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## “Nothing About Us Without Us”

### Disability Rights Activism in European Countries – A Comparative Analysis

#### ABSTRACT

This paper explores disability rights activism as a form of collective political participation. This type of organised civil society has been and continues to be vital in promoting and implementing social and political change in European societies. However, little is known about its structures and resources, activities and effects. First, this paper discusses different typologies of disability rights activism and proposes an own attempt of systematising different forms of disability rights activism. By comparing various, rationalist as well as constructivist, theoretical approaches, this article develops an integrated framework for analysing disability organisations by drawing on approaches that consider the interrelations between structure and agency. Second, applying new social movement theory, we explore identity politics and models of disability as identity frames of disability rights activism. Both aspects relate to the pivotal question of how the interests of persons with disabilities are represented in disability politics. Finally, based on documentary analysis of primary data and structured national reports findings of a comparative analysis from a sample of nine European countries (Czech Republic, Germany, Italy, Ireland, Norway, Serbia, Sweden, Switzerland, United Kingdom) are offered. There is evidence that the principle of self-representation—which is a crucial demand of the disability rights movement—has resulted in different practices at the level of national disability assemblies.

Keywords: *disability rights movement, disability studies, self-help groups, participation, civil society, new social movements*

#### Introduction

Considering the long history and political relevance of disability rights activism it is surprising that this realm of civil society engagement has so far not caught the attention of much academic research, although this topic is relevant for several discourses. Ingrid Guldvik, Ole Askheim Petter and Vegard Johansen highlight this point:

The political citizenship of disabled people is [...] a topic that is much overlooked, for neither welfare research nor political science research has been particularly concerned with such issues. Therefore, knowledge of the field is lacking. This recognition implies a challenge for the research community to take the subject seriously.<sup>1</sup>

We will face this challenge by focusing on disability rights activism in the European context. In the following, we offer first results of a research project, which is part of the on-going European Union funded research consortium DISCIT whose acronym stands for “Making Persons with *Dis*abilities Full *Cit*izens – New Knowledge for an Inclusive and Sustainable Social Model.”<sup>2</sup> The members of DISCIT include universities, research institutes and civil society organisations that together aim at producing new knowledge to enable the European Union and its Member States as well as affiliated European countries to achieve full and effective participation of persons with disabilities in society and the economy. In operationalising the notion of “full and effective participation” as described in the United Nations’ Convention on the Rights of Persons with Disabilities (CRPD), DISCIT uses a multifaceted understanding of “Active Citizenship”, in which participation in political and public life plays a crucial role. As part of this interdisciplinary research, our project at the University of Cologne focuses on the collective political action of disabled people in the European context.

The first aim of this paper is to review existing typologies and theoretical concepts on international disability rights activism. Further, this article develops an integrative framework for empirical analyses which emphasises the interrelations of structure and agency.<sup>3</sup> As a second step, we will concentrate on questions of special relevance for

- 1 Ingrid Guldvik/Ole Askheim Petter/Vegard Johansen: Political Citizenship and Local Political Participation for Disabled People, in: *Citizenship Studies* 17:1 (2013), pp. 76–91, pp. 88f.
- 2 Our research receives funding from the European Union’s Seventh Framework Programme for research, technological development and demonstration under grant agreement no. 320079. It is part of the consortium “DISCIT – Making Persons with Disabilities Full Citizens – New Knowledge for an Inclusive and Sustainable Social Model” ([www.discit.eu](http://www.discit.eu)). For their contributions we are grateful to our project partners at Norwegian Social Research at Oslo and Akershus University College of Applied Sciences, Charles University of Prague, National University of Ireland at Galway, University of Florence, University of Uppsala, Swiss Paraplegic Research, University of York, Mental Disability Rights Initiative of Serbia and the European Disability Forum. We greatly appreciate that the research partners provided substantial knowledge by writing structured national reports for our empirical analysis as well as offering additional comments. We are also grateful to the two anonymous reviewers of this paper for their valuable remarks.
- 3 Rob Stones: *Structuration Theory*, Basingstoke 2005; Dave Elder-Vass: *The Causal Power of Social Structures: Emergence, Structure and Agency*, Cambridge 2010; Karen O’Reilly: *International Migration and Social Theory*, Basingstoke 2012.



new social movement (NSM) theory, namely identity politics and disability models as collective identity frames both of which are frequently discussed in existing studies on disability rights activism. The social model of disability has been a driving force for the disability rights movement to involve a demand for the self-representation of persons with disabilities in all their concerns. The slogan “Nothing About Us Without Us” highlights this claim. Against this background, we will offer in our third part a section out of our empirical work in progress, a comparative analysis of national disability assemblies from a sample of nine European countries, namely the Czech Republic, Germany, Italy, Ireland, Norway, Serbia, Sweden, Switzerland, and the United Kingdom.<sup>4</sup> Based on deskwork and national reports our investigation explores the national disability assemblies as an example of disability rights activism. The analysis shows that current structures and practices are diverse, even when it comes to the pivotal criterion of self-representation.

## Typologies of Disability Rights Activism

When aiming at investigating disability rights activism, one is right from the start confronted with terminological problems. There is a variety of terms that are used synonymously, but many imply different connotations, so it is difficult to determine key characteristics.

For our own attempt of systematising disability rights activism, Anne Waldschmidt’s typology of collective political participation for persons with disabilities, differentiating between self-help groups, disability organisations and the disability rights movement proves helpful as a heuristic device for several reasons.<sup>5</sup> First of all, this approach uses major analytical categories such as group, organisation and social movement that can be analysed with sociological instruments. Secondly, this proposal is consistent with inductive approaches that aim at informing theory by means of significant empirical data. This is of relevance as there are not yet any comprehensive studies on collective political

4 Our article is based on this online publication: Anne Waldschmidt et al.: A Comparative Analysis of Disability Rights Activism: With Reference to the Concept of Active Citizenship, A working paper of the EU research consortium DISCIT (Making Persons with Disabilities Full Citizens – New Knowledge for an Inclusive and Sustainable European Social Model), public report published on 15 September 2014, available online at: [https://dl.dropboxusercontent.com/u/65507706/DISCIT%20Uploads/Publications/DISCIT%20D9\\_1%20WP9-med-abstract-rev-tsa-a.pdf?dl=1](https://dl.dropboxusercontent.com/u/65507706/DISCIT%20Uploads/Publications/DISCIT%20D9_1%20WP9-med-abstract-rev-tsa-a.pdf?dl=1) (accessed on 5 October 2014).

5 Anne Waldschmidt: Politische Partizipation von Menschen mit Behinderungen und Benachteiligungen, in: Dagmar Orthmann Bless/Roland Stein (eds.): *Lebensgestaltung bei Behinderungen und Benachteiligungen im Erwachsenenalter und Alter*, Baltmannsweiler 2009, pp. 118–152.

participation of persons with disabilities that consider disability rights activism from a cross-national level through the lens of social movement theory. In the following, we use the differentiation between self-help groups, disability organisations and the disability rights movement as a tentative device for outlining the empirical field.

First, self-help groups are based on the principle of reciprocity,<sup>6</sup> a form of voluntary action of persons with similar problems who are directly and personally affected and who share the intention of mutual help.<sup>7</sup> The relevance of self-help groups of persons with disabilities is highlighted by Günther Cloerkes, who presents a typology that relies on the stakeholders, differentiating between self-help groups that are disability-specific or illness-specific, self-help groups with a cross-disability focus and self-help groups of family members.<sup>8</sup> In the international discourse on disability rights activism, self-help groups often appear synonymously with self-determination groups or self-advocacy groups.<sup>9</sup> While smaller self-help groups tend to be oriented inwards to foster individual change, larger and organised groups aim at social change and can be part of the disability rights movement.<sup>10</sup> Self-help groups share the characteristics of being spontaneous, mostly limited in time and rather loosely organised. Typical self-help groups are ephemeral phenomena that are not easily accessible for social research, as they are often not organised as formal associations but are loosely connected groups.<sup>11</sup> An additional aspect to qualify self-help groups is their attitude towards experts. Some self-help groups strongly adhere to the principle of being regarded as “experts in their

6 Dieter Rucht: Bürgerschaftliches Engagement in sozialen Bewegungen und politischen Kampagnen, in: Enquete-Kommission “Zukunft des Bürgerschaftlichen Engagement” des Deutschen Bundestags (ed.): Bürgerschaftliches Engagement in Parteien und Bewegungen, Opladen 2003, pp. 17–155, p. 23.

7 Anne Waldschmidt: Politische Partizipation von Menschen mit Behinderungen und Benachteiligungen, p. 131.

8 Günther Cloerkes: Soziologie der Behinderten: Eine Einführung, edited by Kai Felken-dorff/Reinhard Markowetz, 3<sup>rd</sup> ed., Heidelberg 2007, p. 77.

9 Dan Goodley: Empowerment, Self-Advocacy and Resilience, in: *Journal of Intellectual Disabilities* 9:4 (2005), pp. 333–343, p. 339; G. Ronald Neufeld: Advocacy: Applications in the Early Years of Childhood, in: David R. Mitchell/Roy Irwin Brown (eds.): *Early Intervention Studies for Young Children with Special Needs*, London 1991, pp. 192–210; Cathy Charles/Suzanne DeMaio: Lay Participation in Health Care Decision Making: A Conceptual Framework, in: *Journal of Health Politics, Policy and Law* 18:4 (1993), pp. 881–902.

10 Anne Waldschmidt: Politische Partizipation von Menschen mit Behinderungen und Benachteiligungen, p. 130.

11 *Ibid.*, p. 131.

own right”.<sup>12</sup> Other groups cooperate with (medical) experts, while some self-help groups are even formed by experts and promote an uncritical view on experts’ status and knowledge.<sup>13</sup>

Concerning involvement in political and public life, there are blurring boundaries. Usually self-help groups do not engage in politics. However, some groups choose to engage actively in outreach activities to generate public interest in their concerns.<sup>14</sup> Bernd Guggenberger judges the political relevance of typical self-help groups as being “quieter citizen initiatives”, which are successful in local politics but less visible than prominent greater initiatives.<sup>15</sup> Claus Offe classifies self-help groups as politically irrelevant forms of collective action that support the fragmentation of societal problems by means of individualisation,<sup>16</sup> while Joachim Braun and Michael Opielka characterise them as forms of practical critique of patronising social services.<sup>17</sup> Waldschmidt considers self-help groups as a form of political participation in the wide sense, insofar as they provide group consciousness and positive experiences of collective action. Thus, they can constitute starting points for political involvement.<sup>18</sup> In the case of disability-related self-help groups, the critical stance to professional expertise can be used as an indicator of the groups’ affinity to the disability rights movement.

Second, disability rights activism ranges in reality from small self-help or advocacy groups with informal character to disability organisations of medium or large size that function as interest groups.<sup>19</sup> The latter are formalised organisations, which are usually

- 12 Peter Radtke: *Selbsthilfegruppen*, in: Otto Speck/Klaus-Rainer Martin (ed.): *Sonderpädagogik und Sozialarbeit: Handbuch der Sonderpädagogik* 10, Berlin 1990, pp. 252–266, pp. 264f.
- 13 *Ibid.*, pp. 264f.
- 14 Bernd Guggenberger: *Bürgerinitiativen*, in: Uwe Andersen/Wichard Woyke (eds.): *Handwörterbuch des politischen Systems der Bundesrepublik Deutschland*, 5<sup>th</sup> ed., Opladen 2003, pp. 44–48, p. 44.
- 15 *Ibid.*, p. 46.
- 16 Claus Offe: *Strukturprobleme des kapitalistischen Staates: Aufsätze zur Politischen Soziologie*, 4<sup>th</sup> ed., Frankfurt am Main/New York 1977, p. 162.
- 17 Joachim Braun/Michael Opielka: *Selbsthilfeförderung durch Selbsthilfekontaktstellen: Abschlussbericht der Begleitforschung zum Modellprogramm “Informations- und Unterstützungsstellen für Selbsthilfegruppen” im Auftrag des Bundesministeriums für Familie und Senioren*, Schriftenreihe des Bundesministeriums für Familie und Senioren 14, Stuttgart 1992.
- 18 Anne Waldschmidt: *Politische Partizipation von Menschen mit Behinderungen und Benachteiligungen*, p. 130.
- 19 Language praxis in everyday conversations, mass media and academic discourses tends to be confusing concerning the differentiation between groups and organisations. In fact so-called interest groups, pressure groups and advocacy groups are in their vast majority, from a sociologist point of view, formal organisations, but the use of the term “group” for these formations is very common.

legal entities with written statutes, an official division of labour, fixed organisational and membership structures, programmes, and distinct ideas whose interests they represent. Besides, they exist for relatively long time periods.<sup>20</sup> To consider the merging field which ranges from small and local groups to large, internationally operating formations a typology suggested by James I. Charlton is useful. He differentiates between local self-help and advocacy groups, national advocacy organisations and coalitions/federations, and worldwide organisations.<sup>21</sup> This typology is of interest for scholars of disability rights activism on different governmental levels.

Among many, Ema Loja, Emília Costa and Isabel Menezes make use of Michael Oliver's typology to describe disability organisations.<sup>22</sup> To consider the scope and control in these organisations exercised by persons with disabilities they differentiate between a populist/activist model, a consumerist/self-help model and a patronage/partnership model. Further, Joachim Malleier employs a typology to classify disability organisations into three different types referring to Colin Barnes and Geof Mercer: charity organisations, organisations focusing on disability-related themes and self-help groups founded by persons with disabilities.<sup>23</sup>

- 20 Anne Waldschmidt: Politische Partizipation von Menschen mit Behinderungen und Benachteiligungen, p. 131.
- 21 James I. Charlton: Advocacy, International, in: Gary L. Albrecht (ed.): *Encyclopedia of Disability*, Thousand Oaks/London/New Delhi 2006, pp. 50–54, p. 52; James I. Charlton: *Nothing About Us Without Us: Disability Oppression and Empowerment*, Berkeley/Los Angeles 2000.
- 22 Ema Loja/Emília Costa/Isabel Menezes: Views of Disability in Portugal: 'fado' or Citizenship?, in: *Disability & Society* 26:5 (2011), pp. 567–581, pp. 569f.; Michael Oliver: *The Politics of Disablement: A Sociological Approach*, New York 1990.
- 23 Joachim Malleier: Lobbying für Behinderte: Interessenvermittlung am Beispiel des europäischen Behindertenforums in der Europäischen Union, Frankfurt a.M. et al. 2011, p. 61.

Major topics in the research describing and analysing disability organisations<sup>24</sup> are their purposes,<sup>25</sup> their relations to the state,<sup>26</sup> to their membership<sup>27</sup> and to the disability rights movement as well as their tactics and resources.<sup>28</sup> Mary Ann McColl and William Boyce list the dimensions of purposes, tactics, and views of disability, membership and resources in order to characterise and compare disability organisations. Thus, they provide “a jumping off point for further discussions of the effectiveness of disability groups at achieving their objectives of full and equal participation”.<sup>29</sup>

While many authors discuss identity issues and disability models when dealing with disability rights activism, it is striking that at the same time research findings on the groups and organisations are relatively scarce. Notwithstanding, the discourse often refers to the diversity of organisational structures, embodied by great numbers of different self-help and advocacy groups as well as impairment-specific organisations. In turn, this diversity leads to a fragmented disability rights movement which is not only heterogeneous but also frequently blocked to effectively exercise cooperation.<sup>30</sup>

- 24 Theo Blackmore/Stephen Lee Hodgkins: Discourses of Disabled People's Organisations: Foucault, Bourdieu and Future Perspectives, in: Dan Goodley/Bill Hughes/Lennard Davis (eds.): *Disability and Social Theory: New Developments and Directions*, Basingstoke 2012, pp. 70–87; Mary Ann McColl/William Boyce: *Disability Advocacy Organisations: A Descriptive Framework*, in: *Disability and Rehabilitation* 25:8 (2003), pp. 380–392; Teodor Mladenov: *Institutional Woes of Participation: Bulgarian Disabled People's Organisations and Policy-Making*, in: *Disability & Society* 24:1 (2009), pp. 33–45.
- 25 Teodor Mladenov: *Institutional Woes of Participation*; Agneta Hugemark/Christine Roman: *Diversity and Divisions in the Swedish Disability Movement: Disability, Gender, and Social Justice*, in: *Scandinavian Journal of Disability Research* 9:1 (2007), pp. 26–45; Tom Shakespeare: *Disabled People's Self-Organisation: A New Social Movement?*, in: *Disability, Handicap and Society* 8:3 (1993), pp. 249–264; Daniel Holland: *The Current Status of Disability Activism and Non-Governmental Organizations in Post-Communist Europe: Preliminary Findings Based on Reports From the Field*, in: *Disability & Society* 23:6 (2008), pp. 543–555; Joachim Malleier: *Lobbying für Behinderte*; Mary Ann McColl/William Boyce: *Disability Advocacy Organisations*.
- 26 Theo Blackmore/Stephen Lee Hodgkins: *Discourses of Disabled Peoples' Organisations*.
- 27 Agneta Hugemark/Christine Roman: *Diversity and Divisions in the Swedish Disability Movement*.
- 28 Teodor Mladenov: *Institutional Woes of Participation*; Tom Shakespeare: *Disabled People's Self-Organisation*; Daniel Holland: *The Current Status of Disability Activism and Non-Governmental Organizations in Post-Communist Europe*; Mary Ann McColl/William Boyce: *Disability Advocacy Organisations*; Lisa Vanhala: *Disability Rights Activists in the Supreme Court of Canada: Legal Mobilization Theory and Accommodating Social Movements*, in: *Canadian Journal of Political Science* 42:4 (2009), pp. 981–1002; Lisa Vanhala: *Making Rights a Reality?: Disability Rights Activism and Legal Mobilization*, Cambridge 2011.
- 29 Mary Ann McColl/William Boyce: *Disability Advocacy Organisations*, p. 391.
- 30 Daniel Holland: *The Current Status of Disability Activism and Non-Governmental Organizations in Post-Communist Europe*; Agneta Hugemark/Christine Roman: *Diversity*



Repeatedly, authors point out that the institutionalisation and professionalisation of collective action involve changes which concern the roles of the groups and organisations, their policies and strategies as well as the interests of their members. In some publications, the process of organisation building is equalised with trends of depoliticisation and depersonalisation.<sup>31</sup> Most poignantly, in one article disability organisations are labelled “pseudo-government agents”.<sup>32</sup> Furthermore, the question of “alienation” between the leadership and their constituency is addressed.<sup>33</sup> The critique aims at those organisations that shift from semi-professionalised organisations to end up as fully-professionalised organisations. These organisations are initially committed to the demands of the disability rights movement, but professionalisation results in the use of neo-corporatist means and less radical claims raised for persons with disabilities. This debate indicates that disability organisations need to be differentiated according to their degree of commitment to the principles of the disability rights movement.

In fact, in disability politics one can find a complex and confusing picture of interest representation: many disability organisations act as conventional lobby or pressure groups with a disability focus or are (also) service provider organisations; additionally there are organisations belonging to the social movement of disabled people. All these associations claim to work on behalf of persons with disabilities, and there is also a tendency of disability organisations to attribute themselves to the disability rights movement, but in actual fact, disability organisations differ greatly from each other in terms of histories, memberships, structures and practices. For the purpose of systematising the knowledge on different types of organisations, we will in the following distinguish “disability movement organisations” (DMOs)<sup>34</sup> from traditional “disability advocacy organisations” (DAOs)<sup>35</sup> and “service provider organisations” (SPOs). Of

and Divisions in the Swedish Disability Movement; Bonnie O’Day/Marcie Goldstein: Advocacy Issues and Strategies for the 21st Century: Key Informant Interviews, in: *Journal of Disability Policy Studies* 15:4 (2005), pp. 240–250; Laurie E. Powers et al.: Leadership by People with Disabilities in Self-Determination Systems Change, in: *Journal of Disability Policy Studies* 13:2 (2002), pp. 126–134; Michelle Putnam: Conceptualizing Disability: Developing a Framework for Political Disability Identity, in: *Journal of Disability Policy Studies* 16:3 (2005), pp. 188–198; Richard K. Scotch/Kay Schriener: Politics of Disability: Policies and Protest, in: Gary L. Albrecht (ed.): *Encyclopedia of Disability*, Thousand Oaks/London/New Delhi 2006, pp. 1268–1274.

31 Teodor Mladenov: Institutional Woes of Participation.

32 Theo Blackmore/Stephen Lee Hodgkins: Discourses of Disabled Peoples’ Organisations, p. 70.

33 Teodor Mladenov: Institutional Woes of Participation, p. 34.

34 As explained below we are drawing here on the “social movement organisation” concept of John D. McCarthy/Mayer N. Zald: Resource Mobilization and Social Movements: A Partial Theory, in: *The American Journal of Sociology* 82:6 (1977), pp. 1212–1241.

35 We use McColl and Boyce’s term, but in a restricted meaning, only referring to political interest groups lobbying for disability-related issues, but not affiliating to the social move-



course, the boundaries are not clear-cut, and there may be overlaps, but for an orientation this taxonomy proves to be helpful. Which type of organisation an individual disability organisation belongs to cannot be identified beforehand, but is to be the subject of empirical research.

Third, a significant part of the research presents key characteristics of the *disability rights movement* and discusses implications of its historical development from relatively small but deeply politicised action groups to a broader social movement.<sup>36</sup> Existing studies focus on the comparison of different national disability rights movements in terms of historical background, engagement and future trends.<sup>37</sup> In this context, starting in the 1970s, one can find contributions describing the conditions that politicised persons with disabilities, encouraged them to protest against discrimination, public stereotypes and bureaucratic oppression.<sup>38</sup> An important aspect discussed in the literature is the question of similarities with and differences to other social movements, but unfortunately comparative studies are not available.<sup>39</sup>

In general, there are only few studies that address the disability rights movement by drawing on the new social movement (NSM) concept. In 1993, Tom Shakespeare claimed that the social movement of disabled people should be characterised as a liberation movement rather than as a NSM, since it centres less on cultural issues, but rather on material resource allocation and political rights.<sup>40</sup> However, he also conceded that independent living as a central issue, the emphasis on self-organisation as well as the rejection of medical approaches link the disability rights movement with other NSMs. Three years later, Jane Campbell and Michael Oliver argued that the disability rights movement meets the criteria of a NSM because of its focus on autonomy, empowerment and transformation of consciousness as well as civil rights

ment of disabled people.

- 36 Allison C. Carey: *On the Margins of Citizenship: Intellectual Disability and Civil Rights in Twentieth-Century America*, Philadelphia 2009; Jacqueline V. Switzer: *Disabled Rights: American Disability Policy and the Fight for Equality*, Washington 2003; Joseph P. Shapiro: *No Pity: People with Disabilities Forging a New Civil Rights Movement*, New York 1994; Doris Z. Fleischer/Frieda Zames: *The Disability Rights Movement: From Charity to Confrontation*, Philadelphia 2001; Paul K. Longmore: *Disability Rights Movement*, in: Susan Burch (ed.): *Encyclopedia of American Disability History*, New York 2009, pp. 280–285.
- 37 Lisa Vanhala: *Making Rights a Reality?*; Patrick Devlieger: *Politics of Disability: International*, in: Gary L. Albrecht (ed.): *Encyclopedia of Disability*, Thousand Oaks/London/New Delhi 2006, pp. 1264–1268; Jerome E. Bickenbach: *Ethics, Law, and Politics*, Thousand Oaks/London 2012.
- 38 Joseph P. Shapiro: *No Pity*; Jacqueline V. Switzer: *Disabled Rights*.
- 39 Matthew T. Wappett: *Self-Determination and Disability Rights: Lessons From the Women's Movement*, in: *Journal of Disability Policy Studies* 13:2 (2002), pp. 120–125; Angharad E. Beckett: *Reconsidering Citizenship in the Light of the Concerns of the UK Disability Movement*, in: *Citizenship Studies* 9:4 (2005), pp. 405–421.
- 40 Tom Shakespeare: *Disabled People's Self-Organisation*.

and internationalism.<sup>41</sup> It took a decade before Angharad E. Beckett again discussed the issue. Her contention was “that the disability movement’s continuing focus on a range of persistent social inequalities means that it is *very unlikely* to be a ‘new’ social movement.”<sup>42</sup>

There seems to be consensus that the disability rights movement is a *social movement*, but is it a *new* social movement? Leanne Dowse’s conclusion that there are “differing interpretations of the nature of the disability movement”<sup>43</sup> is still valid, so for the purpose of our study a clarification is needed. Following Dieter Rucht, we understand new social movements as open networks of activists, groups and organisations existing for a certain period of time that together make up an informal structure with no centralised form.<sup>44</sup> Crucial aspects of these movements are collective identities that tie the different stakeholders together. At the same time, due to the complex, fluid and changing nature of social movements, structures and practices are difficult to analyse.<sup>45</sup> NSMs are in principle open and do not have a fixed, formalised structure. In contrast to other collectives, they exercise power by means of (potential) mass mobilisation, social sanctions, direct action and social protest. Typical issues of NSMs encompass culture, identity politics and struggles for recognition whereas “old” movements rather focus on material redistribution and social inequality. In this regard, we rather take a pragmatic stance, arguing that it is up to empirical investigation to find out the actual priorities of given networks of collective action. Probably, there is no NSM that is not also concerned about material aspects and in reality overlaps of “new” and “traditional” orientations are very likely.<sup>46</sup>

Without doubt, what regards internal structures and main practices, the disability rights movement as a whole exhibits key features of a new social movement.<sup>47</sup> It can be understood as a collective actor comprising of individuals as well as groups (for

41 Jane Campbell/Michael Oliver: *Disability Politics: Understanding our Past, Changing our Future*, London 1996.

42 Angharad E. Beckett: *Understanding Social Movements: Theorising The Disability Movement in Conditions of Late Modernity*, in: *The Sociological Review* 54:4 (2006), pp. 734–752, p. 745. Emphasis in Original.

43 Leanne Dowse: *Contesting Practices, Challenging Codes: Self Advocacy, Disability Politics and the Social Model*, in: *Disability & Society* 16:1 (2001), pp. 123–141, p. 129.

44 Dieter Rucht: *Modernisierung und neue soziale Bewegungen: Deutschland, Frankreich und USA im Vergleich*, Frankfurt am Main 1994, p. 76–77.

45 *Ibid.*, p. 87.

46 See for this point of view also Greg Martin: *Social Movements, Welfare and Social Policy: A Critical Analysis*, in: *Critical Social Policy* 21:3 (2001), pp. 361–383.

47 Alan Scott: *Ideology and the New Social Movements*, London 1990, p. 6; Tom Shakespeare: *Disabled People’s Self-Organisation*, p. 252; Sharon Barnartt: *The Globalization of Disability Protests 1970–2005: Pushing the Limits of Cross-Cultural Research?*, in: *Comparative Sociology* 9:2 (2010), pp. 222–240.

instance, self-help groups, as mentioned above) and organisations that share common interests and a common identity,<sup>48</sup> aim at social change and use unconventional forms of political action.

While disability organisations are not to be viewed as identical with the disability rights movement and vice versa, every social movement contains organisations that are of relevance for their effectiveness to pursue interests.<sup>49</sup> These social movement organisations, as “complex, or formal” associations that identify their “goals with the preferences of a social movement”,<sup>50</sup> have a stabilising function for the movement. Because of their fixed structure, they are entities to connect various stakeholders with each other, and they employ division of labour in order to achieve effective mobilisation. Accordingly, inspired by John McCarthy and Mayer N. Zald we call disability organisations that subscribe to the principles of the disability rights movement, as mentioned above, disability movement organisations (DMOs).

However, our own research focuses on both “old” and “new” disability rights activism at the European level, so we have to consider not only the disability rights movement and its organisations, but the whole field. We suggest to differentiate between the different kinds of stakeholders as follows. We use disability rights activism (DRA) as an umbrella term, consisting of networks of activists, (self-help and advocacy) groups and organisations (disability organisations at different political levels as well as networks, peer support centres etc.) that all are committed to implementing the rights of persons with disabilities, but have different traditions and orientations. The focal point of disability rights activism is mainly made up of disability organisations, of which DMOs commit themselves to the principle of self-representation, while disability advocacy organisations (DAOs) work on behalf of persons with disabilities, whereas service provider organisations (SPOs) mainly follow their own interests as service providers. Thus, we define DRA as a complex configuration of both, on the one hand conventional interest representation and lobbying and on the other hand activities of the disability rights movement.

In conclusion, since we concentrate on collective political action, we cannot deal with individual activists; neither can groups mainly be our empirical field, due to their predominantly local basis and great fluidity. At the national level an analysis of medium- and large-scale organisations makes most sense. Thus, our empirical focus will be on disability organisations and their coalitions, but we are well aware of the great variety of disability rights activism. Further, we contend that disability organisations and the disability rights movement are over-lapping in their structure, aims and activities, but there is no convergence. In order to distinguish in our empirical work

48 Alan Scott: *Ideology and the New Social Movements*, p. 6.

49 Dieter Rucht: *Modernisierung und neue soziale Bewegungen*, p. 87.

50 John D. McCarthy/Mayer N. Zald: *Resource Mobilization and Social Movements*, p. 1218.

between organisations that belong to the realm of conventional interest representation and those committed to the disability rights movement, we will use the principle of self-representation as corner stone.

This approach is inspired by Barnes, Mercer and Shakespeare who differentiate between disability organisations *of* and those *for* persons with disabilities.<sup>51</sup> While there are disability organisations that consist of a majority of persons with disabilities, other organisations represent interests and claims on behalf of persons with disabilities or they provide services for them without having a membership of persons with disabilities. In other words, the involvement of disabled persons is characteristic of disability organisations *of* persons with disabilities, whereas organisations *for* persons with disabilities including charities, parents' associations, pressure groups and service providers *can* advocate actual interests of disabled persons, but do not necessarily do so. In our vocabulary we call the former disability movement organisations (DMOs) and the latter disability advocacy organisations (DAOs) and service provider organisations (SPOs). This simple distinction is helpful to investigate differences in the practices of disability organisations.

## Theoretical Approaches

Having clarified so far our field of analysis, the following section examines relevant theoretical approaches often applied to analyse collective political participation of and for persons with disabilities. Although disability rights activism has not been comprehensively covered by political science, political sociology or NSM theory, there are several theories that can easily be appropriated for investigating the structures and practices of collective political action.

First and foremost, from the political science perspective *political opportunity structures* need consideration. Social movements “cannot escape from the structure of political opportunities and constraints of their own nation-states” and are “particularly prone to respond” to these opportunity structures.<sup>52</sup> This theory implies the idea that collective political participation is not only based on the activities of social movements or the motivations of individual activists, but these should be considered as a reaction on policies and socio-political trends.<sup>53</sup> While the term “opportunity” sometimes is not clearly defined, Lisa Vanhala states that, in contrast to “grievances” or resources,

- 51 Colin Barnes/Geof Mercer: *Exploring Disability*, Cambridge 2010, p. 160; Colin Barnes/Geof Mercer/Tom Shakespeare: *Exploring Disability: A Sociological Introduction*, Cambridge 1999.
- 52 Sidney Tarrow: *Social Movements in Europe: Movement Society or Europeanization of Conflict?*, EUI Working Paper RSC No. 94/8, San Domenico 1994, p. 3.
- 53 Joachim Malleier: *Lobbying für Behinderte*.

opportunities significantly govern the intensity and forms of collective action.<sup>54</sup> The opportunities to mobilise or realise collective political action are determined outside of the group or social movement which generate certain output such as political protests. Gary Marks and Doug McAdam compile existing approaches of political opportunity structures and identify four major dimensions of political opportunities. Additionally, they propose to differentiate between different forms of social movements when studying political opportunity structures.<sup>55</sup> In our own empirical work we are drawing on this perspective by exploring the state of democratic cultures and the openness of the political environments in our country sample. We also use comparative welfare state theory to group our sample of countries, but cannot elaborate on this point in this paper.<sup>56</sup>

There are several studies working with opportunity structures that are relevant for our own research. Malleier focuses on the new political opportunity structures at the level of the European Union with regard to the European Disability Forum (EDF), evaluating the emerging structures of political opportunity as a continuation of national organisational structures.<sup>57</sup> Vanhala widens the concept by adopting a legal opportunity structure approach, claiming that most theories of political opportunity structures neglect the dimension of law and legal structures.<sup>58</sup> Other contributions to the discourse of NSM theory have also paid attention to this research gap.<sup>59</sup> In our study, which is part of the consortium “DISCIT – Making Persons with Disabilities Full Citizens – New Knowledge for an Inclusive and Sustainable Social Model”, we will

54 Lisa Vanhala: *Making Rights a Reality?*, p. 10.

55 Gary Marks/Doug McAdam: *On the Relationship of Political Opportunities to the Form of Collective Action: The Case of the European Union*, in: Donatella della Porta/Hanspeter Kriesi/Dieter Rucht (eds.): *Social Movements in a Globalizing World*, New York 1999, pp. 97–111, pp. 99ff.

56 The selection of countries is based on comparative welfare state theory: Gøsta Esping-Andersen: *The Three Worlds of Capitalism*, New Jersey 1990; Linda J. Cook: *Negotiating Welfare in Postcommunist States*, in: *Comparative Politics* 40:1 (2007), pp. 41–62; J. Menno Fenger: *Welfare Regimes in Central and Eastern Europe: Incorporating Post-Communist Countries in a Welfare Regime Typology*, in: *Contemporary Issues and Ideas in Social Sciences* 3:2 (2007), pp. 1–30. Of the nine countries eight are representing the following welfare regimes: the “Liberal” (Ireland, United Kingdom), the “Conservative” (Germany, Italy), the “Social Democratic” (Norway, Sweden) and “Post-Communist” (Czech Republic, Serbia). Switzerland as the ninth country is used as contrasting case.

57 Joachim Malleier: *Lobbying für Behinderte*, p. 40.

58 Lisa Vanhala: *Making Rights a Reality?*, p. 11.

59 Herbert P. Kitschelt: *Political Opportunity Structures and Political Protest: Anti-Nuclear Movements in Four Democracies*, in: *British Journal of Political Science* 16:1 (1986), pp. 57–84; Hanspeter Kriesi: *New Social Movements in Western Europe: A Comparative Analysis*, Minneapolis 1995.

take up this point and regard the CRPD as a legal opportunity structure, investigating if and how disability organisations use this human rights framework to adjust their activities and strategies, but this analysis is beyond the scope of this paper.

Second, another classic approach in political science is the theory of *resource mobilisation* which primarily deals with the environmental, organisational and financial structures of a social movement or organisation. This approach is helpful to consider, first, the preconditions of mobilisation and formation of political action and, second, the factors that are needed for sustaining operation and successful work in terms of outputs and outcomes.<sup>60</sup> Furthermore, it can be differentiated between external and internal resources, the former implying factors in the environment (such as possibilities to acquire sufficient funding) and the latter covering organisational aspects, such as memberships and their resources.

With regard to membership Nicholas Acheson and Arthur Williamson point out that a major problem for disabled persons is the invisibility of the group as minority, which makes it difficult for them to form collective action.<sup>61</sup> In this respect, the existence of smaller social networks is useful to build a social movement, as these networks can raise group consciousness and support the identification as members of a social minority group or possibly even as activists. Acheson and Williamson also argue that persons with disabilities are dependent on formal welfare arrangements to build social networks as a basis for social movements. Interestingly, welfare institutions can be seen as enabling or hindering resources for disability rights activism, as these structures seem to determine opportunities of collective action for disabled persons, the forms of their actions and the probability of success.<sup>62</sup> More research on this issue is needed to verify this argument.

Furthermore, Daniel Holland, Joachim Malleier, Teodor Mladenov as well as Richard K. Scotch discuss the question of financial resources. Especially with regard to public funding, they raise the question to what extent the independence of disability organisations can be maintained whilst being financed by the state.<sup>63</sup> This aspect is an important reference point when analysing funding strategies of these organisations.

60 John D. McCarthy/Mayer N. Zald: *Resource Mobilization and Social Movements*, p. 1213.

61 Nicholas Acheson/Arthur Williamson: *The Ambiguous Role of Welfare Structures in Relation to the Emergence of Activism Among Disabled People: Research Evidence from Northern Ireland*, in: *Disability & Society* 16:1 (2001), pp. 87–102, pp. 89ff.

62 *Ibid.*, pp. 87ff.

63 Daniel Holland: *The Current Status of Disability Activism and Non-Governmental Organizations in Post-Communist Europe*; Joachim Malleier: *Lobbying für Behinderte*; Teodor Mladenov: *Institutional Woes of Participation*; Richard K. Scotch: *Disability as the Basis for a Social Movement: Advocacy and the Politics of Definition*, in: *Journal of Social Issues* 44:1 (1988), pp. 159–172.

Third, Nancy Fraser's theory of *redistribution and recognition*<sup>64</sup> appears frequently in the literature.<sup>65</sup> This critical and post-structuralist approach is useful to describe both the socio-economic lack of participation as well as the absence of esteem for and of persons with disabilities. Whereas traditional disability organisations have for long concentrated their activities on pursuing the realisation of social benefits and services, the disability rights movement is rather part of the new social movement sector that stands out because of its focus on recognition, like for instance the feminist or gay and lesbian movements. Disability is an issue that can also be considered within this theoretical framework, as disabled persons reclaim recognition instead of mere welfare.<sup>66</sup> But at the same time, especially in the current period of austerity policies in European countries, social rights and thus material claims still matter. Fraser's approach is therefore of interest in order to analyse programmes and public campaigns of disability organisations as to the question whether they claim redistribution or rather strive for recognition.

Last but not least, *framing* as the fourth perspective is of special relevance for social movement theory and also for our field of study. Robert D. Benford and David A. Snow define framing as "an active, processual phenomenon that implies agency and contention at the level of reality construction".<sup>67</sup> This approach focuses on the varying problem or issue interpretations and their impact on the mobilisation within a group or community. Frames determine how individuals and collective actors perceive and understand the surrounding world and everyday life. Expectations and perceptions of individuals and groups are also constructed with regard to existing or evolving norms of what is and what is not acceptable or thinkable.<sup>68</sup> Framing analysis examines how patterns of meaning are developed and established<sup>69</sup> but also "challenged or affirmed, maintained or overturned".<sup>70</sup>

In this understanding, the work of disability rights activism consists at large of framing and reframing activities. These activities can be linked to choices of strategies as the way in which problems and issues are framed by stakeholders may have a direct impact on the respective strategies that seem to be appropriate to foster social change.

64 Nancy Fraser/Axel Honneth (eds.): *Redistribution or Recognition?: A Political-Philosophical Exchange*, London 2003.

65 Ingrid Guldvik/Ole Askheim Petter/Vegard Johansen: *Political Citizenship and Local Political Participation for Disabled People*, p. 76; Agneta Hugemark/Christine Roman: *Diversity and Divisions in the Swedish Disability Movement*, p. 27.

66 Michael Oliver/Colin Barnes: *The New Politics of Disablement*, Basingstoke/New York 2012, pp. 172ff.

67 Robert D. Benford/David A. Snow: *Framing Processes and Social Movements: An Overview and Assessment*, in: *Annual Review of Sociology* 26:1 (2000), pp. 611–639, p. 614.

68 Lisa Vanhala: *Making Rights a Reality?*, p. 30.

69 Robert D. Benford/David A. Snow: *Framing Processes and Social Movements*, p. 613.

70 Lisa Vanhala: *Making Rights a Reality?*, p. 30.



According to Vanhala, frames have determining influence on membership, relationships with other stakeholders as well as on strategies and aims pursued. She concludes that if group identity and framing processes result in members perceived as citizens that bear rights, equality-related goals and strategies (including equality rights and litigation strategies) are more likely to be adopted than if the collective identity is void of the citizenship perspective.<sup>71</sup> In the context of our research the framing approach is fruitful to analyse programmes and activities of disability organisations, for instance to evaluate the relevance of different disability models for the respective identity frames.

In sum, our review of theoretical approaches demonstrates that the academic discourse on disability rights activism, amongst others, draws on rationalist approaches to which political opportunity structures and resource mobilisation belong. Fraser's recognition theory, in contrast, combines critical theory with post-structuralism. In particular, the constructivist approach of framing is frequently used in regard to the analysis of social movements and civil society organisations. All existing concepts have their merits, but overall with regard to theorising disability rights activism they still need elaboration.

## Analysing Disability Organisations: An Integrated Framework

So far, analytical perspectives in political science, political sociology and new social movement theory tend to focus on either structures and resources or (framing) practices, but fail to cover all levels and to explore their intersections. Especially issues, activities and strategies of collective political action of persons with disabilities have barely been touched upon; analysing the external and internal structures of disability rights activism is also rather neglected. To close these research gaps our study is faced with the need of developing our own conceptual framework.

We have coped with this challenge by devising a model for empirical analyses that is both complex and integrated and it aims at covering not only structures *or* activities but both spheres of collective action. Its purpose is to understand interdependencies between national political environments, democratic cultures, welfare regimes and disability rights activism; furthermore it seeks to combine the existing theoretical approaches such as opportunity structures and resource mobilisation as well as the recognition approach and framing analysis.

As a starting point, we draw on structuration theory as general framework as this approach promises to be a productive means to deal with all these aspects and to differentiate between formal structures and actual practices within disability rights

71 *Ibid.*, pp. 31ff.

activism.<sup>72</sup> It also acknowledges the two dimensions of *being structured* as well as *structuring*, therefore allowing to analyse both commonalities and differences between disability rights activisms among different welfare states and also taking the temporal dimension, the question of change into account.

This approach implies that collective political participation is not one-dimensionally determined by opportunity structures that prevail within a certain political context (for example a nation state and its welfare regime, the European Union etc.). Rather, political and legal opportunity structures for disability rights activism constantly change over time due to the impact of collective political action. In other words, they are results of activities. The same applies to organisational structures and resources. Vice versa, practices within and of collective political action, such as framing activities and exercising influence, are not one-dimensionally determined either, as practices are shaped by the structures that enable or hinder certain forms of action. Therefore, structures and practices are mutually interrelated, implying the question which potential actions are needed to reproduce and change structures over time and how structures influence or establish practices. This means that structures and practices are not only interrelated but may evoke change which in turn leads to outcomes that affect both structures and practices. Consequently, in our research we intend to think in circles and processes instead of only assuming fixed structures resulting in pre-determined actions.

As a heuristic device we use Bjørn Hvinden and Rune Halvorsen's version<sup>73</sup> of Rob Stones' framework of structuration theory, which includes the dimensions of structures, practices and outcomes.<sup>74</sup> This version, which guides the coordinated research of the DISCIT consortium, is targeted at analysing disabled persons' exercise of Active Citizenship mainly on the individual level. For the purpose of fitting this proposal to our research we have adapted the dimensions to the study of collective political participation as follows. The dimension of structure was substantiated as national structures (polity and policies) and organisational structures. The dimension of social practice with regard to individual agency was replaced by a more general dimension that refers to collective policies and politics exercised by disability organisations. Lastly, outcomes

72 Rob Stones: Structuration Theory; Dave Elder-Vass: The Causal Power of Social Structures; Karen O'Reilly: International Migration and Social Theory.

73 Active Citizenship for Persons with Disabilities: Current Knowledge and Analytical Framework: A working paper of the EU research consortium DISCIT (Making Persons with Disabilities Full Citizens – New Knowledge for an Inclusive and Sustainable European Social Model), public report published on 31 August 2013, available online at: [https://dl.dropboxusercontent.com/s/u489iqm4x6wz1e9/DISCIT%20D2\\_1%20Active%20Citizenship%20for%20persons%20with%20disabilities\\_October%202013.pdf](https://dl.dropboxusercontent.com/s/u489iqm4x6wz1e9/DISCIT%20D2_1%20Active%20Citizenship%20for%20persons%20with%20disabilities_October%202013.pdf) (accessed on 5 August 2014), p. 35 ff.

74 Rob Stones: Structuration Theory.

on the collective level are understood as issues of polity, policies and politics. With this framework, which ties political and legal opportunity structures, resource mobilisation and framing activities together, we are able to pose the following questions:

- What are the national, political and legal *opportunity structures* for disability rights activism that enable or constrain possibilities to achieve full political participation in society?
- What are the *organisational structures and resources* of disability organisations that enable or constrain possibilities to achieve full political participation in society?
- What are the *practices* (framing and other activities, issues and strategies) exercised by disability organisations to gain influence on behalf of persons with disabilities and secure full and effective participation in society for their constituencies?
- What are the *outcomes* (structures and practices) of disability rights activism to achieve full participation in society for persons with disabilities?

As this paper is written against the background of ongoing research, we are not yet able to present final results. So far, our research has focused on established structures, practices and patterns of political participation and representation for and of persons with disabilities in nine European countries (Czech Republic, Germany, Italy, Ireland, Norway, Serbia, Sweden, Switzerland, United Kingdom). On the basis of documentary analyses and structured national reports from our research partners, we conducted a cross-national comparison of disability rights activism.<sup>75</sup>

The scope of this paper demands that we concentrate on a particular issue. Our literature review indicates that the issue of (self-)representation, i.e. the question of who is exercising influence on behalf of persons with disabilities, is highly relevant not only for those concerned but also as an indicator of disability organisations' commitment to the disability rights movement. Thus, we will present some empirical findings on this particular subject in the last part of this paper. We intend to show that if one wants to explore this issue, not only framing processes but also organisational structures need to be considered. In other words, an integrated approach should be applied. But before that, it is necessary to explore the relevance of identity management, group consciousness and identity politics for disability rights activism.

75 In the following, we refer to the national reports of our project partners using abbreviated references, such as DISCIT-DE for the German or DISCIT-IT for the Italian national report. Each national report is divided into the specific parts A and B and several subsections. For further information on the method and structure of the reports, please consider the respective section of our working paper: Anne Waldschmidt et al.: A Comparative Analysis of Disability Rights Activism, pp. 44–46.

## Individual Identities and Group Consciousness

For new social movements, the issue of identity politics is crucial. In our field of analysis this point is also regarded as highly relevant. To begin with, we consider individual identities and their relevance for political involvement. Various studies emphasise the importance of personal perceptions of oneself as (being) disabled as a constitutive factor that promotes or hinders political participation. Secondly, we take up the issue of collective identities as shared understandings of a group, the making of a “disabled we”.<sup>76</sup> With regard to the first aspect, Scotch discusses the role of identity for disabled persons by raising the following point:

Those individuals best able to reject the disabled role may refuse to identify themselves as disabled, thus avoiding political involvement as a disabled person. On the other hand, those individuals who accept the role are at risk of accepting its handicapping connotations of dependency and thus also avoiding political involvement.<sup>77</sup>

But if this argument was right, there would have been no disability rights activism at all. In contrast, it is conceivable that persons who refuse to accept the disabled role for political reasons may still actively engage in politics due to their views and experiences that they share with those identifying as disabled. Further, persons with disabilities accepting this role may also refer to disability as social oppression and participate actively while at the same time dismissing any handicapping connotations of dependency. Therefore, Scott argues for a redefinition of disability that stresses that persons with disabilities are independent persons and potentially interested in politics.<sup>78</sup>

Shakespeare, referring to the process of identification, also points out the importance of an understanding of disability that focuses on the structural causes of disability instead of blaming the victim.<sup>79</sup> Further, Shakespeare discusses the argument that disability has less unifying impact than other categories like race or gender. He remarks that in contrast to other oppressed groups, such as women or gay persons, it might particularly be difficult for persons with impairments to recognise the fact that they are socially oppressed as disability is often naturalised and understood as an individual issue. He adds that welfare and medicine have the tendency to split up disabled persons,

76 Cristina Flesher Fominaya: *Collective Identity in Social Movements: Central Concepts and Debates*, in: *Sociology Compass* 4:6 (2010), pp. 393–404.

77 Richard K. Scotch: *Disability as the Basis for a Social Movement*, p. 162.

78 *Ibid.*, pp. 162f.

79 Tom Shakespeare: *Disabled People’s Self-Organisation*, pp. 253ff.

separating this constituency into arbitrary groups, such as older and younger persons or persons with physical impairments and those with intellectual disabilities etc. These divides potentially hamper the unity in political struggle.<sup>80</sup>

From these viewpoints, personal definitions of disability are essential for the motivation to get politically engaged. Lisa Schur, Douglas Kruse and Peter Blanck show how individual identities and involvement in collective forms of political actions are intertwined. They describe how (non-)identification with other persons with disabilities promotes or hinders the chance to get politically engaged.<sup>81</sup> They sketch three ideal types of actors depending on their perspectives on disability. First, there are the “fatalists”, persons with a lack of self-efficacy who have given up the hope for change. Many persons with disabilities refuse to identify with other disabled persons due to this image of helplessness. Second, there are “normalisers” who stand out for trying to minimise or rationalise the stigmata related to disability. Schur et al. state that these persons might engage politically but are less inclined to political engagement for disability issues. The third group is called “activists”; these are persons with disabilities who have a large sense of self-efficacy and identify with other disabled persons; for these reasons they are likely to get engaged politically.<sup>82</sup>

With regard to preconditions for political commitment, Ethel Klein identifies three stages that motivate individuals to develop political consciousness.<sup>83</sup> As a first step, a person should become a member of the respective group that shares certain interests. Following this, the marginal status of this group in society needs to be put into question and refused. As a last step, specific personal problems should be understood not as an individual burden, but as consequences of structures and conditions, institutions and, last but not least, of social inequality. According to Klein it is self-evident that self-blaming processes prevent persons from starting political unrest. Therefore “group consciousness” is essential for political engagement. It is a necessary but not sufficient condition for the emergence of social movements. Group consciousness is evolving when members share experiences and develop a common understanding of the group’s concerns, such as political inequality and discrimination.<sup>84</sup>

Finally, the debate deals with the linkage between individual identities and collective identity frames. The interdependency of individual and collective identities is discussed in various studies. Charlton adopts a Marxist perspective on consciousness with regard to identity by claiming that the lack of a common identity among disabled persons

80 Ibid, pp. 255f.

81 Lisa Schur/Douglas Kruse/Peter Blanck: *People with Disabilities: Sidelined or Mainstreamed?*, Cambridge/New York 2013, pp. 92ff.

82 Ibid., pp. 95ff.

83 Ethel Klein: *Gender Politics: From Consciousness to Mass Politics*, Cambridge 1984, p. 3.

84 Ibid., pp. 2ff.

is the principal reason that restricts the potential of the disability rights movement.<sup>85</sup> Shakespeare positions identity in a broader context assuming that identity politics is a precondition that fosters the growth of group consciousness and thus leads to the formation of a new social movement.<sup>86</sup> Oliver and Barnes point out the importance of disability definitions both for the individual and for group identity.<sup>87</sup> They stress that a “positive cultural identity” is of high importance for protest movements.<sup>88</sup>

We take the arguments by Shakespeare and Oliver and Barnes as inspiration for our next step. These authors contend that the development of disability awareness and political consciousness provide the means to refuse victim labels in favour of focusing on societal causes of victimisation and becoming active in the disability rights movement.<sup>89</sup> In other words, collective identity politics has been and is essential for both, the mobilisation of disabled persons and effective disability rights activism.

## Identity Politics and Different Models of Disability

McColl and Boyce’s study on conflicts about representational issues within disability organisations also indicate the importance of recognisable collective identities.<sup>90</sup> However, as Agneta Hugemark and Christine Roman state, when the movement continues to grow, group identities become diversified and more heterogeneous.<sup>91</sup> Closely linked to the debates about the shared “we” of disabled people and the identity of the disability movement is the issue of disability models. Strikingly, many publications on disabled persons’ political participation highlight the importance of the social model of disability which seems to be the heart and basis of disability rights activism. Yet, this model has experienced and is still facing serious competition from other approaches. From a theoretical perspective, we consider framing processes here. When we examine different models of disability as collective identity frames, we can identify at least five concepts which are frequently used. How relevant are these identity frames for disability rights activism?

Due to the fact that the *individual or medical model* of disability situates disability solely in physical, cognitive or psychic conditions of the disabled person, criticism of society as a disabling factor is mostly lacking in works using this kind of approach. If

85 James I. Charlton: *Nothing About Us Without Us*, p. 78ff.

86 Tom Shakespeare: *Disabled People’s Self-Organisation*.

87 Michael Oliver/Colin Barnes: *The New Politics of Disablement*, pp. 14ff.

88 *Ibid.*, p. 171f.

89 Tom Shakespeare: *Disabled People’s Self-Organisation*, pp. 253ff.

90 Mary Ann McColl/William Boyce: *Disability Advocacy Organisations*.

91 Agneta Hugemark/Christine Roman: *Diversity and Divisions in the Swedish Disability Movement*, p. 38.

any, organising in self-help groups for mutual support in the everyday life with chronic ailments is conceivable from the individual model. There are many impaired-specific self-help groups as well as pressure groups – especially DAOs and SPOs – that adhere to this model, while the disability rights movement has right from the start sharply distanced itself from this approach.

In contrast, this social movement has created the *social model* of disability which enables the perception of those societal conditions that are hampering participation in general and with regard to the political realm. Newly developed during the 1970s, this model stresses that persons with disabilities are a social minority group experiencing social oppression and discrimination in and by society. In addition, the social model demands to recognise the expertise, self-help potential and experiences of persons with disabilities.<sup>92</sup> Thus, as “political disability identity”,<sup>93</sup> it provides the basis for emancipation from heteronomy and paternalism. Regarding collective political action, it is conspicuous that disability rights activism is closely linked to the social model of disability, whereas the medical (respectively individual) model is broadly depreciated.<sup>94</sup> Thus, distance to or preference for the social model can be used in empirical analysis as a cornerstone for deciding whether a specific organisation is to be regarded as a DMO or not.

In spite of its relevance, the social model is also frequently criticised.<sup>95</sup> Amongst others, Werner Schneider and Anne Waldschmidt emphasise that this model implies that impairment remains naturalised – as an object of the bio-medical realm – and therefore outside of political activism, since a deconstruction of impairment is said to risk the capacity for political actions of disabled people.<sup>96</sup> Nevertheless, some authors promote a de-constructionist *cultural model* of disability.<sup>97</sup> The cultural model of disability

92 Active Citizenship for Persons with Disabilities: Current Knowledge and Analytical Framework: A Working paper of the EU research consortium DISCIT, public report published on 31 August 2013.

93 Michelle Putnam: Conceptualizing Disability.

94 Lisa Schur/Douglas Kruse/Peter Blanck: People with Disabilities, pp. 8f.; Jerome E. Bickenbach: Ethics, Law, and Politics, pp. 10ff.; Paul K. Longmore: Disability Rights Movement; ; Angharad E. Beckett: Citizenship and Vulnerability: Disability and Issues of Social and Political Engagement, Basingstoke 2006, pp. 95f.; Anne Waldschmidt: Disability Studies: Individuelles, soziales und/oder kulturelles Modell von Behinderung?, in: Psychologie & Gesellschaftskritik 29:1 (2005), pp. 9–31, pp. 15f.

95 See for example Bill Hughes: Disability Activisms: Social Model Stalwarts and Biological Citizens, in: Disability & Society 24:6 (2009), pp. 677–688.

96 Werner Schneider/Anne Waldschmidt: Disability Studies, in: Stephan Moebius (ed.): Kultur: Von den Cultural bis zu den Visual Studies: Eine Einführung, Bielefeld 2012, pp. 128–150, pp. 139f.; Leanne Dowse: Contesting Practices, Challenging Codes, pp. 135–138.

97 Angharad E. Beckett: Reconsidering Citizenship in the Light of the Concerns of the UK Disability Movement, pp. 115f.; Patrick Devlieger: Politics of Disability, p. 71; Anne



highlights the relativity of disability, which is understood differently throughout time and within different countries. It can add the dimension of cultural representation to the claims of social benefits, civil and human rights. Hence, it explicitly links the collective actions of disabled people with NSM approaches,<sup>98</sup> but so far this model just plays a marginal role in disability rights activism.

More recently, the *human rights model* of disability has been developed. Like the social model, it places responsibility for disability-related problems on society rather than on the disabled individual. It can be viewed as a variant or further stage of the older social model and is based on recent innovations in international politics. Adopted by the United Nations' General Assembly in December 2006, the Convention on the Rights of Persons with Disabilities (CRPD) is the path breaking result of the struggle for a human rights approach that explicitly acknowledges disability-specific needs and issues. With the Convention, it has internationally been acknowledged that general human rights are of crucial importance when it comes to disability: the human rights model stresses that persons with disabilities own human dignity and are citizens – without ifs and buts – and, as such, have the same rights as everybody else.<sup>99</sup> Indeed, this model is likely to dominate the disability rights agenda for years to come. As a consequence, understanding disability as a human rights issue could become the future collective action frame for disability rights activism, but until now the social model of disability still seems to be more dominant.

Last but not least, the advocacy for a more inclusive and broader disability rights movement can also be observed in recent publications.<sup>100</sup> This position includes the idea of a *universal model* of disability.<sup>101</sup> A broad understanding of disability emphasises the fact that everybody might face discrimination, barriers and unequal access or treatment from time to time. Disability is regarded not as a minority issue but quite the opposite, as a “universal experience of humanity”.<sup>102</sup> Hence, this model makes a point for general claims acknowledging commonalities with and among persons who might not identify as disabled.<sup>103</sup> However, the universal model bears the risk that the

Waldschmidt: Disability Studies, pp. 24f.

98 Anne Waldschmidt: Disability Studies, p. 27.

99 Bryan S. Turner: Citizenship and Civil Rights, in: Gary L. Albrecht (ed.): Encyclopedia of Disability, Thousand Oaks/London/New Delhi 2006, pp. 264–274, p. 272.

100 Paul K. Longmore: Disability Rights Movement, p. 285; Bonnie O'Day/Marcie Goldstein: Advocacy Issues and Strategies for the 21st Century.

101 Lisa Schur/Douglas Kruse/Peter Blanck: People with Disabilities, pp. 12f.; Paul K. Longmore: Disability Rights Movement, p. 285.

102 Lisa Schur/Douglas Kruse/Peter Blanck: People with Disabilities, p. 13.

103 Ibid., p. 13.

interests of disabled persons could become even more marginalised because the specific discrimination is rendered invisible. Probably for this reason, disability rights activism has so far refrained from adopting this approach.

While the implications of all disability models may stimulate and influence disability rights activism in European countries, our literature review comes to the conclusion that international disability rights activism still mainly refers to the social model of disability. The relevance of this model as a dominant frame is highlighted in many publications.<sup>104</sup> As the social model implies a notion of political participation that aims at overcoming social oppression, it “may be the most effective way to unite people across disabilities and help mobilize them to fight for antidiscrimination and equal rights legislation”.<sup>105</sup> As mentioned above, a key feature of the social model of disability is “the centrality of the voices of disabled people” echoed in the slogan “Nothing About Us Without Us”.<sup>106</sup>

## National Assemblies Representing Disability Organisations: A Comparative Analysis

An important factor for gaining success in the fight for political participation is the capacity to form alliances. In our sample we can witness this capacity: Nearly all countries have experienced a coalition building process resulting in national assemblies of various disability organisations. How is the social model of disability influencing the structures and practices of this mode of disability rights activism? One of the social model’s key claims and thus an essential element of “political disability identity”<sup>107</sup> is the demand for self-representation, i.e. its proponents argue that persons with disa-

104 Diane F. Stroman: *The Disability Rights Movement: From Deinstitutionalization to Self-Determination*, Lanham/New York/Oxford 2003, pp. 14f.; Yari Colon/Christopher B. Keys/Katherine E. McDonald: *Advocacy*, in: Gary L. Albrecht (ed.): *Encyclopedia of Disability*, Thousand Oaks/London/New Delhi 2006, pp. 42–50, p. 45; Patrick Devlieger: *Politics of Disability*; Richard K. Scotch/Kay Schriener: *Politics of Disability*; Michelle Putnam: *Conceptualizing Disability*; Jerome E. Bickenbach: *Ethics, Law, and Politics*, pp. 10f.

105 Lisa Schur/Douglas Kruse/Peter Blanck: *People with Disabilities*, p. 13.

106 Len Barton: *The Disability Movement: Some Observations*, in: John Swain et al. (eds.): *Disabling Barriers: Enabling Environments*, 2<sup>nd</sup> ed., London/Thousand Oaks/New Delhi 2004, pp. 285–290.

107 It is surprising that Michelle Putnam, when conceptualising her framework for “political disability identity”, of all things does not consider this aspect.

bilities are experts in their own cause and should have the say in their organisations as well. In the following, we explore structures and practices of national assemblies of disability organisations with regard to this particular issue.

To avoid misunderstandings, with this object of inquiry we do not deal with disability organisations as member organisations, but only with superior forms of cooperation among these organisations.<sup>108</sup> For terminological consistency, we will use the term “national assembly of disability organisations” for all forms of alliances, coalitions or councils of disability organisations, involving disability movement organisations (DMOs) as well as disability advocacy organisations (DAOs) and service provider organisations (SPOs), which have the purpose of working together towards the realisation of disability rights on the national level.<sup>109</sup>

At first sight, the pluralism of national cooperation structures becomes obvious in the differing terms for the disability assemblies: while Germany, the United Kingdom and the Czech Republic call their national assembly of disability organisations “council”,<sup>110</sup> Norway and Sweden prefer the term “federation”,<sup>111</sup> whereas Italy uses the term “forum”.<sup>112</sup> Serbia calls its disability assembly “National Organisation of Persons with Disabilities”,<sup>113</sup> while Ireland reports that there is none, but states that other structures are established to guarantee the political involvement of persons with disabilities and their organisations (such as the National Disability Authority).<sup>114</sup> Equally, Switzerland reports that there is no disability council or a similar institution on the national level.<sup>115</sup>

Usually, a national alliance of disability organisations gets involved in supranational contexts as well. For reasons of comparison, we therefore use the European Disability Forum as main source for the listing of the national assemblies for persons with disabilities and their organisations:

108 Unfortunately, what concerns national disability organisations the reports of our consortium partners resulted in a very diverse mass of data, which we have so far not been able to review and analyse in detail. Both this mapping and our comparative analyses are part of ongoing research.

109 There are, however, major differences in terms of the possibilities and limits of collective action depending on the legal form of the national assemblies representing disability organisations as delineated in their statutes. This disparity is still subject to ongoing research and results are not yet presentable.

110 DISCIT-DE: A.7; DISCIT-UK: A.7; DISCIT-CZ: A.7.

111 DISCIT-NO; DISCIT-SE.

112 DISCIT-IT: A.7.

113 DISCIT-RS: A.7.

114 DISCIT-IE: A.7.

115 DISCIT-CH: A.7.

*Table 1: European Countries and their National Assemblies  
Representing Disability Organisations*

Country Code	National assemblies representing disability organisations	Established in	Official number of member organisations
<b>DE</b>	<b>Deutscher Behindertenrat</b> (DBR) [German Disability Council] <sup>116</sup>	1999	46
<b>IT</b>	<b>Forum Italiano sulla Disabilità</b> (FID) [Italian Disability Forum] <sup>117</sup>	2008	17
<b>UK</b>	<b>United Kingdom Disabled People's Council</b> (UKDPC) <sup>118</sup>	1981	80
<b>IE</b>	<b>Disability Federation Ireland</b> (DFI) <sup>119</sup>	2000	>130
<b>NO</b>	<b>Funksjonshemmedes Fellesorganisasjon</b> (FFO) [Norwegian Federation of Organisations of Disabled People] <sup>120</sup>	1950	75
<b>SE</b>	<b>Handikappförbunden</b> (HSO) [Swedish Disability Federation] <sup>121</sup>	1942	39

116 Deutscher Behindertenrat: Wir über uns 2012, available online at: <http://www.deutscher-behindertenrat.de/ID25034> (accessed on 5 August 2014).

117 Giuliano Giovanazzo: Nasce il Forum Italiano sulla Disabilità, per parlare con l'Europa 2008, published on 8 July 2008, available online at: <http://www.superando.it/2008/07/11/nasce-il-forum-italiano-sulla-disabilita-per-parlare-con-leuropa/> (accessed on 5 August 2014); Email-correspondence with Giampiero Griffò, member of the FID: Giampiero Griffò: R: Questions regarding your comments on D9.1, unpublished email correspondence, 16 January 2014.

118 United Kingdom Disabled People's Council: About Us, undated, available online at: <http://www.ukdpc.net/site/about-us> (accessed on 5 August 2014).

119 Disability Federation of Ireland: Annual Review of the Disability Federation of Ireland 2012, published on 31 December 2012, available online at: <http://www.disability-federation.ie/index.php?uniqueID=10705> (accessed on 5 August 2014); Company Registration Office: Company Search: National Federation of Voluntary Bodies Providing Services to People With Intellectual Disability Limited, undated, available online at: <http://www.cro.ie/search/CompanySearch.aspx> (accessed on 5 August 2014).

120 Frivillighet Norge: Funksjonshemmedes fellesorganisasjon: Frivillighet Norge, undated, available online at: [http://www.frivillighetnorge.no/no/om\\_oss/vare\\_medlemmer/interesseorganisasjoner/funksjonshemmedes\\_fellesorganisasjon/](http://www.frivillighetnorge.no/no/om_oss/vare_medlemmer/interesseorganisasjoner/funksjonshemmedes_fellesorganisasjon/) (accessed on 5 August 2014); Funksjonshemmedes Fellesorganisasjon: FFO – Medlemsorganisasjoner, undated, available online at: <http://www.ffe.no/Medlemsorganisasjoner/> (accessed on 5 August 2014).

121 Handicappförbunden: The Swedish Disability Federation: 37 Swedish Disability Organisations in Co-Operation, in English: HSO, undated, available online at: <http://www.hso.se/vi-ar-handicappforbunden/In-English> (accessed on 5 August 2014).

<b>CZ</b>	<b>Národní rada osob se zdravotním postižením</b> (NRZP) [Czech National Disability Council] <sup>122</sup>	2000	117
<b>RS</b>	<b>Nacionalna organizacija osoba sa invaliditetom Srbije</b> (NOOIS) [National Organisation of Persons with Disabilities of Serbia] <sup>123</sup>	2007	15
<b>CH</b>	(not represented in EDF)	–	–

Comparing the founding years of the national disability assemblies,<sup>124</sup> one finds that the Italian Disability Forum is the most recent formation, which is the result of the merging of two already existing councils that lobbied for CRPD ratification by the Italian government.<sup>125</sup> At the other end of the spectrum, the British council has been established over 30 years ago, and the Norwegian and Swedish national assemblies can look back to even over 60 years of experience, whereas the national assemblies of Germany, Ireland and the Czech Republic all of whom were established by the turn of the century occupy the mid-range. Although it is somewhat early for conclusions, we believe that the histories of the assemblies could be an indication of the power or weakness of the national social movements of disabled people. Our tentative hypothesis, which we need to review at a later stage of research, is that the older the national assemblies are, the less relevant is the identity frame of the disability rights movement.

Additionally, the number of member organisations which are represented in the national institutions varies notably: while four of them do not incorporate more than 50 disability organisations respectively their umbrella organisations (the German DBR,

122 Czech National Disability Council: Czech National Disability Council, 2010, available online at: <http://www.nrzp.cz/czech-national-disability-council.html> (accessed on 5 August 2014).

123 Nacionalna Organizacija Osoba sa Invaliditetom Srbije: English: Nacionalna Organizacija Osoba sa Invaliditetom Srbije, 2012, available online at: <http://www.noois.rs/english> (accessed on 5 August 2014).

124 It is remarkable that in the European countries covered by our study all existing national assemblies have been established before the ratification of the CRPD was completed by the respective states. By this step the countries commit themselves to implement the Convention's principles amongst which the political participation of disabled people is essential. Of our country sample, Sweden has ratified the CRPD in 2008 and the Czech Republic, Germany, Italy, Serbia and the United Kingdom have done so in 2009. Norway ratified the Convention in 2013, Switzerland in 2014. Ireland signed in 2007, but has not yet ratified the CRPD. See: United Nations: Ratifications and Signatories of the Convention and its Optional Protocol, undated, available online at: <http://www.un.org/disabilities/countries.asp> (accessed on 5 August 2014). However, the intersections between CRPD ratification and disability rights activism on the national level need further exploration and cannot be discussed in this paper.

125 Giuliano Giovino: Nasce il Forum Italiano sulla Disabilità.

the Italian FID, the Swedish HSO and the Serbian NOOIS), two national assemblies are ranked in the medium group with 75 (the Norwegian FFO) and 80 (the British UKDPC) disability organisations and their umbrella organisations. Further, the Czech NRZP and the Irish DFI even incorporate more than 100 organisations and their umbrella organisations. What emerges from these findings? We regard the amount of member organisations as an evidence of the degree of organisational fragmentation. One can presume that the national assemblies with the highest amount of member organisations place greater value on the representation of less influential organisations (e.g. local organisations) than those with a lower number of member organisations which apparently prefer the gathering of the most important umbrella organisations in their countries. This assumption can be substantiated by having a look at the membership structures as determined by the admission requirements in the statutes of the national assemblies.

The statutes of the four national assemblies with the least number of member organisations (the German DBR, the Italian FID, the Swedish HSO and the Serbian NOOIS) all require their affiliate member organisations to be represented in a certain amount of states or regions of their country, and in three of these four cases (with the Italian FID being the exception) the statutes even stipulate a minimum size of its member organisations: The member organisations of the German DBR are to be represented in at least five (out of 16) federal states and have to have at least 750 members.<sup>126</sup> The member organisations of the Swedish HSO need to have local associations in at least half of Sweden's federal states and/or regions and have to comprise at least 1,000 members,<sup>127</sup> whereas the Serbian NOOIS expects its member organisations to have at least five local and regional subdivisions and to comprise at least 500 members.<sup>128</sup> The statute of the Italian FID requires its member organisations to have offices in at least 90 per cent of Italy's regions,<sup>129</sup> but it does not demand a minimum size. The statute of the Norwegian FFO (with 72 member organisations) solely expects their

126 Deutscher Behindertenrat: Statut des Deutschen Behindertenrats, published on 3 December 2013, available online at: <http://www.deutscher-behindertenrat.de/ID25199> (accessed on 5 August 2014).

127 Handikappförbunden: Stadgar – HSO, published on 9 May 2011, available online at: <http://www.hso.se/vi-ar-handikappforbunden/Var-organisation/Stadgar/> (accessed on 5 August 2014).

128 Nacionalna Organizacija Osoba sa Invaliditetom Srbije: Statut – Nacionalna Organizacija Osoba sa Invaliditetom Srbije, published in 2010, available online at: <http://www.noois.rs/statut> (accessed on 5 August 2014).

129 Forum Italiano Sulla Disabilità: Statuto, published in 2008, available online at: [www.uiciechi.it/AttivitaInternazionali/StatutoFid.doc](http://www.uiciechi.it/AttivitaInternazionali/StatutoFid.doc) (accessed on 5 August 2014).

member organisations to be “open for members from the whole country”,<sup>130</sup> whereas the three national assemblies with the highest amount of member organisations – the British UKDPC, the Irish DFI and the Czech NRZP – do not have any of these requirements.<sup>131</sup>

As outlined above, a main point of interest in our research are the ways of (self-) representation of persons with disabilities in the assemblies. To what extent do these national bodies follow the slogan “Nothing About Us Without Us” and hence the identity frame of the disability rights movement? To begin with, we have to differentiate between three types of self-representation.

First, self-representation can be understood as the formal status of membership within an organisation. Second, self-representation cannot simply imply solely formal embeddedness in organisations but also the opportunity to exercise influence. Third, self-representation may be practised at the level of hierarchies, which means holding important positions and thus being able to exert influence more directly and effectively. We will just refer to the first type of self-representation for feasibility reasons in our analysis. Notwithstanding, it would be of major interest to investigate the two other types of self-representation as they go far beyond formal representation, but due to lack of data this point has to be investigated elsewhere.

When having a closer look at the admission requirements for membership in the assemblies, a broad spectrum of different practices is revealed, ranging from very liberal approaches (as in the case of the Irish DFI) to approaches with comparably strict determination of quotas (as in the case of the British UKDPC).<sup>132</sup> We can divide the national assemblies into four groups regarding the quality of the representation requirements which their member organisations have to meet:

1. *No explicit representation requirements:* The statutes of the national assembly representing disability organisations are not explicit on the representation of persons with disabilities in their member organisations.

130 Funksjonshemmedes Fellesorganisasjon: FFOs vedtekter – vedtatt, published on 24 November 2013, available online at: <http://www.ffa.no/Organisasjonen/Vedtekter/> (accessed on 5 August 2014).

131 United Kingdom Disability Council: New Articles of Association, published in November 2010, available online at: [http://www.ukdpc.net/site/images/New\\_Articles\\_of\\_Association\\_-\\_Nov\\_2010.doc](http://www.ukdpc.net/site/images/New_Articles_of_Association_-_Nov_2010.doc) (accessed on 5 August 2014); Disability Federation of Ireland: Membership Strands and Eligibility, 2008, available online at: <http://www.disability-federation.ie/index.php?uniqueID=139> (accessed on 5 August 2014); Národní rada osob se zdravotním postižením: Stanovy – Národní rady osob se zdravotním postižením české republiky, 2010, available online at: [http://www.nrzp.cz/images/PDF/stanovy\\_nrzp\\_cr\\_2010.pdf](http://www.nrzp.cz/images/PDF/stanovy_nrzp_cr_2010.pdf) (accessed on 5 August 2014).

132 For detailed overview of classification see Table 2 in the appendix.



2. *Low representation requirements*: Member organisations are required to guarantee that persons with disabilities and/or persons close to them (i.e. relatives and other supporters) have influence in their organisation but the statutes of the national assembly do not stipulate quotas.
3. *Moderate representation requirements*: Member organisations are required to guarantee that persons with disabilities and/or persons close to them make up the majority of their members.
4. *High representation requirements*: Member organisations are required to guarantee that (solely) persons with disabilities make up the majority of their members (i.e. relatives and supporters are not included in the respective passage on representation requirements).

According to these criteria we differentiate our sample as follows (for details see Tab. 2 in appendix). Of the eight countries in which national disability alliances exist, Ireland stands out for having no specific requirements on (self-)representation. Norway and Serbia have a low profile in this respect, whereas four countries (Germany, Italy, Sweden, the Czech Republic) exhibit the use of some representational criteria in favour of disabled persons, but the United Kingdom is the only country in which the national disability assembly is established on the principle “Nothing About Us Without Us”. In actual fact, it is no accident that the British assembly strictly follows the identity frame of the disability rights movement as it was founded by DMOs with the explicit objective to be an opponent of existing charities and DAOs.<sup>133</sup> In contrast, the German Disability Council was set up by both conventional DAOs and DMOs as a result the representation requirements reflect a compromise. Similarly, in the case of the Czech Republic as a post-communist country, we assume with Holland that for historical reasons the set-up of this assembly followed a consensus rather than a conflict model.<sup>134</sup> In general it seems that parents’ associations have great influence in nearly all considered national assemblies. In countries with low or no regulations for (self-)representation, service provider organisations may have a say, but we can only speculate here, as sufficient information for empirically based conclusions on these cases is still insufficient.

Even though the presented formal requirements of the national assemblies provide so far only limited evidence about the actual representativeness of its member organisations, we believe that they offer insight to what extent the national disability

133 The British assembly started in 1981 as “British Council of the Organisations of Disabled People” (BCODP) and was later renamed (see for details Tom Shakespeare: *Disabled People’s Self-Organisation*, p. 253–254).

134 Daniel Holland: *The Current Status of Disability Activism and Non-Governmental Organizations in Post-Communist Europe*, p. 548.

organisations have incorporated the principle of self-representation. In this regard, a relevant question is how an organisation qualifies as “representative” and is thus legitimised to act on behalf of disabled persons. It is self-evident that self-representation and legitimacy are closely connected, but what about disability organisations that are composed mainly of persons *without* disabilities? Or, in other words: Advocacy organisations of parents or service provider organisations are certainly important collective actors in disability politics. In the case of parents’ associations it is important to note that they are representing the interests of minors, i.e. their own children. Yet, from the perspective of identity politics and with regard to the initial concern of the disability rights movement, i.e. its fight against paternalism and for individual autonomy, it is questionable whether these two types of organisations are entitled to be called “disabled people’s organisations” (DPOs) in the strict sense of the term. Our suggestion is that for these organisations the more general expression “disability policy organisation” would be more appropriate, whereas the name “disabled people’s organisations” should be reserved to disability organisations “comprised by a majority of persons with disabilities – at least half of its membership –, governed, led and directed by persons with disabilities”.<sup>135</sup>

Additionally, it is critically remarked in the Czech and the Serbian national reports that especially persons with intellectual and psycho-social difficulties are eminently underrepresented in their national coalitions.<sup>136</sup> It is our impression that this may also be the case in the other countries. Dowse’s study on the marginal involvement of people with learning difficulties in the British disability movement confirms this line of thought.<sup>137</sup> We could not yet advance our analysis in this direction, but our findings already underline the importance of further investigation on this issue, also with special regard to the self-representation of persons with restricted legal capacity.

## Conclusions

Over the last thirty years, disability rights activism has gradually become a common feature in European societies. Under the principle “Nothing About Us Without Us” social movements of disabled people have succeeded to gain considerable influence in disability-related politics despite the fact that they are representing a social minority

135 Office of the High Commissioner for Human Rights: CRPD/C/11/2, Annex II: Guidelines on the Participation of Disabled Persons Organizations (DPOs) and Civil Society Organizations in the work of the Committee, undated, available online at: <http://www.ohchr.org/Documents/HRBodies/CRPD/guidelinesDisabledPersons...> (accessed 02 June 2015).

136 DISCIT-CZ: A.6; DISCIT-RS: A.6.

137 Leanne Dowse: *Contesting Practices, Challenging Codes*.

group with only weak interests. Today disabled people's organisations and disability policy organisations are prominent players in disability policies, not only in European countries, but also worldwide and at supranational levels of governance. Our literature review shows that despite the relevance of this part of organised civil society substantial knowledge is still lacking. Disability models, identity politics, theories and typologies of collective action of persons with disabilities are in the centre of the discourse. However, there is no comprehensive knowledge on political and legal frameworks for the political action of and for disabled persons. Neither are extensive cross-national research findings available. And there are only few studies on organisational structures, memberships, philosophies and procedures of national disability organisations and their networks at national and international levels. Discussing established theories, such as opportunity structures, resource mobilisation, framing and recognition, this paper aimed at systematising the field in terms of clear definitions and developing an analytical framework that integrates both rationalist and constructivist approaches as well as the perspectives of structures and practices.

In the current debates on different models of disability, identity politics and typologies of disability rights activism the issue of who is representing whose interests occupies a prominent role. Our empirical analysis of national disability assemblies in nine European countries brought to the fore that organisational structures are heterogeneous and representation practices also diverge greatly. Although the social model of disability and its demand of self-representation seems to be the dominant identity frame of current disability rights activism, there is still a long way to go when it comes to implement this principle into organisational structures. Further research is needed, especially to assess the new windows of opportunities that have been opened by the CRPD for disability rights activism to influence national and international policies.

## Appendix

*Table 2: Comparison of Representation Requirements in National Assembly Institutions*

<b>Representation requirements</b>	<b>National assembly</b>	<b>Conditions of membership as required by the statutes<sup>138</sup></b>
<b>No representation requirements</b>	<b>DFI (IE)</b>	“Each organisation has to be voluntary in terms of governance and its sole or primary purpose has to relate to the support and advancement of people with disabilities and/or disabling conditions.” <sup>139</sup>
<b>Low representation requirements</b>	<b>FFO (NO)</b>	“In order to achieve membership status in FFO: a) The organisation has to organise persons with disabilities and chronic disease, or their relatives who need assistance to exercise their own interests, b) has to ensure that persons with disabilities and chronic illness as well as persons close to them have crucial influence in the organisation, c) [...] all persons with disabilities and chronic illness and their families have to be able to be member.” <sup>140</sup>
	<b>NOOIS (RS)</b>	“The organisations which meet the following criteria can become fully entitled members: organisations whose majority respectively major part of their joint members are persons with different types of disabilities and those organisations which work on specific issues relevant to persons with different types of disabilities.” <sup>141</sup>

138 The quotes in this table are non-authoritative translations into English by the authors of this paper. For the original texts see: Anne Waldschmidt et al.: *A Comparative Analysis of Disability Rights Activism*, pp. 80–81.

139 Disability Federation of Ireland: *Membership Strands and Eligibility*.

140 Funksjonshemmedes Fellesorganisasjon: *FFOs vedtekter – vedtatt, section 2, art. 4.*

141 Nacionalna Organizacija Osoba sa Invaliditetom Srbije: *Statut – Nacionalna Organizacija Osoba sa Invaliditetom Srbije, art. 12.*

<b>Moderate representation requirements</b>	<b>DBR (DE)</b>	“The members of the German Disability Council are organisations of persons with disabilities and their relatives and supporters. They have to ensure that persons with disabilities and/or chronic illness and their relatives and supporters make up the majority both among members and the board.” <sup>142</sup>
	<b>FID (IT)</b>	“The Italian Forum on Disability is composed exclusively of organisations, federations and national associations of persons with disabilities and/or their families, non-profit, which strive continuously and in any form after the protection of the rights of persons with disabilities. Members of the FID are organisations, federations and associations of persons with disabilities and/or their families in their statutes guaranteeing the presence, among the members of the statutory bodies and the management of a majority of people with disabilities and/or family members of people who cannot represent themselves. The FID is an organisation open to accession by organisations representing any type of disability.” <sup>143</sup>
	<b>HSO (SE)</b>	“[The organisation] has to be representative for the group of persons with disabilities whose interests they advocate. [...] “Representative” in this context means that more than half of the members of the board and other decision-making bodies either have a disability themselves, are relatives of children with disabilities or are close to adults who, because of their disabilities, need support to be able to claim their rights in society.” <sup>144</sup>
	<b>NRZP (CZ)</b>	“[Civil society] organisations of persons with disabilities for the purposes of these statutes are considered organisations which consist of persons with disabilities or their legal representatives by a majority of the individual members.” <sup>145</sup>

142 Deutscher Behindertenrat: Statut des Deutschen Behindertenrats, art. 3.

143 Forum Italiano Sulla Disabilità: Statuto, art. 3.

144 Handikappförbunden: Stadgar – HSO, section 3.

145 Národní rada osob se zdravotním postižením: Stanovy – Národní rady osob se zdravotním postižením české republiky, art. 6.

<b>High representation requirements</b>	<b>UKDPC</b> (UK)	“Full membership of UKDPC shall be open to any organisation of disabled people in the United Kingdom whose constitution prescribes that the majority of its full or voting membership shall be disabled people and that the majority of members of its governing body shall be disabled people” <sup>146</sup>
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