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DISCIT

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

Deliverable 2.1 – Milestone MS4

Active Citizenship for persons with disabilities - Current knowledge and analytical framework - A working paper

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DISCIT aims to produce new knowledge enabling Member States, affiliated European countries and the European Union to achieve full and effective participation of persons with disabilities in society, policy making and the economy. The possibility for exercising ‘Active Citizenship’ - through social agency and practice – depends on the social conditions for participation in Europe.

DISCIT has set itself the tasks of identifying factors or conditions that currently prevent or discourage persons with disabilities from exercising Active Citizenship, and more positively, to identify means or ways to enable persons with disabilities to exercise Active Citizenship. Using the UN Convention on the Rights of Persons with Disabilities (CRPD) as a framework of reference, DISCIT will identify more effective ways to remove and prevent physical, attitudinal, social and organisational barriers to Active Citizenship and participation on an equal basis with others.

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Foreword

Deliverable 2.1 consists of four interrelated parts:

- One part by Rune Halvorsen and Bjørn Hvinden (coordinators for Deliverable 2.1, NOVA, Oslo, Norway) presenting a broad review of the state of art in the scholarship on social citizenship and Active Citizenship in particular as well as a proposal for how to specify dimensions of Active Citizenship and conditions for persons with disabilities achieving Active Citizenship (Sections 1-5)

- One part by Anne Waldschmidt (University of Cologne, Germany) on the relevance of Active Citizenship for persons with disabilities, partly pointing to the ambiguities in the notion of Active Citizenship, partly discussing the necessity of persons with disabilities experiencing security, autonomy and influence at the same time to support them in exercising Active Citizenship (Section 6)

- One part by Rita Barbuto, Mario Biggeri, Federico Ciani and Giampiero Griffo (University of Florence, Italy), partly calling for a rethinking of the collective and individual processes involved in building Active Citizenship for persons with disabilities, partly examining the relationship between the a Capability-based conceptual framework and Active Citizenship, and partly discussing how to translate the idea of Active Citizenship into real policies for the benefit of Europeans with disability (Section 7)

- An annotated bibliography of recent scholarly literature on Active Citizenship (Appendix)

We are grateful for all the comments and suggestions we received from members of the Consortium and the Scientific Advisory Board to a draft version of this deliverable. We have sought to take these comments and suggestions into considerations when we amended and edited the document. The responsibility for remaining shortcomings remains with us.

Oslo, 30 August 2013

Bjørn Hvinden and Rune Halvorsen
**Rune Halvorsen and Bjørn Hvinden, NOVA**

1. **Introduction: What do we mean by Active Citizenship?**

**Our point of departure**

In contemporary Europe many persons with disabilities are denied the possibilities of full and effective participation in society, policymaking and the economy on an equal basis with others. The DISCIT project aims to produce new knowledge enabling Member States, affiliated European countries and the European Union to change this situation. In investigating the social and political conditions for making full and effective participation a reality, the project adopts a multifaceted understanding of *Active Citizenship*.

So what do we mean by ‘citizenship’? We follow the currently dominating way of defining citizenship in the social science sense as:

> “… full and effective membership of society (that is, regardless of differences in social position or other characteristics) … Non-stigmatising generous social rights enable full citizenship. But being a full and equal citizen is, basically, a question of *practices*: living a decent life in accordance with the prevailing standards in society, being able to act autonomously, being able to participate in social and political life in the broadest sense, and having ‘civic’ orientations to the political community and to one’s fellow citizens”

(Andersen and Halvorsen 2002:12-13, our emphasis)

Adopting a multilevel and institutional perspective, DISCIT examines how different types of policies (social benefits, social services and social regulation instruments) can be made mutually supportive in enhancing Active Citizenship for persons with disabilities. Using the UN Convention on the Rights of Persons with Disabilities (CRPD) as a framework of reference, DISCIT will identify more effective ways to remove and prevent physical, attitudinal, social and organizational barriers to Active Citizenship and participation on an equal basis with others, in a context of rapid social and economic change and evolving conceptions of disability across European societies.

Existing research has rarely examined the conditions that hamper or enable persons with disabilities to exercise Active Citizenship in a systematic and thorough way. In most existing research issues or challenges related to the Active Citizenship of persons with disabilities are completely absent or invisible. DISCIT aims to fill this gap in existing research. In order to reach this aim we need to clarify what we mean by social citizenship in general and more specifically by Active Citizenship and the conditions for persons with disabilities achieving such full and effective participation in society on an equal basis with others.
2. Three main approaches to social citizenship

The following review of existing scholarship on citizenship deals primarily with different meanings of social citizenship. We find a range of different perspectives on and approaches to social citizenship – in political philosophy, political science, sociology and social policy. If we look at what has been the main focus, interest or concern for each of these perspectives, we follow Miller (2000) by claiming that these perspectives tend to cluster in three main approaches to social citizenship. Each cluster of approaches has a distinct image of what Active Citizenship entails (see Table 2.1):

- **Socio-liberal approaches** being concerned about the citizen’s rights and duties vis-à-vis the community (other citizens) or the state, and the rights and duties of community or state vis-à-vis the citizen, with a focus on what degree and form of protection against insecurity, uncertainty or risk (e.g. lack of income or maintenance, illness, incapacity, violence) the citizen ought to receive or be able to expect from others than his or her own family or kin. These approaches tend to emphasise the reciprocity and interdependence between the responsibilities of the community and the citizen, involving encompassing sets of mutual rights and obligations.

- **Market-Liberal (Libertarian) approaches** being concerned about the citizen’s autonomy and freedom in relation to the community or the state, with a focus on what degree and form of protection of this autonomy and freedom the citizens ought to enjoy or be able to expect. Although these approaches may also refer to rights and duties vis-à-vis the community or state, these are constructed as basic and few and in principle based on contractual agreements. Hence these approaches tend to emphasise the citizen’s

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2 While social citizenship was historically closely related to having formalised membership in a nation state – state citizenship – there has been a notable trend towards of weakening of this relationship, as especially rights to social protection (rights to cash benefits and services and associated duties) are dependent on having legal residence in a country, through birth or being granted permission to stay in the country. In other words, immigrants do not need to be formally naturalised, i.e. become state citizens, to have such rights and duties. In a growing number of countries immigrants with legal residence are also granted some political rights, e.g. to participate in local elections (e.g. Guirandon 2002). Moreover, in Europe a growing number of people also enjoy EU citizenship as well as citizenship of member state. To be EU citizen is a formal legal status which also confers rights on the individual.
independence and self-responsibility combined with limited and narrowly defined activity on the part of the state.

- **Civic-Republican approaches** being concerned about the citizen’s participation in the life of the community (e.g. through voluntary engagement), with a focus on what degree and forms of participation in deliberation and decision-making related to promoting the common good should be expected of the citizen. This moral duty to participate does, however, imply a democratic right to co-determination and influence.

**Table 2.1 Three idealised images of Active Citizenship and their affinities to the main directions in social citizenship studies**

<table>
<thead>
<tr>
<th>Three idealised images of Active Citizenship found in the scholarly literature</th>
<th>The images’ affinity to the main directions in social citizenship studies</th>
</tr>
</thead>
<tbody>
<tr>
<td>Citizens exercising a range of rights and duties vis-à-vis the community (other citizens) or the state</td>
<td>Socio-liberal approaches</td>
</tr>
<tr>
<td>Citizens exercising autonomy, freedom and self-responsibility in relation to the community or the state</td>
<td>Market-Liberal (Libertarian) approaches</td>
</tr>
<tr>
<td>Citizens exercising co-responsibility for the common good, and by implication; co-determination and influence</td>
<td>Civic-Republican approaches</td>
</tr>
</tbody>
</table>

It is worth stressing that the three clusters of approaches to citizenship are simplified or idealised constructions, focusing on different but complementary aspects of citizens’ relations with or membership in the community. The distinction between the clusters of approaches is analytical; in the social practices of citizenship the focused aspects will co-exist in various ways and degrees. Yet, we can see a tendency in the existing research to frame investigations of citizenship solely in terms of one of the clusters of approaches, rather than consider whether one could enrich the analysis by drawing on other approaches. Finally, all the approaches are to a great extent describing norms for action; whether citizens are in a position to live up to these norms is another matter. For this reason, scholars have contrasted passive and active citizenship or they have described citizens’ actual behaviour as being somewhere on a continuum from a passive to an active pole.
The fact that many people for various reasons are not very active citizens have together with the many challenges facing contemporary welfare states sparked a renewed debate over just how ‘active’ citizens ought to be (Johansson & Hvinden 2012). This debate has focused predominantly on notions of conditionality within Socio-Liberal citizenship, as expressed in slogans like ‘no rights without responsibilities’, for example. Yet, we can observe similar tendencies to separate active citizenship from passive citizenship with regard to the other two approaches to social citizenship.

In DISCIT we seek to incorporate the various versions of the active/passive divide in one framework, as persons with disabilities are being encouraged – and also themselves expect – to shoulder more responsibilities, exercise more choice or engage more actively in the public sphere, deliberation and decision-making, or in self-organised or voluntary efforts. We suggest a unified framework for studying Active Citizenship that enables us to examine issues of rights and duties in relation to social protection; autonomy, self-responsibility and choice; and participation and self-government in the same time in context of the situation and lives of persons with disabilities.
3. Recent directions in the international scholarship on social citizenship – emerging varieties of Active Citizenship

When reviewing the social citizenship debate that has taken place over recent decades we find a threefold development that appears to challenge aspects of the classical codification of social citizenship by T.H. Marshall (1950/65): i) a renewed emphasis on citizens’ duties; ii) a renewed emphasis on citizens’ participation and agency and iii) the emergence of ideas about citizen consumerism.

3.1 A renewed emphasis on citizens’ duties

One major criticism of Marshall’s conception of social citizenship has been that he placed excessive emphasis on individual social rights, especially formal and enforceable rights, while saying little about the duties or responsibilities of citizens (e.g. Marquand 1991; Turner 2001). For some critics, Marshall served as a straw man for a more general criticism of how generous redistributive welfare arrangements, especially income support, are supposed to have an adverse effect on citizens’ attitudes to self-reliance and paid work, responsibility for personal welfare and risk protection. These critics have argued that the proliferation of unconditional social rights, underpinned by welfare provisions, have in fact led to widespread passivity on the part of citizens, even causing economic and social exclusion, and a weakening of the work ethic (e.g. Mead 1986 & 1997).

Today, critics often link such arguments to the kind of external and internal pressures that are now facing contemporary welfare states. The general argument is that governments need to slim down their welfare provisions to prevent these provisions from becoming a liability in a more globalised system of market competition. Governments have to reduce their ambitions to provide redistributive welfare financed through taxation, while individuals and families must take greater responsibility for their own protection against risks. On the basis of these arguments, many participants in the recent debate have called for new conceptions of citizenship, striking a better balance between individual rights and duties. The slogan of ‘no rights without responsibilities’ expresses the general thrust of these conceptions (Giddens 1998: 65; Dwyer 2001; Levitas 1998; Lister 2001).

Arguably, much current reasoning on social citizenship exaggerates the contrast between active and passive social citizenship, where active social citizenship means that people should not only enjoy the rights associated with citizenship but also meet certain obligations. It is also possible that key writers in social policy have contributed to the understanding of social citizenship as only being concerned with the expansion of social rights. For instance, Esping-Andersen (1990:
21) makes a direct link between ‘decommodification’ and Marshall’s concept of social citizenship. Here, decommodification implies that ‘… citizens can freely, and without potential loss of job, income or general welfare, opt out of work when they themselves consider necessary’. Similarly, Dean and Melrose (1999: 82-85) focus exclusively on the rights side in their presentation of Marshall’s theory of social citizenship.

Significant changes in social security legislation, and, more specifically, attempts by governments to switch from passive to active measures in social protection, have been motivated by such concerns. We have found these governments in welfare states associated with Social Democratic, Conservative as well as Liberal welfare models or regimes. Arguably even welfare states seen as the prototypes of Social Democratic welfare model were from the start based on a strong activation or work orientation.

Activation reforms aim to shift the balance towards the duties and responsibilities of citizens, most clearly seen in the activation of income maintenance schemes for people of working age and in pension reform. The focus is on promoting participation in paid work and prolonging working careers, providing stronger financial incentives, and in the case of activation reform, also combining ‘sticks’ and ‘carrots’. For instance, public authorities may offer more systematic guidance and follow-up, introduce co-determination into the planning of personalized measures, and provide the opportunities to acquire new vocational skills – the ‘carrots’, but also enforce their requirements more vigorously, making the granting of cash benefits conditional on participation in active measures and punish failure to comply – the ‘sticks’. However, different European governments have not given the same relative emphasis to these sticks and carrots (Johansson & Hvinden 2007).

3.2 The active/passive divide in broader perspective

Much of the current reasoning on social citizenship relies on an arbitrary and rigid separation between active and passive dimensions. In order to move towards a framework that can transcend this separation, we make three points:

- Marshall’s original understanding of rights/duties is richer and more complex than many critics suggest.
- Many countries’ income security systems were never completely ‘passive’ but rather hybrids, combining ‘active’ and ‘passive’ aspects of social citizenship.
- Participation in gainful employment need not be the only recognized or socially valuable activity that qualifies for the status and recognition as an ‘active’ citizen.
First, Marshall was a sociologist who fully accepted the main premises and assumptions of the dominant sociological paradigm of his time. The chief concerns of this paradigm were the conditions for societal integration and social inclusion. According to this paradigm generally shared norms for action, based on a fundamental consensus over values and norms, served as integrating mechanisms. People’s acceptance of and compliance with the basic norms were ensured through socialization (the internalization of values and norms) and social control (positive and negative sanctioning of behaviour). Marshall’s preoccupation with integration and inclusion involved a stronger collectivist orientation than typically found in liberal thinking. Moreover, this collectivism and belief in a reciprocal or ‘organic’ relationship between individual and society implied ‘duties’ (the action prescribed by shared norms), as well as ‘rights’ (the action that can be expected from others on the basis of the same norms).

In Marshall’s essay, the relationship between the modern state and the individual emerges as a special case in the general relationship between the societal community and its members, as this was analysed within the sociological paradigm. When he emphasized that citizenship involved both rights and duties on the part of the individual, these corresponded to rights and duties on the part of the state. Some of these rights and duties were of a formal and legally enforceable nature (e.g. the right and duty to schooling, the duty to pay taxes or do military service, the right to be provided income maintenance under certain circumstances). Other rights and duties were more concerned with what might legitimately be expected (e.g. from individuals to do what they can to be self-sufficient, not only to work but of their work as well as possible, take an interest in political affairs and exercise their right to vote). It was no accident that Talcott Parsons and other leading representatives of the sociological paradigm of the mid-twentieth century easily absorbed Marshall’s work into their own (e.g. Parsons 1967, 1971, Bendix and Rokkan, Bendix 1964/1977, cf. also Ferrera 2005).

While Marshall argued that there ought to be a balance between rights and duties, he noted with some regret that rights had proliferated more rapidly than duties under the modern welfare state. It had become more difficult to promote a sense of duty when people had to relate to a more distant and abstract construction as the nation-state. Similarly to Durkheim (1893/1947), one of modern sociology’s forefathers, Marshall suggested that one should aim to develop people’s sense of having both rights and duties in the context of intermediate institutions, for instance within their local community or the organization where they are employed. When participants in the contemporary debate on the relationship between employment and income security argue for an appropriate balance between rights and duties, Marshall would probably have agreed.

Second, some calls for a more active side to social citizenship are based on a selective understanding of national welfare systems. Despite much talk of universal, generous and unconditional benefits in some countries (e.g. the Nordic countries), citizens’ eligibility for many benefits has presupposed their prior participation in the labour market and/or their willingness to
participate in measures to improve their employability. In other countries, means-tested, short-term and low benefits have diminished the need for governments to enforce the work ethic; poverty and meagre public provision have forced people to work.

Third, a sharp distinction between active and passive social citizenship resonates with recent claims about ‘the end of the work society’, or ‘the end of the full employment society’ (Beck & Beck-Gernsheim 2002). Turner (2001) provides a more nuanced picture on the relationship between labour market participation and entitlement to social provision arguing that wage labour (together with reproduction and military service) was the main conditions for the enjoyment of the social rights described by Marshall. Turner claims that wage labour is now undergoing considerable change; work is no longer the stable social institution and a gateway to worker-citizenship that it was during the ‘golden age’ of the post-war welfare state. Higher levels of unemployment, new ways of organizing work and less predictable career paths are making labour market participation a less secure route by which to gain social rights and effective entitlements3.

As a general claim, Turner’s argument obviously has some validity but seems exaggerated, given the expansion of overall labour market participation in many European countries, even if it is largely related to the increase in employment among women. In many European countries, demographic ageing is expected to lead to labour shortages within a few years.

This prospect leads us to a fairly narrow perception of what currently counts as economically and socially valuable citizen activities. In their current welfare reforms, few governments recognize participation in activities which are not oriented towards paid employment or do not serve as ‘stepping-stones’ to the fulfilment of citizen duties, although there are some cross-national nuances in this respect. Very few governments have fully acknowledged the value of women’s unpaid care in the family, although in their current pension reforms they are paying lip-service to it through ‘care credits’ (Siim 2005; Lister et al. 2007; Orloff 2009). Some governments as well as the EU appear to have been somewhat more willing to recognize participation in voluntary social and cultural work, self-help activities, organizational, co-operative or ‘social economy’ work as alternatives for people who are deemed to be distant from the mainstream labour market (e.g. DSD 2006; EC 2011). For a long time volunteering was promoted as means to strengthen social capital, social cohesion and even Active Citizenship.

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3 Even if that is not Turner’s point we may add that the trend toward “flexicurity” policies in several European countries probably reinforced the insecurity experienced by many persons with precarious relationships to the labour market, including a fair number of persons with disabilities.
3.3 A renewed emphasis on citizens’ participation and agency

The second shift within the current debate on citizenship concerns Marshall’s focus on citizenship as a status rather than as practice – that is to say, something exercised by citizens, and not simply a status involving a certain set of rights and duties. By contrast, many scholars construct the citizen as an agent, with the capacity to make individual choices and take part in decision-making (e.g. Le Grand 2003; Hoggett 2001; Deacon 2004; Jensen & Pfau-Effinger 2005). A more dynamic relationship between welfare states and citizens is evolving since citizens themselves expect (or are expected) to play a more active role in handling a diverse set of risks and promoting their own welfare. We need to complement Marshall’s notion of social citizenship with new models of citizenship, involving the participatory dimension of social citizenship (e.g. citizens in the role of users, partners in dialogue with authorities and service-providers, self-organizers, etc.).

Throughout Europe, we see the emergence of new discourses on the involvement of citizens and a search for new forms of civic participation beyond representative democracy, often under the headings of ‘civil dialogue’, ‘collaborative governance’ or ‘participatory governance’ (Grote & Gbikpi 2002; Fung & Wright 2003).

The European Union (EU) has made ‘participatory democracy’ a key objective, aiming at an open, transparent and regular dialog with citizens, representative associations and civil society (Kohler-Koch & Rittberger 2007). The Lisbon Treaty introduces provisions for so-called “Citizens’ Initiatives”, an instrument which shall overcome the barriers that exist between European citizens and Brussels decision makers by calling on the European Commission to make a legislative proposal through the collection of one million signatures. In addition, the European Commission has set up a platform (Your voice in Europe) as a “single access point” to public consultations, open discussions and other tools to interact with the European policy-making process. Finally, the European Parliament has also installed a model of the Citizen’s Agora, bringing together citizens, representatives of civil society and elected politicians to debate the key challenges faced by the EU.

Similarly, national governments are establishing new forums and channels for participation and the articulation of interests, including not only long-term actors (e.g. social partner organizations), but also self-help groups, user organizations, community-based organizations and other civil society actors speaking on behalf of marginalized groups (Barnes et al 2007). Across Europe, welfare states are focusing more on the role that citizens could play as co-producers of

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4 http://ec.europa.eu/citizens-initiative/public/welcome
5 http://ec.europa.eu/yourvoice/index_en.htm
welfare, by volunteering in voluntary organizations and hence demonstrating their commitment and solidarity with society and fellow citizens (Evers & Laville 2004).

Marshall could not have foreseen these developments, and in any case he was mainly interested in (social) citizenship as a status, rather than the participatory side of citizenship (Turner 1990, 1993 and 2001). Nevertheless, recent calls for a more participatory and active form of citizenship can be seen as a reaction to a Marshall-inspired understanding of social citizenship. For political theorists, however, this is hardly a new aspect of citizenship. Janoski and Gran (2002: 39-40), for instance, define the active citizen as someone who participates in many political activities, is concerned about people who belong to the same group, identifies with altruistic goals, opposes established elites, and pursues some form of social change. Others list active citizenship as one of several aspects of ‘thick citizenship’, together with elements like mutually supportive rights and duties, participation in a political community, the interdependence of public and private, and civic virtues (Faulkes 2000: 11, 108). Similarly, Habermas (1994: 24-28) conceives of active citizenship as analogous to achieving membership of a self-determining ethical community.

As argued by Siim (2000, 2005) and Lister et al (2007), much of the current debates around the participatory vein of citizenship rest on a rigid active/passive divide. This rigid divide glosses over the historical exclusion of women and marginalized social groups from the public sphere. We need an understanding of the active/passive axis that is sensitive to a wider range of activities by various social groups, formal and informal associations in civil society, and the mechanisms by which groups may be included within or excluded from the public sphere.

Williams (1998) and Lister (1998) raise similar concerns and highlight notions of active citizenship that involve mutual aid and collective self-help, and efforts by citizens to create themselves as subjects rather than objects for others – for instance as expressed in movements of poor or disadvantaged people. These authors point to the increasing influence of user organizations, citizen groups and new social movements, as a challenge to much current reasoning on state/citizen models in existing welfare state research. Criticizing established models of social citizenship, Williams (ibid.) argues that we need a new thinking that ‘… involves a shift away from seeing people as passive beneficiaries of welfare provided through state interventions and professional expertise…’ As a way of conceptualizing this new relationship between states and citizens, she proposes a notion of ‘welfare agency’ to address the strategies and activities of ‘welfare subjects’.

The core element of this new conception of citizenship is the identification of citizens (claiming benefits or services) as creative and reflexive agents, who do not respond to benefits and services in uniform ways. Fitzpatrick (2002) has made similar suggestions in relation to notions such as the ‘welfare democracy’. He claims that even though people in marginalized positions in society are subordinated to existing power structures and possibly denied full citizenship by public
institutions, they are still active agents, capable of exercising power and affecting their own welfare and well-being (see also Lister 1998 & 2003; Lister et al. 2007).

These authors create an analytical space in which we can reconsider the participatory dimensions of social citizenship. When welfare claimants challenge their ascribed identity as silent or passive objects and as occupants of fixed social categories, give voice to their opinions and demonstrate the capability to develop strategies independently, they contest established public and professional boundaries and practices. This new dynamic might imply that citizens develop new and alternative strategies to make their voice heard in relation to public services, which they feel are violating their integrity and personal rights.

3.4 The emergent idea of consumer-citizenship

Citizenship studies have focused increasingly on notions such as ‘consumer citizens’ (Clarke et al. 2007), ‘welfare consumerism’ or the ‘marketization of welfare’ (Crouch, Eder and Tambini 2001; Taylor-Gooby 2009). These notions add yet another dimension to previous models of citizenship, by asserting that consumers are active, orient themselves in markets and choose to maximize their welfare. Consumer-oriented conceptions of citizenship have an affinity to the Libertarian understanding of the state–citizen relationship. This defines the relationship between state and citizen as of a limited and explicitly contractual nature (Nozick 1974; Miller 2000). People should take responsibility for their own well-being and risk protection, and as part of this responsibility seek the best services available. Apart from its role in protecting and enforcing basic personal and property rights, it is not obvious what goods and services the state should provide. However, to the extent that the state does provide welfare services, it should operate as an enterprise with the citizen as a rational consumer of public goods.

Crouch argues that the consumer-citizen communicates with producers or providers through market signals (Crouch 2001: 111-113). According to the premises of this citizenship model, individuals are to enjoy consumer sovereignty, and this is to be accomplished through choice and contract. People’s role as consumer-citizens may be limited to exercising a choice between a given set of providers or ‘suppliers of services, whether private or public, expressing any dissatisfaction through complaints or by demanding a change of provider. The instrument of contract means that consumers who feel they have not been given the service they are entitled to may take legal action against the provider. In this kind of mixed or semi-private welfare market, people’s demands for a service may be regulated through user fees or charges covering at least part of the cost of providing it.

Jones (2005) and Taylor-Gooby (2009) argue that citizens have become more assertive and critical, both as tax-payers and as consumers of social policy. But the practical impact of consumer-citizenship has so far been more limited than the widely adopted rhetoric might
suggest. Nevertheless, a key analytical issue is to what extent the consumer-citizen model interacts, contradicts or reinforces Marshall’s original interpretation of social citizenship, or the participatory models of citizenship outlined in the previous section. Aberbach and Christiansen (2005: 233) express concern that the notion of consumer-citizenship will undermine the collective and participatory dimensions of citizenship. They suggest that people are beginning to be oriented more exclusively towards the consumer role, meaning that they try to influence service provision directly while neglecting other (collective) channels of participation. Taylor-Gooby (2009) asks what impact consumer-citizenship will have on the solidarity-based and redistributive Socio-Liberal approach to citizenship.

Whether attempts to adopt ideas of consumer-citizenship and new governance practices will actually undermine citizen practices and individuals’ social rights, is an issue that future research needs to explore in greater detail. Arguably, the aim of consumer-citizenship is to hand more choice and self-responsibility to the individual. This goal calls for a thorough investigation into citizens’ capability to exercise this choice and self-responsibility, including the extent to which citizens feel able to take advantage of the opportunity to act as transnational citizen-consumers in the emerging European welfare market on which multinational corporations are competing to offer insurance, health and care services.

3.5 Summary

Returning to Miller’s (2000) distinction between three main approaches to citizenship, we can make the following summarising comments:

First, citizenship in a Socio-Liberal sense is a relationship between the individual and the state, involving encompassing and reciprocal sets of mutual rights and obligations. Here, a move towards active citizenship could for instance imply that the state demands citizens to meet specific obligations more actively, such as taking part in different forms of welfare-to-work (activation) programmes in return for social benefits of different kinds.

Second, in a Market-Liberal (Libertarian) sense, the relationship between state and individual is conceived more narrowly, with the emphasis on the self-responsibility and autonomy of the individual. The responsibilities and legitimate tasks of the state are therefore limited to guaranteeing and protecting the limited but fundamental rights of the individual. Individuals should be able to exercise choice and enter freely into contracts to promote their own well-being and protection against risks of various kinds. According to this understanding, a move towards active citizenship could mean that citizens have greater scope for exercising individual choice and providence, as knowledgeable consumers in a mixed welfare market.
Third, citizenship in a *Civic-Republican* sense generally focuses on the citizen’s participation in the affairs of his or her community, and the expectation that the individual will be committed to acknowledging and promoting the well-being of the community as a whole. A shift towards active citizenship defined in this way could be a means of achieving broader and more intensive citizen participation, both in deliberation and dialogue with relevant agencies and in self-directed activity, with regard to welfare and well-being. Increased participation may take both individual and collective forms. On the one hand, individual ‘users’ may engage in a dialogue to clarify appropriate measures or courses of action; on the other hand, they might be involved in consultation and negotiation over the design and planning of new policies.

The active dimension of each approach and the ways in which elements associated with each of them *combine* are of particular interest within current debates on welfare reform in Europe and most EU member states, including those reforms that are relevant for persons with disabilities.

In several reform packages, most clearly in relation to activation and pension reforms, we can observe several attempts to *combine* notions such as

- fulfilling duties (obligations);
- exercising choice and self-responsibility, and/or
- participating in dialogue with providers, deliberation and decision-making.

Hence, one important task for research into social citizenship is to describe and analyse the ways in which new and ‘hybrid’ forms of social citizenship give rise to tensions, conflicts and ambiguities. By ‘hybrid’ we mean combinations of elements from at least two of the three forms of citizenship we have outlined in this Section.

A related task is to gain more systematic knowledge about how the Europeanization and denationalization of social policy may promote such hybridization and a relative shift in the overall configuration of social citizenship – in other words, a more prominent role for Market-Liberal (Libertarian) or Civic-Republican elements at the expense of Socio-Liberal elements.

*For Reference list, see after Section 4*
4. How does the shift toward Active Citizenship affect persons with disabilities?

4.1 What does Active Citizenship involve?

As suggested by our earlier discussion, approaches to social citizenship tend to take as their departing point one of the following (somewhat contrasting) three sets of basic principles or values in contemporary societies, as seen from the perspective of citizens:

- ‘Security’: Enjoying social protection against major life risks (such as illness, poverty, violence etc.), diminishing major uncertainties or the need for individual risk-taking (for instance in relation to financial matters), and avoiding constant worries about the future.

- ‘Autonomy’: Enjoying opportunities to live independently, exercising freedom choosing the life one has reasons to value and avoiding dependence on or interference from others.

- ‘Influence’: Participating in discussion and decisions setting the framework for one’s own life as well as participating in public deliberation and decision-making aimed at the promotion of the common good and regulating social behaviour, given the interdependence of human action.

The three sets of values are analytically different but in practice probably interrelated facets or dimensions of Active Citizenship. DISCIT has set itself the task of identifying the conditions for Active Citizenship becoming an experienced reality for persons with disabilities (see Table 4.1.).

While in Europe different countries have different arrangements for providing for and protecting their citizens against risks, and some of these arrangements are closer to one of these citizenship models than to others, a country’s actual configuration of social provision and risk protection is always more complex than the pure and simplified picture drawn by a model. Nonetheless it is fair to say that the social policy systems of some countries (e.g. Norway, Sweden) have given relatively greater emphasis to the public redistribution of resources and collective risk protection (‘security’) than others. Vice versa, some countries (e.g., Germany, Ireland, Italy, and the UK) have in diverse ways granted a greater role to individual or family responsibility and risk protection (‘autonomy’) than others. Last but not least, citizens’ opportunities for exerting influence on public affairs or the contents of personalised public provision have also varied among European countries.
Table 4.1: Dimensions of Active Citizenship – their relevance for the practices of persons with disabilities

| Dimensions based on key values from citizens’ perspective | Main focus of recent discussions of Active Citizenship | Examples of relevant practices on the part of persons with disabilities

| ‘Security’ | Citizens exercising both rights and duties; reciprocity and complementarity between individuals’ and the community’s responsibilities | Experience with and reaction to duties (imposed as conditions for receiving cash or services) or poverty traps (caused by the structure of cash benefit systems); Participation in individual or collective efforts to improve security (e.g. get providers to sustain or improve provisions; increase their relevance; change rules for qualifying) |

| ‘Autonomy’ | Citizens exercising freedom of choice; taking responsibility for their own future and risk-protection | Living independently in the community; Participating in paid work; Participation in individual or collective efforts to achieve greater autonomy (e.g. independent / community living, access to paid work, full accessibility to transport, buildings, ICT; personal assistance, mobility or communication supports) |

| ‘Influence’ | Citizens exercising co-determination, individually or collectively, participating in self-organised, voluntary and political activities & in civil society | Participation in discussions with relevant authorities / service providers to influence quality and contents of personal services (or personal payments to purchase services) Participation in campaigns, advocacy groups, organisations (e.g. DPOs) Participation in conventional politics (active in parties, voting, standing for elected positions) |

In the course of the last two or three decades the contrasts in relative emphasis have, however, diminished or become blurred. We can even observe some convergence in different European societies. As an overall tendency and relating to global developments such as the growing impact of international organisations, we can observe that the value of influence has gained increasing

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7 We return to these and other examples of practices of relevance for Active Citizenship in Section 5.
prominence as a new context for existing arrangements for social provision and risk protection, both across different groups of countries and across levels of governance.

Such trends have partly been driven by the ways in which governments have responded to the challenges facing traditional or previous social policy arrangements (e.g. globalization pressures, growing economic interdependencies, demographic ageing, migration flows, public cost explosions, deficits or debt problems). International policy learning and diffusion (e.g. through the UN, EU, Council of Europe, OECD) have stimulated governments to adopt a number of reforms and innovations that have implications for Active Citizenship. Both international policy innovation and policy transfer are driven by civil society organisations, especially by the international disability rights movements.

The reinforced role of Active Citizenship understood as citizens exercising both rights and duties can be traced back to an OECD-driven policy discourse about turning from ‘passive’ to ‘active’ forms of employment-related provisions (the OECD Jobs Study, later the Jobs Strategy of the early 1990s). With the 1997 Employment Strategy this discourse was fully adopted by the EU and by the EU Member States via the formulation and implementation of national action plans. While during the early years the respective guidelines explicitly pointed to the development of more active (i.e. employment promoting) measures targeted at persons with disabilities, later guidelines dropped the explicit mention of disabled persons in the name of mainstreaming. Several studies indicated that countries differ considerably in the priorities which they give to providing training, education and other measures in order to strengthening the vocational qualifications of persons with disabilities. To the extent that countries provide such ‘active’ measures, they tend also to impose duties to take part in such measures which in some cases link the continued receipt of income maintenance benefits with individual participation. Member States have until recently varied considerably in the extent to which they include persons with disabilities among the target groups for employment-promotion or ‘activation’ efforts (OECD 2010; Halvorsen & Hvinden 2009; 2011).

The emerging role of Active Citizenship understood as citizens exercising freedom of choice and taking more individual responsibility for their well-being and risk-protection has been particularly prominent in recent pension reforms of many European states. These reforms are part of the efforts to make pension arrangements more sustainable and they tend to effectively shift the risks related to economic security in old age from the state to the individual. These reforms are relevant for persons with disabilities as future old age pensioners, but they also raise additional challenges for them, since the individual capacity for risk-protection in the case of old age is closely related to the income one earns during one’s adult life, i.e. one’s life-time earnings. When persons with disabilities are excluded from gainful employment during major phases of their adult life, their life-time earnings will be reduced accordingly. Some Member States (e.g. Norway and Sweden) have sought to take such restricted earnings-capacity into account when
designing their pension reforms, e.g. through the provision of guarantee pensions for those with no or low life earnings. Yet, there is a considerable risk for economic hardship in old age for many pensioners-to-be with disabilities, unless their possibilities for paid employment in adult age are improved substantially, since access to paid labour is closely linked with the possibilities of building up financial assets (pension entitlements or nominal accounts, savings, house ownership).

Many Member States (e.g. Norway, Sweden, the UK) have, however, also introduced a number of reforms that have led to positive improvements in the conditions for exercising autonomy and self-determination in everyday life, e.g. by closing down previous institutions and offering persons with disabilities possibilities to live independently in the community, and by providing personal assistance, care and support, innovative use of new technologies, universally designed or appropriate accommodation for persons with disabilities, accessible physical environments and transport systems, etc.

More generally, for a considerable period the scope for Active Citizenship understood as exercising influence on the decisions of public services or professional agencies impacting one’s own well-being improved in many Member States (e.g. Ireland, Sweden, the UK) through a trend towards more individualized or personalized service provision and the adoption of individual ‘(action) plans’ (or even ‘contracts’) to be agreed upon jointly by the person concerned and the service provider(s). Arrangements for individual ‘co-governance’ have been found in a range of different services. There are reasons to ask whether such arrangements still exist after the crisis and shift towards austerity measures.

Before the crisis, Active Citizenship understood as involvement in dialogue, deliberation and decision-making related to policies and provisions of a more collective nature also gained a boost in many countries (e.g. Germany, Italy, UK and Sweden) through the setting up of consultative boards, ‘user panels’, public hearings, internet consultations with citizens, etc. In some cases these arenas for collective co-governance invited citizens to be directly involved, by physical or virtual participation, in other cases representatives gave voice to the views and demands of groups or organisations, for instance of persons with disabilities.

The framework for understanding Active Citizenship presented here synthesises and condenses key elements of the scholarship on Active Citizenship as it was in early 2012 (e.g. Miller 2000; Hvinden & Johansson 2007; Bothfeld & Betzelt 2012, Newman & Tonkens 2011). Additional literature has appeared later, but does not give strong theoretical reasons to change the framework in a fundamental way. We do, however, present an annotated bibliography of some the key recent academic literature on Active Citizenship in an Appendix to this deliverable.
4.2 The relationship between the concept of Active Citizenship and the Capability Approach

While the Capability Approach has a different starting point and direction that the scholarship on Active Citizenship it can still serve as inspiration and instrument for making the idea of Active Citizenship more precise and clear. In the terminology of Capability Approach, “functionings” refer to the various activities or identities a person may value doing or being, while “capability” refers to the alternative combinations of functioning that are feasible for her to achieve (e.g. Sen 1999: 75).

As developed by Amartya Sen, Marta Nussbaum and others, the Capability Approach originated in a dialogue with - and as a critique of - the philosopher John Rawls and his *A Theory of Justice* (1971). Especially Sen has criticised Rawls for not putting greater emphasis on how persons have different possibilities for converting the resources (or “primary goods”) they may have access to into the ways of living these persons have reasons to value and strive for. Significantly, Sen has on a number of occasions referred to the situation of persons with severe disabilities as example of persons who face such obstacles of conversion or conversion deprivation (e.g. Sen 1979: 215-19; 1992, pp.20, 28, 81, 82, 91; Sen 1999, 69-70, 74-75; Sen 2004; Sen 2009, pp., 253,-55, 258-61; 306).

In these contexts, Sen points to consequences of the nature of the person’s impairment or activity restrictions, as well as to the adverse impact of barriers in the social environments. For instance, he refers to the extra costs that some persons with disabilities have in everyday life related to diets, wear and tear on clothes, transport, etc. Evidently it will vary a lot whether or to what extent individual countries’ cash transfer systems compensate for such extra post. Sen emphasises that impact of such extra cost may be reinforced if the person has diminish possibilities for earning an income (Sen 2009: 258).

A student of Sen, Wiebke Kuklys (2010) has demonstrated that one gets widely different estimates of the prevalence of poverty in a population, depending on whether the extra costs of families with disabled members are taken into account. Similarly lack of physical accessibility in social environment faced by persons with mobility restrictions may also reduce their freedom to pursue their values, wishes and interests, e.g. in terms of social, economic, political or cultural participation, for instance because of extra costs created by lack of accessibility.

Warning against seeing such conversion obstacles as unique issues for a minority of the overall population Sen comes close to a Universalist perspective on disability:
“The variations in conversion opportunities are not just matters of what can be seen as ‘special needs’, but reflect pervasive variations – large, small and medium – in the human condition and relevant social circumstances” (Sen 2009: 261).

Sen is very clear in his criticism of complacency in the societal response to the situation of persons with disabilities:

“The relevance of disabilities in the understanding of deprivation in the world is often underestimated, and this can be one of the most important arguments for paying attention to the capability perspective. People with physical and mental disability are not only among the most deprived human beings in the world, they are also, frequently enough, the most neglected …. Given what can be achieved through intelligent and humane intervention, it is amazing how inactive and smug most societies are about the prevalence of the unshared burden of disability” (Sen 2009: 258-260).

Although Nussbaum has given the Capability Approach a twist that differs to that of Sen, for instance expressed in her interest in formulating a list of ten central human functioning capabilities (e.g. Nussbaum 2000: 78-80; 2011: 33-34), she has also given issues related to disability considerable attention (Nussbaum 2006; 2011). She insists that this list of capabilities apply to all human beings. In particular she has focused on the situation of persons with cognitive disabilities or mental impairments. Yet, she explicitly adheres to a Universalist understanding of disability:

“A good analysis requires recognizing the many varieties of impairment that “normal” human beings experience, and thus the real continuity of between “normal” lives and those of people with lifelong mental disabilities” (Nussbaum 2006: 92, 191).

Of particular interest for the DISCIT is that she sets herself the task of developing “an adequate conception for the full and equal citizenship of people with disabilities” (Nussbaum 2006: 92) and “of people with physical and mental impairments and those who care for them” (ibid., p. 99). She even explicitly refers to the potential of persons with disabilities for developing capacity for Active Citizenship, given appropriate forms of social arrangements, including varieties of care (ibid. 99, 137).

Nussbaum emphasises the principles of accessibility and universal design as necessary conditions for enhancing capabilities for persons with disabilities on an equal basis as others (Nussbaum 2011: 57-58), illustrating that the Capability Approach is not solely an individual capacity-oriented perspective, as it is sometimes alleged.
In our work on elaborating the concept of Active Citizenship and our assumptions about conditions for persons with disabilities achieving Active Citizenship we will be able to find inspiration for clarification from the Capability Approach, especially in relation to these areas:

- **The security dimension**: The Capability Approach reminds that we in principle should be able to take into consideration whether persons with disabilities have extra costs that will reduce their effective purchase power compared with persons with same disposable income but not extra costs related to the impairment or the social or built environment. We should ask whether the cash benefit systems in the participating countries are compensating for extra costs.

- **The autonomy dimensions**: Following the suggestions of Sen and Nussbaum, we should not limit interest to the extent to which persons enjoy more narrowly defined government-managed or market-provided freedom of choice, but also effective or substantial freedom in the wider capability meaning of having the possibility to choose the life one has reason to value and pursue the ambitions and goals of life that one has reasons to cherish.

- **The influence dimensions**: The Capability Approach also emphasises that we need to be sensitive not only to formal limitations in the rights to co-determination and participation in deliberation and decision-making for persons with disabilities but also to the possible gaps between formal possibilities for co-determination and participation and the effective possibilities for such co-determination and participation.

- More generally, the Capability Approach can help us to identity factors that enhance or hamper the process of moving from having a formal scope for Active Citizenship to Active Citizenship as practice or expression of active human agency.

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4.3 A condensed review of scholarly literature on Active Citizenship for persons with disabilities

As we have noted earlier, we do not find a huge literature that have dealt with Active Citizenship for persons with disabilities. Yet, in recent years we can observe an increase in this literature. We here present a short overview of this literature to illustrate the varieties of the approaches and topics covered.

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8 We refer the reader to the more detailed discussion of the relevance of the Capability Approach for Active Citizenship by the Italian team of DISCIT (Section 7).
- Betzelt and Bothfeld (2011) provide an interesting and innovative analytical framework focused on individual, social and political dimensions of autonomy. They discuss the contrast between women’s more traditional citizenship and current expectations of women’s (economically) Active Citizenship and give many references to the situation of persons with disabilities.

- Ebersold (2007) develops a participation- and experience-based model for understanding conditions for Active Citizenship for persons with disabilities, emphasizing the role of full recognition for achieving Active Citizenship.

- Dwyer (2004) contrasts top-down and government dominated versus bottom-up and social movement-based concepts of Active Citizenship, with the new disability movement as example of the latter.

- Hvinden and Johansson (2007) present a multifaceted concept of Active Citizenship built on a synthetic review of the literature and illustrated with case studies from diverse policy areas, including the role of the disability movement in the development of European disability policy.

- Hästbacka and Nygård (2012) investigate the ambiguities of the concept of Active Citizenship espoused in a 2006 government report on disability policy and develops the distinction between a more conventional concept of social citizenship and the emerging concept of Active Citizenship in Finland.

- Lantz and Marston (2012) analyse the findings of a two-year semi-longitudinal study with participation of 80 persons with disabilities who had claimed welfare benefit, focusing on the intended and unintended consequences of the government’s pressures on recipients of benefits to exercise personal responsibility and become active (= productive) citizens, resulting in a mix of acceptance and resistance from the persons involved.

- Macgregor (2012) taking as point of departure the deeply rooted connection between the ability to exercise social citizenship and participation in paid work, the author argues that the strong values associated with being employed, e.g. independence, self-reliance and productivity should have a less prominent role in society to prevent marginalisation of persons with disabilities.

- Mackenzie et al. (2011) analyse the experience of civically engaged adults with acquired neurological communication difficulties, finding that for the participants civic
engagement had both positive and negative dimension. Participation in disability group meetings gave a more positive experience than involvement in broader community activities, which were associated with fatigue and frustration, commonly resulting from communication difficulties and unmet support needs.

- Newman and Tonkens (2011) provide a combination of more theoretical discussions of the ambiguities of Active Citizenship and national case studies, for instance related to the disability field.

- Power et al. (2013) present the findings of a cross-national study of Active Citizenship defined as broad engagement in a range of valued forms of participation, either through supported employment, volunteering, peer support and mentoring, undergoing training, partaking in local activities in the community or securing open competitive employment, while generally emphasising self-determination, independent living in the community and personalisation of services for persons with disabilities.

In the next section we outline how we may specify dimensions of Active Citizenship and the conditions for persons with disabilities achieving Active Citizenship.

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5. How to specify the dimensions of Active Citizenship and the conditions for persons with disabilities achieving Active Citizenship?

5.1 Introduction

The purpose of this part of D2.1 is to propose how we may go about specifying the dimensions of Active Citizenship as outlined in the original DISCIT proposal and later in the DISCIT Description of Work (DoW) and how we may imagine that these dimensions are related to:

1) the conditions for exercising Active Citizenship,
2) the practices of persons with disabilities and
3) the achieved outcomes.

In social science there has in many years been a lively discussion about how to understand the links between human action ("agency") and the structures that partly are results of human action but also serve as conditions for human action (as constraints as well as opportunities or even enabling factors). The following proposal is inspired by recent developments in this discussion and more specifically in the called ‘structuration’ theory (Stones 2005; Elder-Vass 2011; O’Reilly 2012). These developments may help us to capture:

- What dynamic relationship do we find between the practices\(^9\) of persons of disabilities and the various structures that may hamper or facilitate these practices?

- What potential of the action of persons with disabilities has to reproduce and change such structures over time?

DISCIT’s goal is not only to describe and analyse the current scope for achieving Active Citizenship for persons with disabilities in a number of European countries but also to clarify the important transformations that have taken place in recent decades, as well as to identify ways of achieving further progress to the benefit of persons with disabilities.

In our efforts to reach these goals we need a framework for the empirical work in DISCIT that is sensitive to the heterogeneity of the situation and circumstances of persons with disabilities. This

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\(^9\) We remind the reader of the quotation in Section 1; “… being a full and equal citizen is, basically, a question of practices: living a decent life in accordance with the prevailing standards in society, being able to act autonomously, being able to participate in social and political life in the broadest sense, and having ‘civic’ orientations to the political community and to one’s fellow citizens”. 
is clearly an area where we need more work and a broad and thorough discussion of how our conceptual framework can sharpen this sensitivity.

Clearly it is possible to add many more specifications to the ones suggested here. Especially given the broad and encompassing scope of the United Nations Convention of Rights of Persons with Disabilities (UN CRPD), and that the UN CRPD is indeed an important reference for the DISCIT project, it is tempting to multiply specifications of Active Citizenship. Yet, we need to keep in mind that the final list of specifications of the dimensions of Active Citizenship to serve as point of departure for our empirical work must be manageable and feasible with the resource and time constraints we are working under.

**Figure 5.1:** A simplified model of the dynamic relationship between conditions for achieving Active Citizenship, the practices of persons with disabilities and achieved outcomes (adapted after O’Reilly 2012: 149)

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10 This model is has basically the same form as the more elaborated one presented by the Italian team in Fig. 7.2.1, developing a model presented by Robeyns (2005: 98).
5.2 How are the conditions for Active Citizenship, the practices of persons with disabilities and achieved outcomes linked to each other over time?

Taking as our point of the departure the framework presented by Stones (2004) and adapting it for our purpose we suggest that the following will important elements in our framework:

1) External structures enabling or constraining persons with disabilities in achieving Active Citizenship
   a) Global and Regional forces and transformations (e.g. the emerging international Human Rights regime, where the CRPD is now a key element).
   b) Nation-specific legacies; policies, redistributive provision, legal and other regulation; institutional, organization- and local-level arrangements (e.g. more or less accessible physical/built and informational environments; different prevalence of discrimination, stereotypes, stigmatisation versus societal recognition and representation of persons with disabilities).

2) Internal structures enabling or constraining persons with disabilities in achieving Active Citizenship
   a) Enduring internal structures (e.g. general dispositions. “habitus”, length of experience and ways of coping with capacity or activity restrictions or health issues, habits, established ways of seeing and doing, taken-for-granted assumptions, perceptions and judgments of self and others)
   b) Temporary internal structures (e.g. knowledge, competence and reactions to existing patterns of roles, norms and power relations; critical awareness about the impact of external and internal structures and the possibility of change)
4) Outcomes of relevance for persons with disabilities achieving Active Citizenship

a) Individual-level outcomes (e.g. greater effective freedom, improved well-being and quality of life, increased self-respect and respect from others)

b) Group-level or collective outcomes (e.g. more equal social position, recognition and representation of persons with disabilities in society)

We imagine that outcomes involve feedback to external and internal structures, leading to consolidation or innovation, reproduction or transformation of these – see Figure 5.1.

5.3 The framework in use: an outline of dimensions of Active Citizenship and conditions for persons with disabilities achieving Active Citizenship

Tables 5.1-1.3 summarise a proposal for how to specify the dimensions of Active Citizenship and important conditions for persons with disabilities achieving Active Citizenship as a practical reality.

1. By the term “conditions” we have first of all in mind what we have called “external structures” and “internal structures”. These structures may be hard to change or more malleable or open to influence and change. We do not expect “structures” to be as coherent and strongly integrated. A lack of interconnectedness may in itself create obstacles to persons with disabilities achieving Active Citizenship. Yet, it is also possible that some tensions and ambiguities in the structures create gaps, slack or loopholes, leaving opportunities and openings for the agency of persons with disabilities.

11 The proposal of specifications in Tables 5.1-5.3 partly overlaps the suggestions for specifications given at the end of Section 6, Tables 6.1-6.5. Further discussion within DISCIT will clarify how these proposals may be integrated.
2. A main focus for our empirical work will be what we here call “social practices” to the extent that they include active agency directed towards exercising a) rights and duties, b) autonomy, choice and self-determination, and/or c) influence through participation in decision-making or political processes.

3. We aim, however, also to provide new knowledge about what consequences the developments in external and internal structures have for the social practices of persons with disabilities and the ability of persons with disabilities to use the opportunities created through changes and openings in external internal structures, and how new social practices – in particular the active agency of persons with disabilities – may stimulate change (or contribute to change) in external and internal structures in the next instance.

4. We suggest that our ambition could be to identify a number of cases of such dynamic relationships between structural conditions and the active agency of persons with disabilities and their organisations, both nationally and at supra-national levels (e.g. in relation to the EU, CoE and UN, as well as to national and subnational governments).

5. We adopt Nancy Fraser’s concept of representation, referring to the fundamental question of framing; whether considerations and concerns for a particular group’s situation, interests and well-being are at all included, visible and put on the agenda or table for discussion in political forums or in the public sphere (Fraser 2005; Fraser 2008). In her own words:

“What is at issue here is inclusion in, or exclusion from, the community of those entitled to make justice claims on one another. At another level, which pertains to the decision rule aspect, representation concerns the procedures that structure public processes of contestation. What is at issue here are the terms on which those included in the political community air their claims and adjudicate their disputes. At both levels, the question can arise as to whether the relations of representation are just. One can ask: do the boundaries of the political community wrongly exclude some who are actually entitled to representation? Do the community’s decision rules accord equal voice in public deliberations and fair representation in public decision-making to all members?” (Fraser 2005: 7)
5.4 Do the proposed specifications make sense if they are not matched by existing and commonly accessible data?

We have taken a rather complex conceptual framework as our point of departure for our proposal for specification. Some readers will do doubt the viability of this approach and argue that it will generate many specifications that cannot be examined on the basis of systematic and comparable data or other empirical material.

Certainly many current technically advanced empirical studies are to a great extent driven by a combination of a wish to demonstrate the usefulness of new methods of analysis and a rather pragmatic attitude to the choice of data to be used. Today such preferred data tend to be longitudinal (following the same units or individuals over many years, perhaps their whole life course) and/or allowing the analysis of multilevel interactions and effects.

While such data for instance are available with medical, epidemiological or public health research (often based on rich register data for whole populations) this kind of data are rarely available in disability research in a more narrow social science sense. In relation to many of the issues of interest in social science, research is dependent of the self-identification of a person as having an impairment or restriction in activity. Surveys are usually based on such self-identification.

To collect survey data, especially through personal interviews, is generally much more expensive than to use and link different sets of register data. While the costs are more or less proportional with the size of the sample of persons to participate, for many purposes, especially when our interest is a statistically small subpopulation, the total sample size is critical. Surveys do also often meet problems of non-response, especially from persons in more disadvantaged positions, and sometimes non-response undermines the representativeness of surveys. Panel surveys where the same persons are interviewed or asked to fill out questionnaires more than one time usually meet the problem that a growing proportion of the original sample drops out from one wave to next.

As a result of such challenges the amount of relevant and reliable survey data covering disability, especially longitudinal data, are limited. Yet, what exists of such data have often produced interesting (albeit sometimes intriguing) findings. For instance, this applies to results related to disability in the European Union Labour Force Surveys Ad Hoc modules of 2002 and 2011, the European Community Household Panel (ECHP) 1994-2001, and the current European Union Statistics on Income and Living Conditions (EU-SILC) from 2004 and onwards.
Yet, from the standpoint of disability research, the response to the weaknesses of these and similar data sets (e.g. European Social Survey) should be to offer suggestions for improving the quality and comparability of data, e.g. more extensive testing to achieve greater consistency in the meaning of questions across countries, and strong recommendations to increase total sample size or oversampling of persons with disabilities in some surveys.

In our view such a developmental or step-by-step approach should also guide our specification of dimensions of Active Citizenship and conditions for persons with disabilities achieving Active Citizenship. As a basis for our proposals we do need a precise conceptual framework and clear ideas of what concepts we wish to be able to operationalise and measure. Obviously this conceptually driven approach means that that in the short term there will be some specifications that will not be matched by existing, comparable and easily available data. If considerations of conceptual significance, filling important gaps in knowledge and practical relevance in terms of potential for enhancing the Active Citizenship of persons with disabilities, one of the outcomes of DISCIT ought to be a set of recommendations about how the European Commission and Eurostat can improve the overall volume, quality and comparability (consistency) of disability-relevant and cross-national data.

To summarise, nobody will disagree that proposed specifications in the end of day must be served by data sources that are accessible and relevant. DISCIT’s Deliverables 2.1 and 3.1 are steps towards achieving this goal. We suggest starting with what seems to be the most important and promising implications of the conceptual framework and then move to the question of data availability and end up with making with the necessary concessions or compromises.

We will get no clear sense of direction and relevance if we start with what is available of data. One of the final results of DISCIT ought to be a prioritised list of variables or indicators that the DISCIT team recommends to be covered or made available in future comparative surveys and uses of register-based data from national and supra-national agencies for research purposes. The motivation for this list should simply be that currently available statistical data or indicators are insufficient to give valid and reliable knowledge about important dimensions of Active Citizenship of persons with disabilities, and more generally; to assess what progress state parties make in implementing the UN CRPD. This developmental perspective is even more significant,

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12 Even if their work is not directly comparable to our project, it is instructive to see that the ambitious efforts of the European and Human Rights Commission to establish a British system for monitoring process toward social quality basically also started with specification with basis a conceptual framework (to a great extent inspired by the Capability Approach), even if many of the resulting indicators were not yet matched by available or accessible data (Alkire et al 2009).
as DISCIT does not have resources to undertake any large scale collection of quantitative data in the participating countries.

Finally, for achieving the goals of DISCIT as a whole we must consider how our various needs for empirical information relate to and complement each other (given our overall aims, research questions and framework). Some of the information we compile will give the broader background for the collection of original data to be undertaken in WPs 4-9. This contextual knowledge will make us more able to understand the more or less striking contrasts in the situation of persons with disabilities citizenship in the participating countries. The contextual information will also help us to see how well existing institutional arrangements, provisions and sources of support function as conditions for the active citizenship of persons with disabilities achieving Active Citizenship. This contextual information will primarily be compiled on the basis on existing institutional descriptions and statistical data, complemented by a number of informant / expert interviews (e.g. representatives of policy-makers, responsible agencies, DPOs, academics). The other and main source of information will be the planned series of qualitative and comparative life course interviews.
Table 5.1: Specification of dimensions of Active Citizenship and conditions for persons with disabilities achieving Active Citizenship: Security

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<td><strong>Dimension of Active Citizenship: Security</strong></td>
<td>Status CRPD Implementation (esp. Art. 28); Structure of cash transfer system of relevance for persons with disabilities (e.g. whether universal, targeted, means-tested, rights-based, discretionary; conditional) Structure of social services system of relevance for persons with disabilities (e.g. integrated or, segregated; community or institution-based, rights-based, discretionary); Prevalence of discrimination exclusion, lack of recognition or representation of persons with disabilities</td>
<td>Length of experience and ways of coping with capacity or activity restrictions / health issues: Dispositions, established ways of seeing and doing, taken-for-grants; Perceptions and judgments of self and others; Knowledge, skills, competence; Reactions to existing patterns of roles, norms and power relations; Critical awareness about external and internal structures, their impact and the possibility of change in these structures</td>
<td>Spending and coverage of for benefits in cash and kind among persons with disabilities; Non-take-up of benefits in cash and kind (qualify but do not claim); Risk of poverty before &amp; after transfers among persons with disabilities; Gaps in disposable income between persons with disabilities and others; Severe material deprivation among persons with disabilities; Poverty traps created by cash transfer system</td>
<td>Availability, adequacy and relevance of benefits, as perceived by the person; Social accept or stigma related to receiving benefits as perceived by person; Poverty traps created by cash transfer system, as perceived by person; Experience and reaction related to duties imposed as conditions for receiving cash or services or poverty traps; Participation in efforts to get providers to sustain or improve provisions; increase their relevance; change rules for qualifying</td>
<td>Stability or change in: Status CRPD Implementation (esp. Art. 28); Structure of cash transfer system; Structure of social services system; Changing and coverage of benefits; Indicators of non-take-up; Risk of poverty before and after transfers; Gaps in disposable income; Severe material deprivation; Poverty traps; Prevalence of discrimination exclusion, lack of recognition or representation of persons with disabilities</td>
<td>Expansion / contraction in benefits in cash or kind; improved / deteriorated standard of living, as perceived by the person; Stability or change in: Degree of economic freedom, as experienced by the person; Access to required services of quality and relevance, as experienced by the person; Prevalence of discrimination exclusion, lack of societal recognition or representation; as experienced by the person;</td>
</tr>
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| **Possible types and sources of data** | Existing documentary material, quantitative data, informant / expert interviews | Qualitative data from life course and expert interviews, quantitative data from surveys | Quantitative data from administrative registers (e.g. Eurostat) and surveys | Qualitative data from life course interviews | Documentary material, informant interviews & quantitative data | Qualitative data from life course and informant / expert interviews |
Table 5.2: Specification of dimensions of Active Citizenship and conditions for persons with disabilities achieving Active Citizenship: Autonomy

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<tr>
<td>Dimensions of Active Citizenship: Autonomy</td>
<td>Status CRPD implementation (esp. Art. 19-21, 26-27); Structure of social services / supports system of relevance for persons with disabilities (segmented, institution-based, inclusive, community-based; rights- or discretion-based?)</td>
<td>Structure of social regulation system of relevance for persons with disabilities (non-discrimination, accessibility &amp; related legislation; Prevalence of discrimination, exclusion, lack of societal recognition and representation of persons with disabilities</td>
<td>Length of experience and ways of coping with capacity or activity restrictions / health issues; Dispositions, established ways of seeing and doing, taken-for-grants; Perceptions and judgments of self and others; Knowledge, skills, competence; Reactions to existing patterns of roles, norms and power relations; Critical awareness about external and internal structures, their impact and the possibility of change in these structures</td>
<td>Use of different living arrangements (segmented, semi-segregated, with parents, siblings or relatives, living independently in the community / own housing); Use of in-home, residential or community support services (including personal assistance and similar)</td>
<td>Previous and current living arrangements, as perceived by the person; Social accept or stigma related to living arrangements, as perceived by the person; Accessibility, availability, adequacy &amp; quality of supports related to living arrangements, employment, mobility, communication, as perceived by the person; Participation in efforts to achieve improvements towards independent / community living, access to paid work, full accessibility, personal assistance, mobility or communication supports</td>
<td>Stability or change in: Status CRPD implementation (esp. Art. 19-21, 26-27); Structure of social services / supports system; Use of different living arrangements; Use of in-home, residential or community living supports service; Use of personal mobility &amp; communication supports; Accessibility (mobility, buildings, postal &amp; banking services, ICT); Employment patterns (full/part-time, segregated or mainstream, etc.)</td>
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Possible types and sources of data

| Existing documentary material, complemented by quantitative data & informant / expert interviews | Qualitative data from life course interviews, possibly also from expert interviews and quantitative survey-based data | Quantitative data from surveys, possibly also from expert interviews and administrative registers | Qualitative data from life course interviews | Documentary material, informant interviews & quantitative data | Qualitative data from life course interviews and informant / expert interviews |
Table 5.3: Specification of dimensions of Active Citizenship and conditions for persons with disabilities achieving Active Citizenship: Influence

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<tr>
<th>Perspective</th>
<th>A External structures</th>
<th>B Internal structures</th>
<th>C1 Practices</th>
<th>C2 Practices</th>
<th>D1 Outcomes</th>
<th>D2 Outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dimension of Active Citizenship: Influence</td>
<td>Status of CRPD implementation (esp. Art. 29); Structure of legal and practical provisions of relevance for effective and full participation in public, political and organizational life for persons with disabilities, as well as for voice &amp; co-determination in planning personalised services / supports; Prevalence of discrimination, exclusion, lack of societal recognition and representation of persons with disabilities</td>
<td>Length of experience and ways of coping with capacity or activity restrictions / health issues; Dispositions, established ways of seeing and doing, taken-for-grants; Perceptions and judgments of self and others; Knowledge, skills, competence; Reactions to existing patterns of roles, norms and power relations; Critical awareness about external and internal structures, their impact and the possibility of change in these structures</td>
<td>Prevalence of participation in discussion with service providers (e.g. related individual plans); Rates of participation in organisations, disability-related and others; in campaigns via social media etc., elected to positions, being representative in consultation or dialogue bodies; Rates of participation in conventional politics; voting, membership, activity in parties, having elected positions in national, regional or local government</td>
<td>Extent &amp; outcome of participation in discussion with service providers, motivators / facilitators &amp; barriers, as perceived by the person; Participation in campaigns, advocacy groups, organisations (DPOs and others); motivators / facilitators &amp; barriers, as perceived by the person; Participation in conventional politics (active in parties, voting, standing for elected positions), motivators / facilitators &amp; barriers, as perceived by the person</td>
<td>Stability or change in: Status of CRPD implementation (esp. Art. 29); Structure of legal and practical provisions of relevance for effective and full participation; Prevalence of participation in service provider discussions, Rates of participation in organisations and campaigns; Rates of participation conventional politics, Indicators of the prevalence of discrimination, etc.</td>
<td>Stability or change in: Participation in provider discussions, organisations, campaigns or conventional politics, as perceived by the person; Effective influence (or co-influence) at individual level and collective level, as perceived by the person; Prevalence of discriminatio, exclusion, lack of societal recognition or representation; as experienced by the person</td>
</tr>
</tbody>
</table>

Possible types and sources of data

| Possible types and sources of data | Existing documentary material, quantitative data, Informant / expert interviews | Qualitative data from life course and expert interviews, quantitative data from surveys | Quantitative survey data, qualitative informant / expert interviews possibly also from administrative registers | Qualitative data from life course interviews | Documentary material, informant interviews & quantitative data | Qualitative data from life course interviews |
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6. The Relevance of Active Citizenship for Persons with Disabilities

6.1 Abstract
This paper explores the relevance of Active Citizenship for persons with disabilities. In its first part, it asks what happens when persons with disabilities are demanding access as new citizens to a national community. Further, the case of being a citizen, i.e. owning the formal status, being accepted as community member and practising citizenship rights is explored. The discussion of these two situations demonstrates that citizenship entails ambivalent traditions when it comes to disability. On the one hand, citizenship implies an ideology of ableism, the assumption that citizens ought to be healthy, exercising normal social roles and be, as far as possible, non-disabled. Despite this thinking, persons with disabilities clearly profit, on the other hand, from the idea of citizenship to whose tradition the principle of solidarity belongs. Citizenship as a multidimensional concept provides citizens with basic (political, economic, social and cultural) rights, of which social rights are the most contested, but also the most important for disabled persons.

In its second part this paper discusses the interrelation of social citizenship, human rights and disability. Basically, disability is a case of social inequality, and history shows that persons with disabilities have been and still are a main target group of the modern welfare state. However, exercising social rights often goes along with the loss or the reduction of civil and political rights. The international disability rights movement has focused on this point and has been demanding a social model of disability that draws on human rights and aims at providing social rights as rights and not as charity. The UN Convention on the Rights of Persons with Disabilities (2006) is a path breaking result of this struggle; it will define the agenda of disability policies for the years to come.

In its third part, this paper explores how the combination of social citizenship with a human rights approach opens up the door to a disability-related concept of Active Citizenship that links human rights with three models of participating in a community: the socio-liberal model, the market-liberal model, and the civic-republican model. Each of these models centres on one dimension of citizenship, i.e. (social) security, (personal) autonomy and (political) influence,
each of which is of particular relevance for persons with disabilities. When the practice of Active Citizenship is concerned, these three dimensions prove to be interconnected. In applying a life situation approach and drawing on the demands of the disability rights movements, the UN Convention (CRPD), and the capability approach (Nussbaum 2007), this paper lists, in a last step, relevant conditions which are needed when persons with disabilities are to exercise their citizenship rights. Security, autonomy and influence have to go together when disabled persons are to enjoy non-discriminated life situations on an equal basis with others. Using five areas (protection against poverty, participation in the labour market, freedom of choice and community living, use of new technologies, political participation) for examples, it is demonstrated that in each area disability-specific needs and issues are relevant. If they are disregarded, barriers will be established preventing the realisation of basic rights for persons with disabilities.

In a nutshell, this paper aims at developing the argument that experiencing simultaneously the three dimensions of (social) security, (personal) autonomy and (political) influence in a given life situation without barriers and discrimination will support persons with disabilities to exercise Active Citizenship.

6.2 What happens when citizenship meets disability?

When dealing with the question of citizenship one should differentiate between these two cases: first, persons wanting to change their nationality and demanding access to a different nation-state; secondly, on the basis of owning (full or partial) citizenship status in a given country persons are exercising citizenship rights. Does disability matter in these two situations?

Concerning access to citizenship, one has to bear in mind that in the narrow sense citizenship is simply a legal status that recognizes formal membership of a nation-state (Faist 2013). The recognition of citizenship is, of course, granted automatically if a person is born on a state territory or has parents who are members of a certain national entity. In this formal sense, persons with disabilities own or disown citizenship as any other persons. But what happens when persons with disabilities want, for various reasons, to leave their country they have been born in, and demand access to a different nation-state? At this point disability is intersecting with migration.

The case of naturalization highlights that citizenship is based on certain conditions, because nation-states usually grant citizenship to immigrants if these persons fulfil certain criteria, such as length of legal stay, economic independence, habitation, language competence, law-abiding status or passing of a naturalization test. It is striking that there are states\textsuperscript{13} that link their willingness to let people enter their territory for permanent stay to the health condition of the

\textsuperscript{13} E.g. USA, Australia, New Zealand
immigrants. They demand persons wanting to become full citizens not to have chronic illnesses or impairments. If the latter is the case they will not allow these individuals to entry the national community and get the citizenship status.

Against this background it is not astonishing that CRPD rules in its Article 18 that persons with disabilities have the right of liberty of movement, can choose their place of residence and their nationality, are free to leave any country, including their own, and cannot be denied the right to enter their own country, can acquire and change a nationality. Last, but not least, this Article also rules that children with disabilities have the rights to be registered immediately after birth, to be given a name and to acquire a nationality. It is not astonishing either, that states will find ways to bypass these human rights as it is highlighted in Australia’s initial report under CRPD.14

Already the issue of accessing formal citizenship in a certain state clearly shows: Countries prefer able-bodied persons as their residents and they discriminate against persons with disabilities, because they obviously consider disability as a risk factor and “burden” for the community and its social services. Even in an “age of citizenship” (Cardoso 2000), in times of large migration movements and multiculturalism as well as the expansion of the citizenship concept beyond the national level to transnational, supranational and global citizenships, national citizenship in the traditional sense is still relevant and on this level basically remains a “mechanism of social closure” (Max Weber 1980): it guarantees inclusion for the resident population, but practise exclusion against outsiders.15

14 Concerning Art. 18 this government reports writes: “106.The Convention does not create a right for a person to enter or remain in a country of which he or she is not a national. There is no restriction on entering and leaving Australia for persons with disabilities who are Australian citizens. In relation to non-nationals, persons with disabilities are assessed on the same basis as all other persons seeking to enter Australia. 107. Almost all applicants for a visa to visit or migrate to Australia are required to meet the health requirements outlined in Australian migration law in order to be granted a visa. Under Australia’s health requirements, all visa applicants must undergo health assessments where requested and be assessed as having a standard of health appropriate to their proposed length of stay and activities in Australia. The health requirements are designed to ensure that risks to public health in the Australian community are minimised, that public expenditure on health and community services is contained and Australian residents, including Australians with disabilities, have access to health and other community services. Persons with disabilities are assessed on the same basis as all other persons seeking to enter Australia. Australia’s interpretive declaration in relation to article 18 of the Convention sets out the Government’s understanding of our obligations under this article. Australia considers that its health requirements for non-nationals seeking to enter or remain in Australia are based on legitimate, objective and reasonable criteria and are therefore consistent with the terms of article 18.” (Australian Government 2010)

15 Since this paper focuses on the practice of citizenship by persons already being members of a certain country rather than the problems of persons acquiring access to a certain nation, we will in the following not deal with the question of migration and the situation of migrants with disabilities.
Having applied a general perspective for the beginning, in the following the scope of this paper will be reduced: We will focus on the topic of having citizenship rights and exercising them, in the sense of citizenship being a “practice, something one does”, and not only a status; something one has, as some readings of T. H. Marshall suggest (Johansson and Hvinden 2007, 36).

However, the ease of access brings to mind that citizenship is not simply a formal right that everybody can gain on an equal basis with others, but there are also qualitative dimensions and states have the privilege to decide whom they choose to belong to the community and whom they regard as unwanted. There is a hierarchy among citizens, they are ranked according to their value for the community: All citizens are equal, but some are more equal, to use the famous phrase by George Orwell.

Not only migrants, but also persons with disabilities are often claimed to be “second class citizens”, despite the fact that disabled persons usually belong to the local population and have a secure formal status: What makes persons with disability to be considered as second class?

Essentially, citizenship as a historical, social and political construction is based, in the tradition of the liberal state (Hobbes, Rousseau, Locke, Kant etc.), on the idea of the “social contract” which is concluded by free subjects on their own will who agree to form a society in which certain powers and the governance of common interests, the “res publica” are handed over to a state that in turn is obliged to provide protection for its people. To simplify, citizenship is basically a relationship of rights and duties between citizen(s) and a superior body called the state. On the one hand, there is reciprocity, the principle that benefits or rights that are granted by a state to the citizens should be returned in the form of obligations by citizens; on the other hand, there is the expectation of trust, solidarity and security between the state and its citizens and amongst citizens.

From the part of the citizen the idea of social contract means, to use a phrasing by Bryan S. Turner, that “… the effective entitlement of citizenship has been historically based on three contributions: work, war, and parenting.” (Turner 2006, 269) Citizens have basic duties such as to pay tax, to have a place of residence, to defend the nation as a soldier in warfare, to engage in business and/or in employment, to obey the law and to go to school. Citizens also have basic rights such as to work and live in the country (right of residence), to have access to education, to participate in political life (freedom of assembly and expression etc.) and to enjoy the rule of law (habeas corpus, jurisdiction by the state, equality before the law, property law, freedom of

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16 See for example Eisenberg et al. (1982)

17 In some states (e.g. in Belgium and Liechtenstein) citizens have the duty to vote in national elections.
contract etc.). Other civil duties are not juridified as legal norms, rather they are normative expectations in society such as to engage in parenting, to live independently on own income or capital, to care for and support own family, to speak the national language etc.

If one considers these examples, it becomes clear: When disability meets citizenship, an ambivalent relationship is generated in which the principle of reciprocity needs special regard. The balance of rights and duties is just achieved in the case of war veterans who lost their health in the service for the community and the nation-state. Reciprocity may also apply to victims of work accidents who have acquired their impairments at the work place. Further, older persons with disabilities possibly experience less overt discrimination, because in the case of age-related impairments the normal assumption is that these persons have already contributed to society and now deserve solidarity, as they have earned their living, cared for their families, paid tax and social insurance contributions before acquiring the disability status. But what about all those who have become disabled without own fault, but not in the context of war, work and old age? Especially in the case of impairments being inborn or acquired in early childhood, the idea of reciprocity cannot easily be applied, so why should, as one could argue from the rationality of reciprocity, persons with these impairments, as they are expected not to fulfil normal social roles, be entitled to full citizenship rights?

In actual fact, regardless of the causes of their impairments most persons with disabilities are experiencing barriers, discrimination and stigmatization. It seems that for social and cultural reasons persons with disabilities tend to be “under suspicion” in society and common sense is inclined to impute that they are not able to make valuable contributions to the community: “The conventional view of citizenship assumes an ideology of ablement that excludes people with impairments from social participation.” (Turner 2006, 269) The principle of reciprocity may be only one aspect, but it is definitely an important factor in society’s interaction with disabled persons.
6.3 Why is citizenship of great relevance for persons with disabilities?

However, citizenship is a necessary condition for the wellbeing of persons with disabilities; they cannot be content with only the formal status, but they require Active Citizenship as a prerequisite to obtain basic needs and rights. When it comes to the exercise of citizenship, it makes sense, in a first step, to differentiate between the four dimensions of social, economic, political, and cultural citizenship.

To start with the last and youngest concept, cultural citizenship (cf. Kymlicka 1995) is, of course, of special relevance in the context of global migration movements; it has been developed during the 1980s emphasizing the rights of cultural minorities and acknowledging the importance of different languages, histories and traditions, socio-cultural knowledge and skills. In the context of disability, Deaf people draw on cultural citizenship when they fight for the recognition of sign language and their cultural community.

Second, political citizenship is the oldest and, at least in the Western world, best established aspect; it forms the centre of citizenship in the modern age. According to T.H. Marshall (1992) the political element of citizenship refers to the universal franchise, namely the right to participate in the exercise of political power, as a member of a body invested with political authority or as an elector of the members of such a body. The struggles of past centuries in liberal democracies have delivered basic civil rights such as personal freedom, the freedoms of speech, opinion and belief as well as the right to legal procedure. In short, the rule of law is the very first modern right. When it comes to disability, it is obvious that disabled people have been and are still among those whose basic civil rights are being disregarded. The long-lasting practice of detaining persons with disabilities in “total institutions” (Goffman 1973), frequently against their own will, is only one, but striking example; it violates the basic right of “habeas corpus”, the protection against arbitrary internment.

Thirdly, liberal state and capitalist society also guarantee and rely on economic citizenship that entails property law, the freedom of contract and free movements of goods, capital, services, and people. Capitalism needs in particular “human resources”, persons who are willing and able to sell their labour force on the market, i.e., who are prepared to undergo “commodification”. Clearly, disabled persons have great difficulties in realising economic citizenship; despite their motivation to be employed they frequently do not have non-discriminated access to paid employment on the general labour market, as a consequence they usually lack economic resources such as sufficient income or private assets. As a result of the exclusion from the labour market, they cannot not fulfil their role as taxpayers.

Against this economic background it is, fourthly, social citizenship that is of greatest value for persons with disabilities. According to Marshall the social element of citizenship includes “the
whole range from the right to a modicum of economic welfare and security to the right to share to the full in the social heritage and to live the life of a civilized being according to the standards prevailing in society”. (Marshall, 1992, 40)

Social rights have evolved parallel to the making of the welfare state during the end of the 19th century and in the course of the 20th century. Balancing economic inequality by providing basic social security is one essential function of the modern welfare state. In the beginning of capitalism, the liberal state ignored the mass of landless and unemployed persons who suffered from the policy of “hire and fire” at the workplace, but in the face of increasing impoverishment among the working population the lesson of social assistance had to be learned. In German Empire, for example, Chancellor Otto von Bismarck enacted, as a reaction to the growing labour movement, the first social insurances which covered health (1883), accidents at work (1884), invalidity and old age (1889). In other words, the first social rights granted by the German state were all disability related.

The two World Wars in the first half of the 20th century proved further milestones in the development of public welfare. To deal with the masses of war veterans and war victims in the population, the rehabilitation system was established, here again we meet an arrangement of social benefits and social services that is of special relevance to persons with disabilities. The welfare state finally succeeded in the Western world with the consequence that (social) security is now provided to (almost) all members of society, although its legitimacy has been put into question again and again over the last decades.

Concerning disability in the context of traditional welfarism, it is obvious that disability is a case of social inequality; its intersections and interdependence with poverty, war, work accidents, health, education, [un-]employment, and old age are evident and need consideration. Against this background it is not astonishing that persons with disabilities have been among the first target groups of the modern welfare state and social citizenship still is of central importance for persons with disabilities. They rely on the principle of solidarity, as they cannot, or have major difficulties to call manpower or private property their own. In other words: With regard to disability, full and effective social citizenship proves to be the pre-condition for having access to the other (economic, political, cultural) dimensions of citizenship.
6.4 Why is social citizenship ambivalent for persons with disabilities?

Certainly, social citizenship provides social security for the working population and the middle class, but it is also ambivalent and goes along with some adverse aspects. It conflicts with civil rights and tends to take the form of patronizing bureaucracy. As a result, social security systems often produce discrimination and stigmatization.

Most important, there is a complex and conflictual relationship between social rights and civil rights. Civil rights and social rights seem to be an irreconcilable couple (cf. Marshall 1992, 52-65). As an effect of the differentiation of these rights, in practice a line between social and legal citizenship was drawn. Until the beginning of the twentieth century poverty relief has often led to a loss of civil rights. In going back to the early times of poverty relief, one will find a combination of social welfare and stripping of civil rights. The system of social assistance stemming from the Middle Age and early modern times was the first pillar of social security, but it also involved repression and social control, measures of intensive surveillance and discipline. The poor had to pay a prize for getting social support: disfranchisement, internment in working houses, loss of the rights to privacy and free movement etc.

But even today the welfare state makes a distinction between the working population and the middle class on the one hand, and those people, on the other hand, who cannot even rely on the "work of their hands" in order "to live and survive" (Castel 2005, 34). The effective enjoyment of social citizenship is usually based on two principles, either contribution or benefice. Depending on which principle applies, social security will be different for the individual: “Where the contributory principle is dominant, individuals who do not pay tax [or social insurance contributions] do not in general receive the full range of entitlements. People who do not have employment and hence do not pay taxes [or contributions] tend in practice to be second-class citizens.” (Turner 2006, 264) The group mentioned in this quote of which the rate of persons with disabilities is rather high is left with social benefits under the condition of dependency and stigmatization.

As persons with disabilities are among the addressees of the welfare state who are frequently experiencing in their everyday life the drawbacks of social rights, the social dimension of citizenship is “the central issue in modern interpretations of disability and impairment.” (Turner 2006, 264) It is therefore not astonishing that international disability rights movements have right from their start been criticising social security practices; their dissatisfaction with insufficient benefits, bureaucratic and patronizing social services and the permanent surveillance of their lives has led to the development of the social model of disability.

This model understands persons with disabilities as a social minority group that experiences social oppression and discrimination in and by society. The social model highlights that disability
is a social problem in need of social support and community action, but persons with disabilities are unnecessarily controlled and humiliated. In contrast to the individual model of disability that focuses on professional knowledge and support, it demands to recognize the expertise, self-help potential and experiences of persons with disabilities. From the perspective of the social model, disabled persons are not passive recipients of welfare, but citizens who, if empowered, are able to exercise self-determination and democratic participation.

Against this conceptual background disability rights movements in Europe have in their beginning primarily focused on initiating changes in social welfare policies. They have demanded social rights as rights and not as charity. Organizations advocating for disability rights have argued for the elimination of stereotypes that cast people with disabilities as vulnerable and in need of community care. In the current system, health and service providers have been and still are in control of assessing the needs of persons with disabilities. Many disability rights organizations have therefore pushed against this system in which the expert’s expertise takes precedence over the experience and assessment of persons with disabilities who want to be recognised as experts in their own cause.

With this argumentation, it was but a short step to combine the social model of disability with human rights policy. Turner (2006, 264) brings the case of the disability rights movements to this point: Disability in the sense of the social model of disability is “a lack of citizenship”. To be more precise, disability means from the point of view of disability rights activism the want of not only social rights, but of “full and effective” (cultural, political, economic, social) citizenship. The different dimensions of citizenship are interwoven and interdependent. In order to realise one set of rights, one has to fight for the whole rights package. Social citizenship is depending on economic citizenship which in turn needs political and civil citizenship being again reliant on cultural citizenship – and vice versa! In consequence, to gain full social rights for persons with disabilities and so as to ensure that they be treated on an equal basis with others, it has proven necessary for disability policy to adopt a human rights approach.

6.5 Linking social citizenship with the human rights model of disability

Like the social model, the human rights model places responsibility for addressing the problems of disability on society rather than on the person with disabilities. It can be seen as the most recent development of the social model. Basically, it states that all human beings are equal and have rights that should be respected without distinction of any kind; that persons with disabilities are citizens, without ifs and buts, and, as such, have the same rights as those without impairments; that all actions and policies to support persons with disabilities should be rights based.
But why are human rights so important for persons with disabilities? The following quote is getting to the heart of the issue: “Human rights discourse is a promising arena for the development of rights for disabled persons, because they are not based on a notion that entitlement must be based on duty and contribution, but rather on a concept of human dignity.” (Turner 2006, 274) To advocate human rights in the context of disability is to demand that the human dignity of persons with disabilities be respected.

From a human rights perspective, every human being is considered a member of the human family from birth and without condition. Human rights are held equally, universally, and forever by all persons with and without disabilities. They are inalienable, indivisible, and interdependent: An individual cannot lose these rights any more than he or she can cease being a human being, a certain human right cannot be denied because it is “less important” or “non-essential”, all human rights are part of a complementary framework and are essentially linked to each other. For example, a disabled person’s capability to participate in politics is directly affected by his or her right to obtain the necessities of life, to get an education, and to have a secure place of residence.

The discourse of human rights has a long history, but the Universal Declaration of Human Rights was articulated only in 1948 by the United Nations. Following the horrific experiences of the Holocaust and World War II, many people sought to create a document that would capture the hopes, aspirations, and protections to which every person in the world was entitled and ensure that the future of humankind would be different. The 30 articles of the Declaration together form a comprehensive statement covering economic, social, cultural, political, and civil rights. A declaration, however, is only a statement of intent, a set of principles to which United Nations member states commit themselves in an effort to provide all people a life of human dignity. It is not a treaty and lacks any enforcement provisions.

For the human rights defined in the Declaration to have full legal force, they must be written into documents called conventions which set international norms and standards. When a government signs and ratifies a convention, it becomes legally bound to uphold those standards. For this reason the Convention on the Rights of Persons with Disabilities (CRPD, adopted by the United Nations in 2006) was a path breaking result of the struggle for an approach of human rights policy that explicitly acknowledges disability specific needs and issues; it will define the agenda of disability policies for the years to come. With the CRPD, it has internationally been acknowledged that general human rights are lacking important aspects when it comes to disability: Persons with disabilities do not only need basic rights, but they are also dependent on accessibility and (reasonable) accommodation as pre-conditions of being able to exercise citizenship at all.

Human rights principles imply the vision of a free, just, and peaceful world and set minimum standards for how institutions and individuals should treat members of the human family. But
human rights ought to be practical as well. Human rights conventions as supranational instruments that are legally binding if signed and ratified define a comprehensive framework for action and secure that those in power recognize, implement and protect the human rights agenda. However, UN conventions are dependent on the national level for the implementation of the different rights. It needs the nation-state to breathe life into the different articles and provisions, it is a state’s privilege to secure their realisation. Here again, the concept of citizenship comes into play. It provides the linkage between human rights as universal normative framework and concrete institutional conditions of a given nation-state. National citizenship offers the crucial “bottom up” position from which government, parliament, courts and public institutions in a specific country can be directly addressed with claims and demands, since they are responsible for implementation.

In conclusion, when it concerns persons with disabilities, understanding citizenship as a human rights based notion means counterbalancing the weaknesses of both the social citizenship concept and the human rights approach: The latter implies universality and un-conditionality, but it is weak when it comes to implementation; the first has an exclusionary potential, as it is based on nationhood and ableism, but it secures the institutional scope for implementing human rights policies.

6.6 Active Citizenship for persons with disabilities as a combination of three dimensions: (social) security, (personal) autonomy, (political) participation

Citizenship can be considered only as a legal status which entitles the individual to be a resident and claim the benefits and services of a specific country. But in the case of disability this passive citizenship is not enough. Rather persons with disabilities should aim at employing their citizenship rights actively. By exercising Active Citizenship\(^\text{18}\) as something one is practising in everyday life instead of being content only with the formal level, persons with disabilities are fighting against their role of “invisible citizens”; they claim their basic rights of (social) security, (personal) autonomy, and (political) participation instead of being only formally included. The

\(^{18}\) The big letters imply that I am referring to DISCIT’s concept of Active Citizenship. There is a whole range of active citizenship concepts that are not discussed in this paper. However, there are at least three basic criticisms about the notion in general that deserve mentioning: First, active citizenship is based on the assumption of effective and rational agency by persons who are capable of understanding and articulating their own interests and needs; this aspect has an exclusionary potential. Second, active citizenship is a normative concept that gives not only rights, but also demands full involvement in society. Thirdly, in social policy active citizenship is a neoconservative concept which involves activation strategies promoting individualism and responsibility; it focuses on reciprocity (from "welfare" to more "workfare") instead of (unconditional) solidarity.
legal citizen role promises equal opportunities, but social practise leads to actual participation and real social inclusion.

The state may promote active citizenship as an ideology of confronting people with activation policies and demanding that citizens are ready to take up employment, refrain from claiming social benefits and engage in voluntary commitment in self-help organisations. From the part of citizens with disabilities Active Citizenship is rather a descriptive concept meaning the exercise and practise of citizen roles of which three are of special importance and will be discussed in the following: the roles of the “citoyen”, the “autonomous subject”, and the “social citizen”. Each citizen role links up with a certain model of citizenship: First, the socio-liberal model centres on solidarity as a norm and is providing social security for the citizens; secondly, the market-liberal (libertarian) model focuses on freedom and aims at personal autonomy; thirdly, the civic-republican model has power as its focal point and is offering political influence for the citizens. These three models have been described elsewhere (cf. Johansson and Hvinden 2007), so this paper can only cursorily deal with them.

First, the making of the “social citizen” of course refers to the socio-liberal model of citizenship. Its proponents follow liberal understandings of citizenship, but at the same time do not close their eyes “on the continued existence of substantial class differences in income, wealth and living conditions in liberal capitalist economy.” (Johansson and Hvinden 2007, 35) Concern for the collective good, the community and the wellbeing of society as well as the idea of solidarity have created, parallel to the development of capitalism and liberalism, the modern welfare state providing some “repair” of the market forces and social protection for those who are destitute and deprived, who live in society as outcasts and outsiders.

It is self-evident that persons with disabilities need social security and are, first of all, “social citizens”. They are dependent on the principle of solidarity which has taken the concrete shape of the welfare state with its coherent efforts to counterbalance the impact of so-called "social risks". Of these social risks usually one is explicitly named “disability” and nearly all others are related to disability: Illness, accidents at work and occupational diseases, unemployment and poverty, ageing, care and family responsibilities are all relevant in the daily lives of person with disabilities.

Basically, social security can take two forms, either income maintenance or personalized support by social services. It implies having both the right and the obligation to participate in the labour market, and in turn ensures access to the social right of “de-commodification”. Of the latter Esping-Andersen gives this minimum definition: "De-commodification occurs when a service is rendered as a matter of right, and when a person can maintain a livelihood without reliance on the market.” (Esping-Andersen 1990, 22) In short, the right of de-commodification means the right to
personal freedom from the market and the duty to go to work, either temporarily in the case of illness, parenting and care, or permanently in the case of old age and, last but not least, disability.

Secondly, the citizen role of the “autonomous subject” can be traced back to the market-liberal (libertarian) model of citizenship. This model focuses on the role of the market, the freedom of contract and property law. “The notion of libertarian citizenship is paradox, because it sees society as comprising individuals and their preferences and values, through exchanges in the market or voluntary and contractual relations with like-minded individuals.” (Johansson and Hviden 2007, 36) For the proponents of the market-liberal model the idea of the market plays the crucial role: It provides “a space where the individual can act freely and rationally, following his or her own self-interest.” (Johansson and Hviden 2007, 37) Whereas the socio-liberal citizenship model highlights the relevance of work and employment, the market-liberal model is centering on the treaty as fundament of the libel state and as essential pre-condition of bourgeois society. The contract, which is the basis of trade, production and traffic, is concluded between free and equal subjects. But not all persons of a community fit into the contract framework. Especially persons with disabilities have difficulties to be considered as contract partners on an equal basis with others, because their personal autonomy tends to be denied.

To understand why persons with disabilities have difficulties not only to enter contracts, but also to assert their free will and lead an independent life, it is useful to deal with the philosophy of autonomy as an important element of liberalism (see Waldschmidt 2012, 17-75). For this discourse Immanuel Kant's approach is fundamental; for him a human being is able to self-determination, because he or she owns practical reason, the ability to align own actions regardless of needs, emotions and motivations, in short, irrespective of the "physical world", the world of senses and emotions. The practical reason makes a human being a person, i.e., a rationally acting subject.

When it comes to disability, these ideas prove to be exclusionary. In particular, they affect persons whose reasoning powers are classified as permanently weak, such as persons with intellectual and developmental impairments or psycho-social difficulties. On the basis of the philosophy of enlightenment they have considerable difficulties to be recognized as autonomous subjects. The self-determination of those deemed for various reasons as "unreasonable" is quickly called into question in liberal society. In general, persons with disabilities are suspected to have no or only limited reason or own will. Chronically ill and disabled persons, it is assumed, are so strongly attached to the physical world, so that they cannot or only to a limited extent develop a rational will. As a consequence, personal freedom is denied to them.

Nevertheless, finding resonance for their demands of personal autonomy proved possible for persons with disabilities. It needed a historical development over centuries, but during the late 20th Century the hitherto marginalized have quite successfully reclaimed an autonomous life for
themselves, they demanded basically what they deserved as human beings, they claimed to gain subject status. Influenced by the idea of "Independent Living" disabled women and men have started during the early eighties to fight for an end of institutional accommodation and for their right to organize their lives and support needs themselves. The independent living movement soon found widespread international distribution and recognition; since then the demand of self-determination has gained high priority on the disability rights agenda. In the CRPD (preamble; Art. 3, 9, 16, 19, 25) the notion of individual autonomy and independence plays a prominent role. The struggle for exercising the right to live independently has of course not yet come to its end, but it is remarkable that at least society and the political level have by now recognized that persons with disabilities be included in the idea of personal freedom.

In order to understand why the demand for self-determination is so important for persons with disabilities, one has to take into account the general trend towards “individualization” (Beck 1986) in society. It opens up a space for all those who have previously been left at the gates of liberal society. For outsiders, individualization and the move to acknowledge diversity, pluralism and heterogeneity in society provides the decisive moment to claim the role of the autonomous subject.

At the same time one has to concede that in advanced modernity one cannot only live independently, one even has to. Individualization implies not only emancipation from old-fashioned traditions and confining dependencies, but also the willingness to release from traditional bonds, the readiness to “tinker” personal biographies and “careers”, and to apply self-management in everyday life. Nowadays autonomy promises not only liberation, but has also become a social obligation - not just for able-bodied, but also for disabled persons. Against this general societal background it is not astonishing that personal autonomy on the one hand implies exercising the freedom of choice, the right to decision-making and agency autonomy, in short, exercising independent living. On the other hand, it also requires to take individual responsibility for one’s own future and to manage own risk-protection by practising, for example, health prevention and an healthy life style; by concluding contracts with private insurances for health, invalidity, care needs, and old age; and last but not least, by accumulating private assets with the purpose to provide for social protection of one’s own and the family.

Thirdly, the civic-republican model of citizenship centres on “politics”, the realm of public discussion, negotiation and decision-making; it takes the “agora”, the central meeting place of a town in Ancient Greece, as point of departure. In the Ancient world, citizens regularly gathered at this public place to discuss and decide common interests. Drawing on this tradition, for the republican citizen of today participation in public affairs is “a key aspect of life, being a republican citizen thus means being connected with the polis, public sphere or space, or community.” (Johansson and Hvinden 2007, 38) However, modern republicanism distances itself from the elitist practise of Ancient Greece where only citizens in the narrow sense of the word,
i.e., the male and wealthy population and neither slaves nor women, were entitled to take part in the “res publica” and to hold public office. Here again, formal citizenship proved a necessary, but exclusionary condition for being able to exert influence and participate in the public sphere.  

It was the merit of European enlightenment and the French revolution to create the role of the “citoyen” (Rousseau 1977), a person who is typically fully engaged in public affairs, exercises responsibility in the community and pursues the common good. The civic-republican idea of equal citizens coming together for discussing, negotiating and deciding the collective interests was extended and universalized. “Republican citizenship focuses on the direct participation of citizens in the public realm and in deliberation and decision-making related to common affairs. The public realm is identified as a space open for everyone.” (Johansson and Hviden 2007, 38) The theoretical roots of political participation also stem from the idea of the social contract in the tradition of liberal political theory; it forms the basis of participatory democracy, in which it is assumed that only the participation of all citizens on an equal basis constitutes a fully valid democracy. Today the idea of democracy as a political system that is not only representative, but also participatory and deliberative is generally accepted.  

Against this background, all forms of political participation are faced with the question whether they promote political equality or rather rely on exclusion. Political equality does not only mean the guarantee of equal political rights, but should also lead to equal political opportunities for everyone and to all forms of political engagement. Further, political participation ought to promote republican awareness and consciousness among the member of a community; it should increase citizens’ competence in political judgment. Furthermore, it has a functional role for the stability of the political system, since the probability of implementation and hence the effectiveness of policy decisions is increased, if stakeholders participate in the decision-making processes, in short, if “legitimation through participation” is guaranteed.  

Within this general framework, participation can mean an “end in itself”. Such a normative concept of participation acknowledges the interdependence of human action and is consensus-oriented, communitarian and expressive; it implies the realization of direct democratic action. In contrast, participation can also understood as “means to an end”, when citizens individually or collectively try to influence political decisions directly or indirectly to their own advantage. Thus, under the heading of political participation, there is a wide range of practices to take part as a “citoyen” in the concerns of the community.  

For persons with disabilities, having been excluded from the political realm for centuries, political participation is an indispensable right nowadays. At all political and institutional levels, under the slogan “Nothing about us without us”, disabled persons are demanding, as an “end in itself”, their individual or collective rights to exercise co-determination, to get involved in self-organised, voluntary and political activities and in civil society, to take part in public deliberation
and decision making processes at all political levels that will set the framework for personal lives; lastly they want to exert influence in decisions aiming at the promotion of the common good.

Accordingly, the UN Convention on the Rights of Persons with Disabilities (CRPD) uses the notion of „full and effective participation in society on an equal basis with others” as a core concept (see Preamble (e), (k), (m), (y); Articles 1, 3, 19, 24, 26, 29, 30, 34) and contains the special Article 29 which defines the right to participation in political and public life and emphasizes accessibility as a necessary condition. Political participation in concordance with the CRPD includes active and passive electoral rights, the exercise of public functions and the formation of and participation in non-governmental associations.

With regard to formal entitlements, citizens with disabilities are permitted as any other citizens to vote and be elected as well as to pursue other political rights, such as the freedoms of expression and assembly and the right to form civil society organizations such as political parties, associations, professional associations and interest groups. To begin with, individual participation in politics takes concrete shape in elections, where the rights to vote and to be elected are exercised. While all other forms of political participation imply a higher intensity and are also associated with a (sometimes far) higher level of commitment and costs, the right to vote is the most common, simplest and most egalitarian form of political participation.

However, persons with disabilities frequently experience exclusion from election rights for two reasons. Either they are considered as not eligible to vote because of their missing or reduced legal capacity. This applies not only to persons with mental health problems, but also to persons with cognitive or learning difficulties who are under legal guardianship. Further, in addition to this formal exclusion there is also the case of legally existing, but in practice restricted voting rights, such as when communication problems exist or persons with disabilities can vote only in the company and with the help of third parties because places or documents are inaccessible. For instance, missing tactile voting devices with appropriate additional texts in braille for blind people or polling stations that are not accessible to persons with mobility impairments will prevent exercising the basic civil right of voting.

In the second place, collective participation usually implies the existence of interest groups or organizations that unite people on a voluntary basis for the aims of exercising influence and lobbying for common interests. In democratic systems that guarantee the freedoms of assembly and association collective political action is usually exercised by legally registered associations. But nearly always there is the sphere of “sub politics” (Beck 1993) that refers to forms of politics outside and beyond the representative institutions of the political system, it also comprises unregistered associations and informal networks that address the public by using the idea of “agora”; they represent specific interests and beliefs. In other words, all forms of public engagement, either registered associations and (trade) unions or self-help and community groups
as well the networks of social movements, make up, in addition to the mass media, the realm of civil society. They belong to the so-called intermediate sphere, as they are acting between and in addition to the state, the market and the family.

With their emphasis on advocacy, self-representation and influence disabled people’s associations and interest groups are largely synonyms. An interest group is any group that has claims against other social groups or the political system. Political interest groups are then those that make their claims against political institutions and the lawmaker. They are representatives of special interests on the one hand, and on the other hand they are actors in public governance, i.e., their job is to take individual expectations, to transform them into collective policies and claims and to fulfil a constructive role in political decision-making. At the same time interest groups are expected to convey the results of political action back to the social groups represented by them.

From the perspective of citizens with disabilities associations and interest groups are attractive, because as “means to an end” they offer an arena for the exercise of influence; they turn disabled persons into stakeholders and ensures opportunities for political participation beyond the limited act of voting. But, from a political science perspective, it is not self-evident that disability interests have taken the shape of a broad range of associations, since in general interest organization in contemporary society obeys an economic logic in which some interests – such as those of big industries, employers but also workers and employees – are usually well represented and others are not. In short, disability interests are considered as “weak interests”, because their constituency is a socially marginalized group. Forms as well as chances of success of disabled persons’ political participation are significantly linked to their financial, educational, communicative, technical and organisational resources. Accessibility and mobility issues play an additional role. To enable persons with disabilities to become politically active, they need to have not only equal and continuous access to all levels of the political system, but also other support to ensure the acquisition of skills, resources and self-confidence. Last of all, they are dependent on barrier-free environments in the political realm.

**6.7 Enabling Active Citizenship for Persons with Disabilities**

Finally, Active Citizenship for persons with disabilities is first of all a social practice and exercise; it needs to be brought to light via empirical research, which centres on these two basic questions: How do persons with disabilities exercise citizenship? What conditions hinder or enable Active Citizenship for persons with disabilities?

To undertake empirical work, using concrete life situations as starting points makes sense. These life situations should possibly cover all three citizen roles explored above. For example, protection against poverty and participation in the labour market belongs to the sphere of social security; freedom of choice and community living as well as the use of new technologies are
relevant with regard to personal autonomy; political participation links up to the role of the “citoyen” in the civic-republican model of citizenship.

Using these five areas (protection against poverty, participation in the labour market, freedom of choice and community living, use of new technologies, political participation) and drawing on the demands of the disability rights movements, the CRPD, and the capability approach, this paper lists, in a last step, relevant conditions which are necessary when persons with disabilities are to exercise their citizenship rights. (Social) security, (personal) autonomy and (political) influence have to go together when disabled persons are to enjoy non-discriminated life situations on an equal basis with others. Simply by listing disability-related needs and rights with regard to concrete life situations, it can be shown that in each area disability-specific issues are relevant. If they are disregarded, barriers will be established preventing the realisation of basic rights for persons with disabilities. It also becomes clear that when the practice of Active Citizenship is concerned, all three dimensions prove to be interconnected.

References


Table 6.1:

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<thead>
<tr>
<th>Life situations / AC Dimensions</th>
<th>Security</th>
<th>Autonomy</th>
<th>Influence</th>
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<tbody>
<tr>
<td>Protection against poverty and adequate standard of living</td>
<td>To have the right to and non-discriminated access to social protection programmes and poverty reduction programmes, in particular by women and girls with disabilities and older persons with disabilities</td>
<td>To have non-discriminated access to private insurances</td>
<td>To have influence on the decisions of social services and social agencies impacting one’s own well-being and living standard</td>
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<td></td>
<td>To have barrier-free access to basic income and social benefits</td>
<td>To have non-discriminated possibilities for private asset creation, to own or inherit property, to control own financial affairs, to have equal access to financial services</td>
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<td>To have barrier-free access to social insurances in the case of no or restricted working capacities and care needs (chronic illness, impairments, old age)</td>
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<td>To have barrier-free access to social support (benefits, services) in the case of parenting and care for own family</td>
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<td></td>
<td>To have barrier-free access to social support (benefits, services) in the case of complex impairments and personal assistance needs</td>
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Table 6.2:

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<tr>
<td>Participation in the labour market</td>
<td>To have barrier-free access to equal pay, good work, equal terms of employment, in particular by women and girls with disabilities and older persons with disabilities</td>
<td>To have barrier-free access to employment on an equal basis with others, freely chosen or accepted in the open labour market or in work environment that is open, inclusive and accessible</td>
<td>To have the right on an equal basis with others to exercise labour and trade unions rights</td>
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<td>To have barrier-free access to reasonable accommodation, supported employment and personal assistance in the workplace</td>
<td>To have the right to decide for and against a certain vocational training and job place</td>
<td>To have the right to participate (as member and representative) in trade unions</td>
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<td>To have barrier-free access to social assistance in the case of incapacity to work</td>
<td>To have access to opportunities for self-employment, entrepreneurship, the development of cooperatives and starting one’s business</td>
<td>To have support by a works council and / or a representative of employees with disabilities at the workplace</td>
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<td>To have non-discriminated access to all forms of employment, including conditions of recruitment, hiring and employment, continuance of employment, career advancement and safe and healthy working conditions</td>
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<td>To have the rights to just and favourable conditions of work, including equal opportunities and equal remuneration for work of equal value, including protection from harassment</td>
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<td></td>
<td>To have access to vocational and professional training and rehabilitation, job retention and return-to-work programmes</td>
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<td>Life situations / AC Dimensions</td>
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<tr>
<td>Freedom of choice and community living</td>
<td>To have adequate accommodation and a secure place of residence</td>
<td>To have the right to choose own place of residence and where and with whom the person wants to live on an equal basis with others</td>
<td>To have access to legal capacity on an equal basis with others in all aspects of life</td>
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<td>To have access to a barrier free environment and accommodation</td>
<td>To have the right to decide for and against living in a particular living arrangement and for and against going into an institution for permanent stay</td>
<td>To have access to supported decision-making free of conflict of interest and undue influence</td>
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<td>To be protected against arbitrary or unlawful interference with own privacy, family or home</td>
<td>When living in an institution, to have to right to leave this institution on one’s own will</td>
<td>To have barrier-free access to adequate personal assistance</td>
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<td>To have access to barrier-free public housing programmes</td>
<td>To have access to a range of in-home, residential and other community support services, including personal assistance</td>
<td>When using personal assistance, to have the following five rights: control of the staffing, control of the instructions and performance of the assistants, control of the budget, control of the execution and implementation of the services, control of the places at which assistance is carried out</td>
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<td>To have non-discriminated access to accessible and affordable rented housing and to residential property</td>
<td>To have influence on the decisions of public services or professional agencies impacting one’s own well-being</td>
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<td>To have barrier-free access to personal budgets, to have the right to decide for and against using them</td>
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<td>To have non-discriminated access to personal budgets, to have the right to decide for and against using them</td>
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<td>Access to private insurances for health, invalidity, care needs, old age</td>
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<td>To have the right to choose personal assistance by female persons, in particular by women and girls with disabilities</td>
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### Table 6.4:

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<tr>
<td>access and effective use of new technologies</td>
<td>To have access to barrier-free new technologies, including information and communications technologies, mobility aids, devices and assistive technologies</td>
<td>To have the freedom of choice to use or not use new technologies</td>
<td>To have influence on the research, design, development, production and distribution of new technologies to make sure that they are accessible and suitable for persons with disabilities</td>
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<td>To have possibilities to learn the use of new technologies</td>
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<td>To have the right of data protection</td>
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<tr>
<td>Political participation on an equal basis with others</td>
<td>To have access to accessible, appropriate and easy to understand voting procedures, facilities and materials</td>
<td>To have the right to freedom of expression and opinion, including the freedom to seek, receive and impart information and ideas on an equal basis with others and through all forms of communication of own choice</td>
<td>To have the right on an equal basis with others to public and political participation, in particular by women and girls with disabilities and older persons with disabilities</td>
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<td>To have access to barrier-free environments in the public and political spheres, without discrimination and on an equal basis with others</td>
<td>To have the freedoms of free speech, assembly and association</td>
<td>To have the right to effectively hold office and perform all public functions at all levels of government</td>
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<td>To have access to legal provisions of non-discrimination, to have the right to report discrimination and go to court for this</td>
<td>To have the individual right to vote by secret ballot in elections and public referendums without</td>
<td>To have the right to join and participate (as member and representative) in the activities and administration</td>
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<td>reason</td>
<td>intimidation, regardless of legal capacity status and/or existing guardianship</td>
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<td>To have the right to free expression of the will as elector and to assistance in voting by a person at their own choice</td>
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<td></td>
<td>To have the individual right to stand for elections, regardless of legal capacity status and/or existing guardianship</td>
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<td>of political parties</td>
<td>To have the right to form, join and participate (as member and representative) in non-governmental, registered and non-registered civil society organisations and associations as well as social movements concerned with the public and political life of the country</td>
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<tr>
<td></td>
<td>To have the right to form, join and participate (as member and representative) in disabled people’s organisations at international, national, regional and local levels</td>
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Rita Barbuto, Mario Biggeri, Federico Ciani and Giampiero Griffo, University of Florence

7. From Formal to Substantial Citizenship – the Role of Capability\textsuperscript{19}

Key Messages

- Given (i) the persistence of segregating arrangements of services provision, (ii) the existence of material and immaterial barriers and (iii) the consequences of the economic crisis in terms of resource availability, the Active Citizenship for European people with disabilities is a goal far from being fulfilled.
- As suggested by the CRPD, any approach to Active Citizenship should deal with effective and not merely formal definitions of citizenship.
- Security (protection), autonomy and influence are three key components of Active Citizenship (particularly in the case of people with disabilities). It is not possible to imagine a model of Active Citizenship without simultaneously taking into consideration these three dimensions.
- The achievement of Active Citizenship demands the definitive abandoning of the medical model not only in the academic debate but also in actual policies and services provision schemes.
- The Capability Approach helps us to understand the factors and mechanism that foster or prevent Active Citizenship. This approach offers a potentially useful analytical framework as it is (i) person-centred, (ii) inherently pro-participation; (iii) able to take into consideration multilevel structures and cross-level interactions; (iv) appropriate for human diversity valorisation; (v) focused on opportunity and context based processes of freedoms building. As a consequence, it can complement a Human Rights Based Approach.
- As concerns disability policies (re)formulation, the Capability Approach suggests (i) to increase services horizontal and longitudinal adaptivity; (ii) to create structured channels of stakeholders’ participation and dialogue arenas; (iii) to work both on the reform of services provision schemes as well as (iv) on individual and social empowerment.

\textsuperscript{19} We wish in particular to thank Ciro Tarantino, Sara Giunti and Mariachiara Bossi for their comments and suggestions.
7.1 Introduction

Full citizenship is not only the enjoyment of a series of rights with a legal or recognised by legal norms. In itself, the enjoyment of such rights only amounts to formal citizenship. In fact, for persons with disabilities (but not only for them) the enjoyment of such rights is only formally recognized. As a main rule, formal citizenship is often not exercisable due to barriers, obstacles and discriminations. It is impossible to be full citizens without having the opportunity to move freely, to have access to information, to have a dignified job, to be independent for the accomplishment of everyday life activities.

Moreover, persons with disabilities are often segregated in special places, reserved to them, with treatment that is not similar to that of other citizens. This diffused modality of segregation in Europe (in institutions, in special schools, in protected workshops, in special services, etc.) is not only unnecessary, it also highlights an obvious violation of human rights: which other group of citizens is treated in this way? This treatment, which is different to that of other citizens, is hardly ever justified and deeply affects the dignity of the people who are subjected to it (Office of the High Commissioner for Human Rights, 2008).

While Active citizenship presumes that formal citizenship is achieved, to become a practical reality for persons with disabilities they must be able to play an active part of the community in which they live and contribute in making the choices affecting their lives. For persons with disabilities this opportunity is rarely achieved, due to the lack of the concrete possibility to have access to a citizenship on the basis of equality with respect to other citizens. If we examine European citizenship, the actual mobility of persons with disabilities in and between member states and their possibility to be active and passive voters, are extremely limited.

In the Italian Constitution the distinction between formal citizenship and substantial citizenship is clearly expressed in Article 3: the recognition of equality before the law is emphasised by paragraph 1, and is accompanied by the commitment of the Republic (Paragraph 2) to “remove the obstacles of an economic and social nature which are constraining the freedom and equality of citizens, preventing the full development of the human person and the effective participation of all workers in the political, economic and social development of the country.”

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20 Such formal citizenship tends to be the main meaning of social citizenship in the Liberal tradition.
21 Yet, exceptions can be noted for persons with intellectual or psycho-physical disabilities, because of their particular physical conditions, for instance not being able to express themselves with words, etc. …).
22 About 1.200.000 persons with disabilities in Europe are segregated in institutions, where there are evident constraints of fundamental freedoms and violations of human rights (see web-site: www.community-living.info).
23 “All citizens have equal social dignity and are equal before the law, without distinction of sex, race, language, religion, political opinion, personal or social condition”. Among other personal and social conditions in the constituent discussion explicit reference was made to persons with disabilities.
This approach is also that contained in the UN Convention on the Rights of Persons with Disability (CRPD), when it states “that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others”. Disability, therefore, is a social relation dependent on the manner in which society takes into account the functional diversities of each one of its citizens (Palacios et al., 2005; Romanach et al. 2009; Alves et al., 2011). Obstacles, barriers and discriminations impoverish persons with disabilities both individually and socially.

When analysing the limitations that society interposes to the full enjoyment of citizenship we underline the following aspects:

a) Limitations deriving from a negative social stigma: This stigma can be described as the negative perception of capacities and competences (which is described as a layering of negative concepts summarised in the medical/individual model). This stigma deeply affects persons with disabilities, decreasing the consideration which one has of oneself and justifying treatments that destroy dignity. Stigma affects both the individual as well as social behaviour, and stigma can also have adverse effects on public policies on disability;

b) Limitations on access and use of public spaces and built environments;

c) Limitations of mobility;

d) Limitations on access of information and communication;

e) Limitation of spaces for participation in debates on institutional changes;

f) Limitations deriving from the insufficient support provided by public services;

g) Modalities for offering discriminating services (segregating, special, etc.);

h) Limitations on representing their own interests

Most of these limits may be summarised as limitations on participation and inclusion. This distinction is significant because the limitations on participation are prevalently deriving from barriers and obstacles (limitations b, c, d, e, f), while the limitations on inclusion are prevalently derived from discrimination and negative views (limitations a and g). Naturally the distinction between the two typologies of limitations is analytical; in reality they interlink in various ways.

Persons with disabilities are often unable to exercise the rights they are formally granted because of the limitations we have referred to. These limitations, as we will see in the next section, are
disabling factors that reduce participation dramatically, perpetuate exclusion and undermine the freedom to be an active citizen. One may ask whether it is right and morally defensible to ask persons with disabilities to take up the same duties as other citizens (for example contribute to the saving of public resources in the case of current economic crisis) when they do not enjoy the same rights? Arguably this inequality in the conditions of participation widens the gap between the citizens who face barriers, obstacles and discrimination and citizens who do not. This gap puts persons with disabilities at a disadvantage and in social, economic, political impoverishment compared to other citizens.

This social, economic, political impoverishment basically renders full citizenship unfeasible, making such citizenship only formal and theoretical. All limitations mentioned earlier means that persons with disabilities cannot live like other citizens\textsuperscript{24}, reinforced by the impoverishment deriving from economic and time costs created by the conditions of disability. Put together, these limitations clearly reduce their dignity, subjecting them to treatments which are often inhuman and degrading (Office of the High Commissioner for Human Rights, 2008). If the condition of disability is combined with other conditions, like the female sex, being elderly, belonging to other ethnic or religious minority groups or having a different sexual orientation, multi-discriminations will emerge. These are much more complicated to combat.

Moreover, the limitations based on a negative social stigma of disability are perceived by persons with disabilities and produce negative self-stigma (i.e. a form of internalised stigma) that permeates the vision that many persons with disabilities have of themselves and of their value in society.

In stead of being centred on providing appropriate support to achieve the full participation and inclusion of persons with disabilities, public policies and a range of services are often limited to intervening in welfare and health areas. Public policies tend to produce services and programmes based on limiting and stigmatizing approaches (special schools with a high presence of health care professionals, etc.).

Even before the drastic reduction in public support under the current crisis, the resources provided to persons with disabilities were a far cry from the 15% of the resources that should be allocated to them according to their demographic presence in the population (WHO & WB, 2011). Moreover there are reasons to expect that a part of public spending allocated to persons

\textsuperscript{24} In the United Kingdom a research was carried out which brought forth the fact that a family which has a person with disabilities within it has double the chance of becoming poor with respect to another family, because the person with disability has added costs (Prackar, 2008).
with disabilities is used for unproductive interventions, which instead of removing the limitations produced by society, perpetuate the negative medical/individual stigma.

How can persons with disability become an integrated part of society? How is the CRPD to be acknowledged in practice? First of all, persons with disabilities must not only achieve the same conditions of formal citizenship as other citizens, but full substantive citizenship. Interventions for medical prevention as well as social prevention must shift (Coleridge et al., 2010) towards reducing and removing the conditions of disability. While expenditures aimed at the medical prevention and mitigation of disability are widely accepted, investments devoted to social prevention and mitigation are often perceived as unnecessary costs particularly in periods characterised by public expenditure cuts. Yet, the condition of disability is an experience that every human being will experience during the course of his/her life (e.g. WHO & WB 2011). In other words, the reduction and removal of the elements which produce conditions of disability need to be seen as part of society’s general policies, as an investment with both productive effects (reduction of welfare and health costs, achievement of greater participation in economic and social life), as well as effects in terms of quality of life (in terms of improved social life, respect, recognition of contribution to social growth) and in terms of social justice and respect of human rights (for the large groups of people like the elderly, pregnant women, and people with functional diversities, etc., …).

The concept of disability is evolving. Having access to assistive devices is to growing extent becoming the precondition for participation and inclusion (Marchesini, 2002; Halberstam and Livingstone, 1995; Longo, 2003; Haraway, 1991).

Public policies and the resources they provide should therefore progressively transform themselves from means of social protection to means of participation and social inclusion. In this way, instead of being perceived and functioning as transfers of limited resources to unproductive efforts and areas, the provisions would become resources directed to the attainment of the conditions permitting persons with disabilities to practice and exercise the rights of citizenship. In this way the resources would serve to support full and active citizenship. They should be used to support the inclusion of persons with disabilities in all policies (mainstreaming), enabling discriminated citizens without equal opportunities to achieve living a life in the same places as all other citizens, to enjoy goods and services in an equivalent manner to those of others, to have the same possibilities of participation and to choose in conditions of equality with other citizens.

The relationship between individual development and the development of democracy deserves a reflection of its own. The growth of individual freedoms is a constant in Europe in the last two and a half centuries, from the French Revolution to the present, with a shift towards an increasing centrality of the individual in society, through the enlargement of the range of beneficiaries and a widening recognition of the rights to and capacities of participation, of technological
opportunities and personal self-determination. At the same time the centrality of the person, his/her human rights have for a period of time been accompanied by a growth in democracy and Active Citizenship, as if the pair were inseparable. Yet, in the last decades the gap between individual freedoms and democracy has been growing (Zakaria, 2003), involving a weakening of many people’s belonging to communities, groups and political parties, and reduced participation in decisions regarding public affairs. Freedom and citizenship have slowly drifted away, leaving individuals who would only be able exercise full citizenship if they were provided means of adequate social support and a substantial equalisation of their possibilities and opportunities for participation (Castel and Haroche, 2001).

However, for persons with disabilities the process of recognition of their rights is very recent, for many of them the development of their individuality has not yet matured and social belonging to a community where each individual is self-determined is still far from being achieved. Their possibility of playing an important role and exercising Active Citizenship is not only problematic because of the limitations that we have previously analysed, but also because Active Citizenship for persons with disabilities is not yet fully recognised by the community in which they live. Such lack of recognition implies a questioning of the legitimacy of their right to be full and active citizens25 (DISCIT, 2013).

An essential element of the change of perspective on the rights of persons with disabilities is an adequate system of monitoring of policies. The CRPD requires that states as well as the European Union establish a monitoring system (Article 33 of the CRPD). Until now in fact only a few EU States have defined real new goals and policies on disability, followed up by the collection of data based on similar timing and content to that of other citizens, which can “identify and address the barriers faced by persons with disabilities in exercising their rights” (Article 31 of the CRPD). New goals and policies have to be embodied in a national action plan and many local action plans, based on the decentralisation of the state, with an appropriate monitoring system that evaluate the progress made. These goals and policies should lead to a shift of focus and restructuring of existing services, both through mainstreaming in all policies, as well as reinforcing the equalisation of opportunities (including through positive discrimination and positive duties), to support Active Citizenship of persons with disabilities.

In this perspective the three dimensions of Active Citizenship; security, autonomy and influence, are not alternative, but complementary. They are all being essential for the Active Citizenship of persons with disabilities:

25 See for example the document The bioethical approach towards persons with disabilities approved by the Bioethical Committee of San Marino 25th February 2013.
Security is necessary because of the lack of homogeneity in the condition of disability, requiring a range of different types of support among the persons, according to the context of life and the individuals’ capacities and therefore in relation to the context in which they live.

Autonomy as a new perspective must direct the objectives to be achieved, such as overcoming segregation and lack of equal opportunities (Article 19 of the CRPD) and move towards full citizenship.

Influence is the capacity of persons with disabilities to have effect on the decisions with impact their lives, including the broader or more distant context of their lives (Articles 4, par 3 of the CRPD), involving their full participation in politics and community life, and in this way, complete Active Citizenship.

Definitions of Active Citizenship which are based on only one of these dimensions, is likely to result in an ideological twist. For instance, systems of “protection without influence” or “protection without autonomy” have led to the creation of segregating facilities: think of separate classrooms where students with disabilities can receive services of the highest quality but still without benefiting from the conditions of full participation in their community life. Conversely, systems of “influence without protection” point towards participation only of an elite of the groups they are meant to include, a pattern of participation which threatens to mean facilities that produce discrimination (e.g. mutatis mutandis, to South Africa post-apartheid). Finally systems of “autonomy without protection” may give rise to a real social Darwinism in which human diversity is not valued but is progressively eliminated through a process of socio-economic selection.

To sum up, a rethinking of the collective and individual processes involved in building Active Citizenship for persons with disabilities is necessary. In the next section we will try to show how and why the capability approach may offer an interesting and potentially policy-relevant approach (Sen, 1999; Trani et al. 2011).

### 7.2 Capabilities and Active Citizenship

#### 7.2.1 A Capability-based Conceptual Framework for Active Citizenship

The Capability Approach is a general normative framework for the evaluation of individual well-being and social arrangements, the design of policies and proposals about social change in society (Robeyns, 2005). In this section we present a conceptual framework, based on the capability
approach and empowerment perspective in line with the social model and the CRPD. The aim of this framework is to disentangle the mechanisms which may foster or hamper Active Citizenship.

According to Trani (2008: p.47):

“...The capability approach provides broader insights into the issues related to disability since it proposes to look not only at what a person actually does (his/her functionings) but also at the range of possibilities from which he/she chooses that specific functionings.”

Therefore, capability and human development perspectives shift the primary attention away from means to the ends that people have reason to pursue (Sen, 1999: 90). These perspectives give salience to “opportunity freedoms” (capabilities) and “process freedom” (rights, entitlements and empowerment) as well as to the individual’s and communities’ experiences, values and participation.

Figure 7.1 gives an overview of the mechanisms and the factors that may foster or hamper persons’ capability to exercise Active Citizenship for persons with disabilities.

Figure 7.2.1: Factors and process of capabilities evolution: conditions for exercising Active Citizenship (AC)
Becoming an Active Citizen, that is, one who has achieved the functionings referred to in the box on the right of Fig. 7.2.1 depends on several elements (when combined) shape the process of capability expansion or reduction (see also Trani et al. 2009 and Robeyns, 2005).

The process of capability expansion or reduction is influenced by conversion factors which transform resources and goods and services into potential functionings (i.e. capabilities as opportunities) that may become the person’s achieved functionings after the her choice.

Conversion factors are both personal and individual (internal, i.e. internalised) and societal and environmental (i.e. territorial, on the left part of the diagram). The combination of these elements transforms resources into capabilities (achievable functionings). More specifically, according to Biggeri, Ciani and Ferrannini (2013, forthcoming), material goods and services and immaterial aspects generated by territorial/local “functionings” are key conversion factors (enabling or disabling factors) since they may facilitate the possibility for a person with disability to flourish i.e. expand his/her capabilities (Biggeri and Ferrannini, 2013, forthcoming).

Given the dynamic nature of this framework it is especially important to assess how the policies and programs are implemented, by placing clearer emphasis on the way expansion and reduction in resources, conversion factors, empowerment, involvement and achieved functionings shape subsequent human development processes through feedback loops among the different elements of the diagram.

As underlined by the DISCIT kick-off meeting (DISCIT, 2013), the capability domain “to be able to exercise Active Citizenship” and its associated achieved functionings are rooted on three main sub-dimensions: Security, Autonomy and Influence. The three sub-dimensions are key elements for understanding the capability expansion process both for personal well-being and well-becoming in terms of Active Citizenship, as well as in terms of societal achievements. The opportunities to be secure, autonomous and influential and the associated functionings are the basis to improve the agency and the empowerment of the individual and collective/societal levels.

Each person is embedded in a specific socio-institutional context with mutual influencing relationships. These mutual relationships are on the one hand contributing to shape the ability of the context to provide goods and services (both through market and non-market mechanisms) and on the other hand, contributing to the formation of individual preferences, values and beliefs.

As showed in the top of Fig. 7.2.1, policies and actions at the national and subnational levels are affected by the CPRD, guidelines given by the EU and multilateral agencies (like the WHO or ILO). These policies are transformed into activities on a local level thanks to the interaction of national and local governments and disabled people’s organizations, associations and the civil society.
Therefore, the success of actions and policies at national and local level is likely to be co-determined by a process that directly and indirectly (through services or actions aimed at changing behaviour and attitudes) influences conversion factors at individual and community levels. These policies, actions and activities for promoting Active Citizenship are expected to challenge the traditional perception of the community towards persons with disabilities, thus fostering a reduction in the stigma which has both an intrinsic value and an instrumental value by enhancing social inclusion and at individual level reducing self-stigma and a low self-esteem as discussed in the previous section.

In other words, a complex web of linear and non-linear (through feedback loops) linkages between the territorial and individual elements are influencing the dynamic processes of capabilities expansion. This web is shaping the final outcomes of the process. This means that although their significance and objectives are similar, different policies and processes as well as resources may be needed in different countries/territories and for persons to obtain the same results in terms of expansion of capabilities (i.e. achievable functionings they have reason to value).

In addition to this general process linking capability expansion for Active Citizenship, it is relevant to turn our attention on the personal processes by narrowing the scale of the analysis to empowerment. Hence, a person-centred strategy requires the person to undertake a process of individual and social empowerment. This process is represented in Fig. 7.2.2. An individual needs to feel worthy of desiring something before he/she moves towards doing it. Once the elaboration of the willingness is achieved the following step is to acquire knowledge (including information and know-how). At this point, assuming that there are no barriers in term of conversion factors, the person has the capability since he/she is potentially able to act, to be an Active Citizen\textsuperscript{26}, or to claim his/her right to reach that position. In this perspective the empowerment process is not just an individual metaphysical path of interior growth but also a process that lead to the ability to practice collective action, conflict and participation.

To summarise, a two level actions on social and self-stigma is needed to foster this process (the same process is requested at group level for social empowerment).

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\textsuperscript{26} That is, he/she can effectively reach his/her goal or desired achievement functioning of Active Citizenship.
This process of empowerment strengthens individual agency and thus the ability to master and choose which achievable and non-achievable functionings are more relevant. A person-centred procedure such as a ‘mosaic strategy’ is an efficient and effective manner to understand the aspiration, desires and needs of persons with disability. This strategy consists mainly of three steps: (i) unpacking the needs and desires of the person with disabilities, (ii) the validation of the mosaic project or life project and (iii) the implementation phase (i.e. the identification of the barriers and resources connected with the provision of the services, necessary to satisfy the person’s needs and desires).

Following Biggeri et al. (2011b) the potential life project (flourishing) can be represented as a mosaic made up for instance of concentric octagons (see Figure 7.2.3.). The surface of each small octagon is divided into eight wedges, each one corresponding to one of the domains or dimensions of well-being. Each sector of the mosaic consists of tesserae of a given colour whose intensity decreases from the centre to the perimeter of the mosaic. The colours of the tesserae represent

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27 A tessera (plural: tesserae) is an individual tile in a mosaic, usually formed in the shape of a cube.
mosaic represent the dimensions deemed important for a person’s well-being and well-becoming. The centre of the mosaic is characterised by a nucleus where colours are darker and common to all individuals. This inner circle is the level of development in each dimension that, within a society, is considered inalienable for each individual (rights). Beyond this border the freedom of choice begins to matter and the individual should be able to develop himself/herself in the various directions according to their preferences, choices and values. In other words, moving towards the edges of the mosaic, each person decides which colours he/she wants to make more salient, according to his/her preferences or values. In other words, while some dimensions of well-being are essential for the flourishing of any human being (as defined by the CRDP), others play a nuanced role depending on the person’s characteristics and values.

To summarise, the individual mosaic is (i) individual, (ii) empowering, (iii) holistic, (iv) real, (v) in constant evolution (dynamic) and (vi) multidimensional (Biggeri et al., 2011). Therefore policies inspired by the capability approach and CRPD involve some essential changes in the coordination of the system as well as in processes of service provision. Other instruments such as peer counselling and self-help groups could be developed to improve individual and community deliberative processes (Barbuto et al, 2011).

7.2.2 The value added of the capability approach and some caveats

Before examining the mechanism that can foster or hamper the Active Citizenship in a capability and human rights perspective, it is necessary to synthesize the main added value of the capability approach as well as some possible misunderstanding concerning this approach.

From an analytical point of view, the capability approach offers several interesting insights that can create the ground for the development of mechanisms aimed at the promotion of Active Citizenship for persons with disabilities:

First of all, the capability approach is based on a people-centred analysis focused on stakeholders’ outcomes in terms of expansion of capabilities and not on their impairments.

Second, the capability approach positively addresses human and social diversity, capturing the multidimensional and dynamic nature of the human being: in other words it does not propose a stereotypical model of the actor (Terzi, 2005).
Third, the capability approach is inherently based on the stakeholders’ direct participation in their own process of capability expansion through the increase the informational space, voicing power and democratic assessments (see for instance “Creating capabilities” by Nussbaum, 2011).

Finally, the capability approach is able to analyse the multilevel initiatives finalised to promote Active Citizenship for persons with disabilities by giving attention to cross-level interactions.

At the same time it is useful to clarify some potentially ambiguous points to fully exploit the CA as an interpretative framework to analyse disability related issues:

First, the capability approach does not put itself forward as a new model of citizenship. The capability approach describes a process that under certain conditions can lead to the achievement of Active Citizenship.

Second, the capability approach is person-centred but its individualism is solely methodological (Robeyns, 2005). It means that enabling and disabling conversion factors (Biggeri, Ciani and Ferrannini, 2013, forthcoming) are central in the process of individual capability expansion and, moreover, the capability approach does not disregard the community-level contribution in terms of collective action. Furthermore, there are capabilities and functionings that make sense only if they are practiced collectively (e.g. the opportunity of speaking your own language if you are a member of an ethnic minority).
Third, it is not possible to reduce the capability approach’s concept of freedom of choice to the liberal concept of equality of opportunities, given that one adopts an appropriate interpretation of the capability approach. The expansion of the capabilities set derives from the individual empowerment on one hand, and from the active, enduring and explicit support of various form of collective actions (i.e. public policies, formal and informal safety nets etc.) to address issues linked to entitlements, conversion factors etc., see Sen1999).

Fourth, even if participation is extremely relevant in the capability approach (as a capability, as an achieved functioning, and as a source of feedbacks able to influence the whole process of capability expansion), the capability approach does not coincide with the “influence” dimension or approach to Active Citizenship. Participation (with its double role as means and aim in the process of capability expansion) is only a part of the process and it is not appropriate to neglect other aspects including the process aspect of freedom and thus the linkage to human rights and legal frameworks (Sen 2009).

Finally, it is relevant to emphasise the close relationship between the capability approach and the Human Rights agenda (Karkara and Biggeri, 2013, forthcoming). Human rights can be seen as meta-capabilities, and, from the other angle, capabilities can be seen as an expression of values and “local” human rights. In other words, the capability approach can extend the human rights agenda towards notions of secure rights and towards the localisation of international rights. On the one hand, human rights are not flexible enough to capture local contexts, while on the other they could offer a long-term perspective on specific rights and duties and on the allocation of those duties.28

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28 According to the Convention on the Rights of Persons with Disabilities, Article 3: General principles (1): The principles of the present Convention shall be: a. Respect for inherent dignity, individual autonomy including the freedom to make one’s own choices, and independence of persons; b. Non-discrimination; c. Full and effective participation and inclusion in society; d. Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity; e. Equality of opportunity; f. Accessibility; g. Equality between men and women; h. Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities (WHO 2010, p. 25). According to Sen (1999: 38) there are substantial freedoms such as basic capabilities (be nourished, …), basic practical knowledge and basic participation into community life as well as five relevant instrumental freedoms which include political freedom, economic facilities, social opportunities, transparency guarantees and protective security.
7.3 Active Citizenship, the CRPD and the Capability Approach: How to translate the idea of Active Citizenship into Real Policies

The UN CRPD’s policy implications and its transposition into national and EU normative and legal frameworks imply also a need to reshape national and local services provision systems in order to improve their horizontal (interpersonal) and longitudinal (i.e. inter-temporal) adaptivity. In this perspective, the capability approach offers some interesting reflections.

7.3.1 Longitudinal Adaptivity

A direct consequence of the medical approach to disability (maybe obsolete in the scholarly literature but still well present in our society at large) is that the identity of a person with disability is restricted to its own limitations while its evolving complexity is broadly neglected (Mitra, 2006).

One of the pillars of the CRPD is the deconstruction of disability as a static label that is assigned to a person because of a certain degree of impairment. As long as people with disabilities are fully considered as citizens, their dynamic and evolutionary dimension cannot be ignored anymore. As all other citizens, disabilities should be considered as evolving persons characterised by changing needs, values, aspirations, etc. To embrace this cultural (r)evolution is thus one of the most ambitious challenges that European societies have to take on while dealing with disability related issues29.

It is enough to take into consideration the system of disability assessment in the EU to see how far we are from this achievement. These systems are not based on the conditions of life of persons with disabilities and on equality of opportunities parameters but on medical parameters inducing a further stigma and weakening of the capacities of persons with disabilities and thus their flourishing.

In this perspective, the capability paradigm brings a huge shift in terms of policy design, policy implementation, policy evaluation and resource allocation at each level of the public administration (from the EU to municipalities and local communities). The expenditures finalised to the promotion of the full citizenship of persons with disabilities should not be evaluated only from an economic efficiency perspective but as well from rights, social justice and capability

29 Of course the same way of reasoning can be extended to other groups that are marginalised or at risk of marginalisation (migrants, inmates): the membership to such a group should not be considered as an all-encompassing and fossilised form of identity.
perspectives. Even more importantly, given the dynamic nature of disability, resource allocation should be based not only on the flux of costs produced by an investment at time $t$ but also on the flux of benefits (returns) induced by the investment between time $t$ and time $t+\alpha$ (where $\alpha$ is the right time horizon to evaluate the overall effect of the investment). For example, resources devoted to promote access to education for persons with disabilities are likely to induce a flux of private (e.g. higher future income) and collective (e.g. lower expenditure for assistance and more income taxes paid by persons with disabilities) benefits in the future.

In other words, if we go back to the diagram included in the Kick-off Meeting Report (DISCIT, 2013: fig. 1, p. 3), we would need to include “inter-temporal coordination” of policies among the dimensions that are needed to achieve Active Citizenship for persons with disabilities. Short-term policies are usually not able to handle the evolving conditions of persons with disabilities and to channel the resources towards the elaboration of projects of life that are likely to succeed in fostering the achievement of Active Citizenship.

The situation of most European countries after the 2008 crisis is even more dramatic and shows how far the European societies are from the achievement of this goal. In many EU countries severely affected by budget disequilibria, the support to persons with disabilities has been disproportionally hit by costs-cuts if one compares to cuts in other sectors. Just to exemplify, a report elaborated in 2011 by FISH and FAND (the two main Italian Disabled People’s Organizations) highlighted cuts up to 50% particularly concentrated in Southern Italy\(^{30}\). In the UK the Centre for Welfare Reform reported that People affected by severe forms of disability were hit even more than proportionally by the cuts (Duffy, 2013). Similar examples can be given about Greece, Spain, etc.\(^{31}\) The situation is even more difficult if we consider that crisis related cuts not only reduced the amount of resources devoted to disability but also stopped or slowed down the processes of reform of National assistance systems: for example the European Disability Forum underlines the slowing down of the de-institutionalisation policies in Poland, Greece and Hungary (EDF, 2010).

We expect that expenditures aimed to enhance the achievement of Active Citizenship for persons with disabilities are often still perceived as unproductive costs only justified from ethical (or, in the worse cases, charity) considerations than by a dynamic vision of the fluxes of costs and benefits and therefore as investment. While it is interesting that the EU Commission in the spring of 2013 presented a Social Investment package, actual policies in many member states appears to have moved in the opposite direction.

\(^{30}\) See the website [http://www.fishonlus.it/files/2011/06/FISH_FAND_no_ai_tagli.pdf](http://www.fishonlus.it/files/2011/06/FISH_FAND_no_ai_tagli.pdf)

\(^{31}\) For more detailed information see the country reports on the ANED website ([http://www.disability-europe.net/](http://www.disability-europe.net/))
7.3.2 Horizontal (interpersonal) Adaptivity

One of the most relevant aspects of the social model, the CRPD and the Capability Approach is the stress laid on agency and empowerment (Griffò, 2007; Barbuto et al., 2011; Kuklys and Robeyns, 2004; Ibrahim and Alkire, 2011). If an individual is not limited by particular budget constraints or by other factors (e.g. underperforming conversion factors, insufficient access to information, etc.), and if the access to a certain basket of goods or services happens within market mechanisms, the matching between demand and supply arises from the practice of the actors’ agency. Anyway this scenario is not always realistic for many non-negligible reasons:

a) Not all the goods and services which are relevant for individual welfare are marketable (e.g. friendship). Moreover there are goods that are in theory marketable but that, for a certain person in a certain moment, may have value only if are accessible through non-market mechanisms (e.g. to have sex with a partner; to have friends);

b) The production of a good or service may produce positive (e.g. carbon sequestration in a forest) or negative (e.g. pollution) externalities. In this case the market will reach an equilibrium characterised by an under/over production/consumption of the good;

c) Certain goods are non-excludable and non-rivalry (e.g. public lighting, security). As a consequence nor a demand nor a supply of those goods can exist in free markets.

Even if the previously exposed issues are left aside, the case of persons with disabilities is characterised (i) by huge issues concerning conversion factors (Nussbaum, 2006) and (ii) by a higher probability of binding budget constraints as disability and material deprivation are closely related conditions (Braithwaite and Mont, 2009; Prackar 2008).

The solution elaborated by the European societies to deal with the pressing collective justice issues emerging in the described framework has been to grant the access to certain goods and services as a matter of right. In other words, it means that the access has been more or less sharply disconnected from pure free market mechanisms. It is possible to find many examples of such a behaviour: even if there are huge differences among and often intra countries, in large parts of the EU the access to education, health care, housing etc. is not dependent only on the markets’ abilities to match demand and supply. In particular we can define as right-based access to a certain set of goods and services as a form of access that is guaranteed by a public intervention (through direct production or distribution or in other forms) motivated by issues of social justice (Rodotà 2013a and 2013b).

What happens with the person’s agency if the access to a certain set of goods and services is pursued through non-market mechanisms? According to the capability approach, to focus our attention only on outcomes (i.e. the access, in our case) without paying attention to processes (i.e.
agency) implies an intolerable loss of complexity (Trani et al., 2011). In an Active Citizenship perspective too, the loss of agency implies a loss of autonomy and then a departure from Active Citizenship itself (EEEC, 2012). This issue is extremely relevant in the case of persons with disabilities whose ability to achieve a large set of functioning is linked to a rights-based access to particular goods and services: what if the price to pay to have a rights-based access is to give up one’s agency in a large set of life domains, an overall dis-empowering impact is likely to arise for the person as a whole.

As a consequence one of the main challenges that European welfare systems have to face is the creation of ways to preserve the agency and its intrinsic value while offering a rights-based access to the services needed to foster the achievement of Active Citizenship for persons with disabilities. According to the capability approach, this challenge can be taken up through the creation of a person centred approach to disability finalized to the elaboration of individualised life projects for persons with disabilities. In this sense the first step is to support the person during the elaboration of his project of life that is to work on the empowerment and ability of persons with disabilities’ to project themselves in the future (see section 2.1) and then to switch on the services needed for its implementation. It is then the project of life that shapes the system of services and goods provision and not the contrary. Moreover it is the project of life and not the type of impairment that highlights the type of services and goods needed.

The achievement of such a system of services and goods provision is not likely to be achieved through top-down schemes of policy design but by a combination of top-down and bottom-up initiatives and a reorganisation of services and goods production. The creation of institutional and systematic dialogue spaces between policy makers and stakeholders (e.g. DPOs) and of channels devoted to increase the effectiveness of participation in terms of its ability to orient policies is thus a pivotal preliminary step to build a person-centred strategy to foster active citizenship for persons with disabilities.

7.4 Conclusions

Given (i) the persistence of segregating schemes of services provision, (ii) the existence of material and immaterial barriers and (iii) the consequences of the economic crisis in terms of resource availability, the Active Citizenship for European people with disabilities is a goal far from being fulfilled. As suggested by the CRPD, any approach to Active Citizenship should deal with effective and not merely formal definitions of citizenship.

Security, autonomy and influence are three key components of Active Citizenship (particularly in the case of people with disabilities). It is not possible to imagine a model of Active Citizenship without simultaneously taking into consideration all three dimensions. The achievement of
Active Citizenship cannot be abstracted from the definitive abandoning of the medical model not only in the academic debate but also in actual policies and services provision arrangements.

The Capability Approach helps the understanding of the factors and mechanism that foster or prevent Active Citizenship. The Capability Approach offers a potentially useful analytical framework as it is (i) person-centred, (ii) inherently pro-participation, (iii) able to take into consideration multilevel structures and cross-level interactions, (iv) sensitive to human diversity valorisation and values, and (v) concentrating on opportunity and process freedoms. The Capability Approach can complement a Human Rights Based Approach.

As concerns disability policies (re)formulation, the capability approach suggests (i) to increase services horizontal and longitudinal adaptivity, (ii) to create structured channels of stakeholders’ participation and dialogue arenas, (iii) to work both on the reform of services provision schemes as well as (iv) on individual and social empowerment.

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Relevant web pages

http://www.disability-europe.net/
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http://www.ucl.ac.uk/lc-ccr
www.community-living.info
http://www.anmic.it/Fand.aspx
http://www.fishonlus.it/
Appendix:
Annotated bibliography of recent literature on Active Citizenship

Books

Betzelt, Sigrid & Silke Bothfeld (eds.) (2011), Activation and Labour Market Reforms in Europe: Challenges to Social Citizenship, Basingstoke: Palgrave (290 pages)

Provides an interesting and innovative analytical framework summarised on p. 22, focused on individual, social and political dimensions of autonomy; discussed the contrast between women’s more traditional citizenship and current expectations of women’s (economically) Active Citizenship, gives many references to the situation of persons with disabilities


Contains several discussions of Active Citizenship, tends to see Active Citizenship as expressed in participation in civil society, voluntary activities in a broad sense


Contrasts top-down, government-led approaches and more bottom-up approaches to Active Citizenship; emphasises “citizenship culture(s)” and roles of education, capacity building and empowerment in promoting Active Citizenship


Challenges the idea that Active Citizenship needs to be confined to the territory of the nation states, see especially chapter 4

Contrasts top-down and government dominated and bottom-up and social movement-based concepts of Active Citizenship, with the new disability movement as example of the latter.


Discusses conceptual issues related to how the scope for exercising Active Citizenship are interrelated to broader issues of different welfare state architectures, and how aspects of AC have developed in a number of countries.


Presents a multifaceted concept of Active Citizenship built on synthetic review of the literature and illustrated with examples from diverse policy areas, including European disability policy.


In particular on clarifying the contrasts between active and activist citizenship.


Refers to the distinction between formal and substantive citizenship; the later being the result of “practices of making citizens – social, political, cultural and symbolic”; but prefers the concept of “acts of citizenship” to active citizenship.


Explores a range of different evolving meanings of Active Citizenship, demonstrating their empirical relevance with examples from European countries.

*Especially chapter 5 provides a powerful theoretical clarification of contrasting concepts of Active Citizenship, relating these to the (Socio-) Liberal, the Libertarian and Civic-Republican approaches to citizenship.*

Newman, Janet & Evelien Tonkens (eds.) (2011), *Participation, Responsibility and Choice; Summoning the Active Citizen in Western European Welfare States*, Amsterdam: Amsterdam University Press (241 pages)

*Provides a combination of more theoretical discussions of the ambiguities of Active Citizenship and national case studies, e.g. related to disability.*


*Distances himself from other conceptualisation of “citizenship practice» as the total of institutional ties between the citizenry and their polity at certain time, and declares that he seeks to focus on the multiplicity of actual citizenship practices on the ground – both as citizens’ activity and the practices of political, legal, or administrative institutions. He links this concept of citizenship practices with a study of the emerging transnational discourse on what constitutes “modern” social policy, undertaking case studies of shifts towards activation and activating welfare states in Europe and the role of the European Union as driver behind these shifts.*


*Especially the Introduction defines a concept of Active Citizenship as broad engagement in a range of valued forms of participation, either through supported employment, volunteering, peer support and mentoring, undergoing training, partaking in local activities in the community or securing open competitive employment, while generally emphasising self-determination, independent living in the community and personalisation.*


*Argues in favour of a minimalist definition of citizenship as the right to have rights, but says in practice that citizenship is not solely a question of rights as embedded in the laws of a state. The possibility to exercise effective citizenship depends on social inclusion whereby a person becomes member of a social and political community, creating the*
mechanism for translating formal rights into substantive rights. Such membership is not a matter of course and is in particular threatened by market fundamentalism undermining reciprocities and solidarities and replacing them with contractual relationships and market transactions. In this contractualisation of citizenship inclusion and moral worth are not basic rights but conditional on personal responsibility and ability to exchange something of equal value.
**Journal articles**


*Develops a participation- and experience-based model for understanding conditions for Active Citizenship for persons with disabilities, emphasizing the role of full recognition*

Gaynor, Niamh (2009), In-Active citizenship and the depoliticization of community development in Ireland, *Community Development Journal*, 46, 1, 27-41

*Criticizes top-down approaches to Active Citizenship for seeking to substitute self-help for redistribution and self-reliance for state accountability*


*Reports the finding of a partly a methodological exercise, partly an empirical study of Active Citizenship in European countries, defining Active Citizenship as “Participation in civil society, community, and/or political life, characterized by mutual respect and non-violence and in accordance with human rights and democracy”, that is, with an emphasis on “influence”. The authors stress that the then available comparative social surveys were insufficient to fully operationalise and measure Active Citizenship conceptualized in this way*


*Investigates the ambiguities of the concept of Active Citizenship espoused in a 2006 government report on disability policy, and develops a distinction between a more conventional concept of social citizenship and the emerging concept of Active Citizenship in Finland*

Lantz, Sarah & Greg Marston (2012), Policy, citizenship and governance: the case of disability and employment policy in Australia, *Disability and Society*, 27, 5, 853-867

*Analyses findings of a two-year semi-longitudinal study with participation of 80 persons with disabilities who had claimed welfare benefit, focusing on the intended and unintended consequences of the government’s pressures on recipients of benefits to exercise personal responsibility and become active (= productive) citizens, resulting in a mix of acceptance and resistance from the persons involved*
Macgregor, Marian (2012), Citizenship in Name Only: Constructing Meaningful Citizenship through a Recalibrating of the Values attached to Waged Labor, *Disability Studies Quarterly*, 32, 3

*Given the deeply rooted connection between the ability to exercise social citizenship and participation in paid work, it is argued that values associated with being employed, e.g. independence, self-reliance and productivity should have a less prominent role in society*

Mackenzie, Catherine, Amanda Bennett, Melissa Cairney (2011), Active citizenship and acquired neurological communication difficulty, *Disability and Rehabilitation*, 33, 3, 187-194

*Analyses the experience of civically engaged adults with acquired neurological communication difficulties, finding that for the participants civic engagement had both positive and negative dimensions; participation in disability group meetings giving more positive experiences than broader community activities, which were associated with fatigue and frustration, commonly resulting from communication difficulties and unmet support needs*

**European reports**

EEEC (2012), *Active Citizenship for a Better European Society*, Brussels: European Economic and Social Committee ([www.eeec.europa.eu](http://www.eeec.europa.eu)) (70 pages)

*Collection of articles related to the importance of Active Citizenship, includes interview with Yannis Vardakastanis, President of European Disability Forum, [http://www.eesc.europa.eu/?i=portal.en.publications-storybook.25702](http://www.eesc.europa.eu/?i=portal.en.publications-storybook.25702)*


*Policy document setting an agenda for (European) Active Citizenship, with the main emphasis on the role of education in promoting Active Citizenship*


*Relates to Hoskins & Mascherini 2009 and goes into greater detail.*
Mascherini, Massimiliano, Anna Rita Manca & Bryony L. Hoskins (2009), The Characterisation of Active Citizenship in Europe, JRC Scientific and Technical Reports, Luxembourg: Office for Official Publications of the European Communities (93 pages)

Relates to Hoskins & Mascherini 2009 and goes into greater detail.

Osler, Audrey (1997), The contribution of Community Action Programmes in the fields of education, training and youth to the development of citizenship with a European dimension, Final Synthesis Report, The University of Birmingham, School of Education (98 pages)

Presents results of a cross-national European study on learning for Active Citizenship, defining Active Citizenship as “active participation in society and the exercise of rights (civic, political and social) through participatory practices and structures at local, regional, national or transnational levels. This in turn implies a knowledge and understanding of rights and of democratic structures and procedures, and an absence of those discriminatory practices which may operate to exclude certain individuals and groups. Relations between each individual and institutions (local, regional, national or supranational) are characterised by a common set of rights and obligations and have been characterised as aspects of citizenship ” p.7