with experts and the life course interviews is that many interviewees spoke about their dissatisfaction with the public system of provision and the need to change it, while very few of the experts had this view with several praising the public systems of assistive technology provision. Another issue that was highlighted through this method of research was the changing way people with disabilities use and define “assistive devices” with the rise of smart phones and “apps” as replacing traditional technology with the corresponding issue of the lack of law governing this area. Countries must update their laws to keep up with the pace of technology or create more flexible legal regimes that can more easily grow with the technology. In the future law and policy makers should seek out and include people with disabilities when creating laws that relate to accessible technology in order to ensure that the laws further rather than hinder Active Citizenship. The legal regimes that currently exist around accessible technology are generally not serving well all people with disabilities. Steps must be taken to make sure that accessibility and universal design mandates are truly inclusive of all people with disabilities. In many cases, the advances in technology have benefited people with disabilities so we must ensure that the law protects and enhances access to accessible technology.

Fiscal innovation

Many disability policies create poverty or welfare traps by failing to recognise that persons with disabilities are capable of participating in the workforce and consequently devalue the considerable ability of people with disabilities to contribute to their own support through work and by encouraging people with disabilities to retire early even when they still have some work capacity. Support programmes and other policies that assume that people with certain physical or mental conditions cannot work create a poverty trap for many people with disabilities. Instead of helping and encouraging people with disabilities to use their own abilities to stay out of, or escape from, poverty, they are built on the presumption that people with disabilities cannot work, and so they provide most with low levels of benefits. Today’s policies do little to help people with disabilities overcome poverty or protect themselves from poverty in the first place using their own abilities. There is clearly a need to enhance income security programs, in terms of eligibility, adequacy and efficiency, to reduce the high rate of poverty among persons with disabilities and to help offset their associated additional costs.

Economic well-being does not come solely from income, spending, and consumption, but also requires savings, investment, and accumulation of assets, because assets can improve economic independence and stability, connect individuals within viable and hopeful future, stimulate development of human and other capital, and enhance the welfare of offspring. If persons with disabilities become more powerful economically, decision makers and policy makers will need to take them more seriously. The savings plans outlined are a magnificent advance in the journey to end poverty, not just for people with disabilities but all of those that fall below the line of poverty. On their own they offer people with disabilities the chance to accumulate savings and to use them without fear of claw backs by income assistance programmes. Without these types of accounts, many people with disabilities have very limited avenues to save and allow for further independence.

Though these plans are exciting new tools that will go a long way towards improving future financial security, there is still a need to look at the full range of planning options available including wills and estates, trusts, supported decision-making and home ownership. Financial security for persons with disabilities requires a more creative approach than just asset accumulation models. Financial security can only be derived if a person can ascertain gainful employment without losing their social benefits and while continuing to build assets and accumulate assets and wealth from wills, estates, gifts etc.

Political participation

According to the DISCIT team at the University of Cologne, the findings of Work Package 9 indicate that many disability organisations active in policy processes cannot be considered DPOs in a strict sense (i.e. comprised by a majority of persons with disabilities). The lack of resources is one of the most significant problems regarding the opportunities of both individual persons and organisations to effectively engage in disability rights advocacy. Some DPOs raise concerns that high dependence on public funding may interfere with their agendas. In the political arena participation is implemented quite differently, i.e. it can range from mere information and consultation to cooperation and influence up to power and control. Persons with learning difficulties and persons with psychosocial disabilities are among the most disadvantaged citizens. Reduced legal capacity and still prevailing institutional, segregating settings seem to be the causes for their situation.

The UN CRPD marks an important milestone in the field of disability politics at national and European levels. Nevertheless, many of our informants are not able to report concrete impacts what regards political participation and influence of persons with disabilities and their representative organisations.

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 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. Statistics and data collection should be aligned to the principles and definitions of the CRPD. DISCIT recommends adopting measurable 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.

DISCIT Outputs and outcomes by the end of the project (January 2016)

Data based on 217 interviews with persons with disabilities and 85 interviews with other informants/experts, 25 scientific Deliverables (containing suggestions for policies), one dissertation, four peer-reviewed articles (published), 34 presentations and discussions at events, participation in the public consultation for the ‘Science with and for Society’ Work Programme 2016-2017’, public reports from the Midterm and Final Conferences, Seminar at the European Parliament (December 2014) and eight Policy Briefs (partly in different languages), two Briefing notes and one Report proposing options for a policy position by the EU to promote Active Citizenship in Europe, DISCIT videos, at least three press releases, website, discussions and meetings with the European Stakeholder Committee, the Scientific Advisory Committee and the National Stakeholder Committees as well as with colleagues and students at home and other organisations

DISCIT Long Term Impacts

Two edited volumes, four theses, at least 10 peer reviewed article, use of DISCIT results by CMs and members of the SAC in teaching programmes, discussions with DG RTD and National Contact Points for Horizon 20 (influencing Horizon 2020 Work Programmes), discussions at national level, e.g. with members from the NSCs (suggestions for future policies and programmes), participation in the public consultation on the mid-term review of the European Disability Strategy 2010-2020 (influencing the review of the European Disability Strategy), DISCIT videos in different languages (greater attention for the rights for persons with disabilities and their opportunities for Active Citizenship), website.

Conclusion

DISCIT was an intense research project, which demanded close collaboration between the Consortium and Committee Members and with different stakeholders. Very useful for the successful implementation of DISCIT was the close collaboration with DG RTD. The Coordinator (HiOA NOVA) invested more time than originally planned in the implementation of the project and would recommend more Person Months for Impact in future projects than originally planned in DISCIT (which was eight person months for HiOA NOVA). It would be worthwhile to consider whether the involvement of an Impact Manager in future projects would make it easier to achieve scientific and societal impact. In addition, the DISCIT Project Manager suggests including a training session on the topic of understanding and achieving impact during the first six months of the project for all Consortium and Committee Members.

Further Reading
DISCIT will achieve its main scientific impact by publishing two edited volumes at the end of 2016, beginning of 2017.

By January 2016, DISCIT CMs had published four peer-reviewed articles (see list included in 'Project Final Report') and more were planned and accepted for publication, for example from the DISCIT teams in Germany, Norway and Sweden:

- Waldschmidt, Anne: Europäische und Internationale Behindertenpolitik [European and International Disability Policy]. In: Handlexikon der Behindertenpädagogik. Schlüsselbegriffe aus Theorie und Praxis [Handbook of Special Needs Education. Key Concepts of Theory and Practice]. (3rd, revised and expanded edition), Editors: Antor, Georg / Beck, Iris / Bleidick, Ulrich / Dederich, Markus, forthcoming (2016).

- Karačić, Anemari and Waldschmidt, Anne: Biographie und Behinderung [Biography and Disability]. In: Handbuch Biographieforschung [Handbook of Biographical Research], Editors: Lutz, Helma / Schiebel, Martina / Tuider, Elisabeth, forthcoming (2016).

- Hvinden, Bjørn and Halvorsen, Rune: Mediating Agency and Structure in Sociology - The Role of Conversion Factors. In: Critical Sociology (special issue on the capability approach and sociology), forthcoming (2016).

- Hvinden, Bjørn: Beyond the Welfare State - What Next for the European Social Model? (Chapter 2). In Peter Blanck & Eilionoir Flynn (Eds.), Routledge Handbook of Disability Law and Human Rights, London & New York: Routledge, forthcoming (2016).

- Sépulchre, Marie: Thirty years of research about disability and citizenship: a scoping review. In: Disability and Rehabilitation, forthcoming.

- Lindqvist, Rafael and Sépulchre, Marie: Active Citizenship for persons with psychosocial disabilities in Sweden. In: ALTER, Journal of European Disability Research, forthcoming.

List of Websites:
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Swiss Paraplegic Research - SPF - Disability Policy Unit, Nottwil, Switzerland
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