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Disability meta-organizations and policy-making under new forms of governance

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Disability meta-organizations are playing a significant role in influencing the development of disability policy. An example of this is the Disabled Peoples Organizations – Denmark (DPOD), which has managed to unify the disability movement and place itself in a unique position of power. The strategy of DPOD is based on organizational adaptation fitting into the institutional settings of government and building its influence on dialogue, and the establishment of a relationship of trust with political actors in network-based political settings. The change in governance towards cooperation through formal disability councils at municipal level requires the ability to recruit an increasing number of politically active representatives of disabled people. Tensions based on identity conflicts and different political priorities are revealed between different kinds of member organizations when representatives of DPOD are placed in political settings delegated to speak on behalf of disabled people in general.

Keywords: disability meta-organizations; new forms of governance; political representation

Introduction

Disability policy is on the political agenda in many countries today and disability organizations are playing a significant role in influencing policy-making. Policy-making today takes place in multiple places in networks between many actors, which requires that an increasing number of representatives of disabled people become involved with policy-making and present interests and experience that distinguish disabled people from non-disabled and thus widens the sphere of politics to disability issues. In Denmark studies of disability organizations have focused on single disability organizations (Bundesen, Henriksen, and Jørgensen 2001; Kirkebæk 2003; Valentiner 1975), and Danish disability policy in general (Bengtsson 2001, 2005; Bengtsson and Kristensen 2006), whereas the political role and power of meta-organizations has been overlooked. However, disability meta-organizations, i.e. organizations whose members consist of disability organizations, are playing an increasing role in the process of policy-making. The government prefers to negotiate with meta-organizations that can speak on behalf of a number of disability organizations and in this way reduce the number of actors participating in policy-making, which makes the process more efficient and rational (Bendix 2008; Bengtsson 2005; Bonfils 2006, 2007).

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Studying the way the Disabled Peoples Organizations – Denmark (DPOD) has managed to unify the disability movement and place itself in a unique position of political power shows the strategies of a meta-organization adapting to the government structures and new forms of governance. The history of DPOD is in many ways a history of success, which can be used as a guideline for disability movements participating in political systems characterized by a shift towards new forms of governance. The creation of meta-organizations in the disability field is a potential answer to the challenges facing the disability movement as they try to seek influence in an increasing number of political areas. However, the case of DPOD also captures the tension and challenges that follow when a meta-organization strives to meet the multiple and shifting challenges of being a political actor in a political opportunity structure that becomes more and more network-based. In this way, the case of DPOD is an interesting object of research both due to its uniqueness as a strong and powerful disability meta-organization, and also due to way it displays some of the general challenges the disability movement is facing today.

This article presents an analysis of the Disabled Peoples Organizations – Denmark with focus on how this meta-organization has developed and responded to the shift in government structures and changing political opportunity structures, at the same time as the public sector has become decentralized and the policy-making process has become based on cooperation through networks. The article deals with the question of how DPOD has related to changing institutional arrangements of policy-making in the disability field and worked itself into a unique position of power. In order to explain the present characteristics, situation and challenges of DPOD, a historical approach has been taken, looking into the historical background and roots of DPOD. The strategies that have been used to gain a political position and influence on the political processes through the years have been examined. The historical approach also sheds light on how these changes affect the internal relationships between the member organizations of DPOD and the tensions and conflicts that became present, when members of DPOD were negotiating on behalf of the whole community of disability organizations. The analysis of DPOD is used to highlight some endemic characteristics of meta-organizations and dilemmas of representation and identity formation in the disability field. The article is primarily based on a PhD dissertation dealing with the Danish disability movement and its political strategies (Bonfils 2006) and further research from 2009. The PhD dissertation was based on historical research in Danish disability policy and the history of DPOD from 1934 to 2004. It also included case studies of three disability councils studying the strategies of representatives of DPOD. The case studies were made in 2004.[1] This article is based on the research and results from the dissertation and studies of the disability policy area in Denmark made in 2007–09.[2]

Policy-making and new forms of governance

As the literature on governance is multiple, so are the concepts and terms used to capture the changes of the political practices. The concept 'governance and network society' signifies a change in the meaning of government, and refers to a set of changes in the way government seeks to govern. Following Kooimann (2000, 138), we are witnessing a growing interaction and interdependence between public and private actors with the aim of solving societal problems or creating societal opportunities and

with the aim of care for the societal institutions in which these governing activities take place.

The changing governing relations have been characterized as a move from government to governance, where the dividing lines between what we traditionally understand as the public and the private sector have become blurred. The growing interdependence and interaction between public and private actors are not new. However, the pattern of networks between actors is often the result of long-term societal trends and processes that have become increasingly institutionalized with multi-level and multi-sectorial dimensions. Governance theorists have dealt with the numerous public sector reform programmes and how the reform process questions the traditional perception of governance as sovereign rule. This contributes to an image of governance as something executed by a unitary sovereign decision-maker in full control of a bureaucratically organized public administration. The perspective has changed to a focus on how political and administrative leaders can enhance their capacity to meta-govern the increasing number of public and private stakeholders, who possess relevant resources for the efficient and legitimate governing of society (Newman 2001; Sørensen 2002, 2007). The literature on governance is occupied with the changing role of the state, the politicians, the administration, civil servants and the relation between the state and civil society. It is interesting how these shifting conditions affect disability organizations, and how the organizations respond to the challenges they face under these changing conditions of politics and policy-making. An analytical distinction can here be made between disability policy as a 'first-order governing' with the reference to problem-solving and opportunity-creating processes and 'second-order governing' that apply to the structural condition of the first-order governing. Second-order governing influences the conditions under which first-order governing takes place. Second-order governing is the institutional settings that frame, shape, constrain and make opportunities for actors engaged in problem-solving and opportunity-creating processes. This article focuses on the changes in 'second-order governing' that have taken place in the disability policy field in Denmark since DPOD was established in 1934.

The maintenance or renewals of socio-political institutions are often core questions, when the public sector is reformed and new political and administrative structures are implemented. The political opportunity structure in Denmark is characterized by a long tradition of cooperation between a strong civil society and a strong state. The social movements and interest organizations have played a crucial role in Denmark, and their involvement includes both struggles for recognition and for welfare state development. The political system is based on a 'negotiation society', corporatism and network (Bengtsson 2001; Sørensen 2002; Christiansen and Nørgaard 2003) and since the 1980s the emergence of new social welfare movements and collective actions for social clients has been facilitated by the state in order to increase user involvement and active participation among social clients, including people with impairment. Applying to disability policy, three particular periods are of interest, when the focus is on the shift of the political opportunity structure in Denmark: the 1930s, the 1970–1980s and 2007. The three periods are characterized by public sector reforms that open up windows of opportunities, where political actors can place themselves in new positions and gain influence through institutionalizing previous informal or provisional policy network or through shaping new identities and political positions. The following part begins with a brief presentation of DPOD and

goes on to explore the position and strategy of DPOD in the light of the three historical periods of public sector reform.

DPOD and its position in disability politics

The Disabled Peoples Organizations – Denmark (DPOD) is the biggest national non-government umbrella organization in the disability field in Denmark, organizing 32 national member organizations and representing more than 320,000 people with disabilities[3] (around 6% of the Danish population[4]). The organization is possibly one of the oldest disabled people's meta-organizations in the world, celebrating its 75th anniversary in 2009. The members of DPOD are non-governmental organizations of persons with disabilities (and their families). The majority of the member organizations are single disability organizations engaged in activities on national and regional levels – and some are engaged on the local level. The highest body in DPOD is the national board, which is composed of two representatives from each member organization and one from each of the five regions, representing the local branches. The national board elects an executive committee with seven members (one chairperson, one vice chairperson and five board members). DPOD has a national, professional secretariat with about 35 employed consultants and secretaries. At the local level, DPOD has local branches in the 98 municipalities. DPOD is funded by the national lottery. This funding is supplemented by fees from the member organizations and public/non-public project funding.

Through the years, DPOD has become a strong and powerful interest organization and political actor with the legitimacy to represent disabled people in political settings at both national and local level in Denmark. DPOD designates members to the Danish Disability Council set up by the Danish Government and to a number of other public committees and commissions at national and regional level. At local level DPOD's local branches appoint representatives to Municipal Disability Councils, Municipal Committee on the Open Labour Market, Regional Complaints Boards on Social Matters, Regional Councils of users of various services – and other public councils and committees (www.handicap.dk). DPOD can be characterized as a meta-organization. This means that, though it differs from an individual-based organization, it shares some of the same characteristics and challenges as organizations-of-organizations when it comes to foundation of an organization, conflict handling and organizational change (Ahrne and Brunsson 2005). The article addresses some of the theoretical standpoints made by Ahrne and Brunsson about the difference between individual-based organizations and meta-organizations, in order to capture the specific character and challenges facing DPOD in a political opportunity structure under change.

The foundation of DPOD in the light of the social reform of the 1930s

The recruitment of members is fundamental for the creation of any organization, but for meta-organizations, the recruitment of members depends on the very existence of individual-based organizations that share purpose and interest together with a common interest in acting as a collective rather than a single organization (Ahrne and Brunsson 2005). The history of DPOD takes its starting point with the very creation of the organization of disabled people in Denmark in the late 1800s and beginning of 1900s. The first organized group of disabled people was the association of deaf people, which was founded in 1866.[5] Subsequently, the association of blind people

was established in 1911, the association of the hard of hearing in 1912 and the association of physically disabled people in 1925. DPOD was founded in 1934 by these four member organizations representing the blind, the deaf, the hard of hearing and the physically disabled. These four organizations were all founded as organizations *of* disabled people in opposition to associations *for* disabled people, and they express a common interest in developing the public policy and services for disabled people as opposed to private and charity-based help and support (Bundesen, Henriksen, and Jørgensen 2001; Bonfils 2006). Before 1934, the leaders of the four organizations had cooperated on political matters like occupation and disability benefits, and the unification of the four disability organizations was based on a mutual interest in gaining access to the process of policy-making in these areas. The mobilization as a national umbrella organization constituted a platform for political activism and a common representation as an interest group.

The formation of DPOD as a political actor in 1934 took place in a governance situation characterized by a shift in disability policy from being based on private, charity-funded institutions and partnerships between the public and non-government organizations towards public-funded and state-run institutions and support. In the 1930s, social reform took place in Denmark constituting the steps towards the development of a universalistic welfare state (Bengtsson 2001). The reform marked a governing shift towards public accountability and tax-funded services for disabled people. The government's objects in the disability area are conceptualized and framed as part of the social policy discourse with the Ministry of Social Affairs as the accountable governing actor. The disability service was at this time organized in institutions based on the difference between the various disability groups. The intellectually and mentally disabled were seen as the exponent for the degeneration of the human race and were placed in institutions that segregated them from society. The physically disabled, the blind, the deaf and the hard of hearing gained support based on rehabilitation and pensions. DPOD represented the last group of disabled people, and their political struggle was aimed at being recognized as legitimate spokespersons for 'the disabled' in society. DPOD focused on the possibility of disabled people being able to work as long as the government could support them with special aids and other forms of compensation and draw attention to different ways disabled people could be of use to society. In the first years, DPOD tried hard to influence the government to provide education, work opportunities and benefits for people with physical or sensory impairment.

The foundation of DPOD can be interpreted as a strategic answer to the challenges facing the disability organizations at this period of governance change. The shift in governance from private, charity-based support and partnerships towards state-run institutions and publicly funded support placed the disability organizations in a situation, where they could position themselves as an interest group in order to fit into the new system of policy-making. The leader of DPOD expresses this strategy of fitting in, in an article in 1934. He talks about 'the social reform treating the problems of people who are disabled as a common problem', and expresses his approval as: 'the government cannot legislate and make laws aimed at the physically disabled and the blind one day and the next day aim at the deaf and hearing-impaired, but the government must see the disability-related problems as a whole'[6] (Vanførebladet 1934).

The governance shift of the 1930s highlights some general dilemmas and struggles that disability organizations were facing around the world.

Primarily, there is the importance of distinguishing between organizations *of* and organizations *for* disabled people, together with the disabled persons' struggle for being recognized as a political interest group and as legitimate spokespersons for the disabled people's organizations (Shakespeare 1993; Barnes 2002). In Denmark, the showdown between the organizations *of* disabled people and *for* disabled people came to an end in the late nineteenth century and the beginning of the twentieth, when disabled people organized themselves in interest groups and took exception to the charitable-based associations of non-disabled organizations (Bonfils 2006). The organizations of disabled people were supporting the development of the welfare state and the state taking over the support and benefit for disabled people, as this was a means to become independent of family support and charity.

The second dilemma or struggle is revealed in the identity conflict between the member organizations. It becomes evident in the ambivalence of the organization of deaf people, who opposed identifying with other disabled people, but still strived to become recognized as a political actor. The formation of DPOD as a strategic action directed towards achieving influence in the political system is contrasted by a potential identity conflict between the member organizations. The organization of deaf people opposed identifying with the concept of disability, associated with being 'unfit for work'. The organizations of deaf people were based on self-help and the struggle for recognition of sign language as their primary language. The interest of the deaf people reveals how issues of recognition in collective action are combined with issues of redistribution of welfare benefits (Fraser 1995) and how the potential identity conflict between the different member organizations becomes part of an internal organizational tension in DPOD. The idea of shared identity and collective identification as disabled was at this time of history toned down in the strategy of DPOD, and the unification of the four disability organizations can therefore be interpreted as a strategically-based action to gain political influence on resource allocation and develop welfare services for disabled people (Bonfils 2006).

The development of DPOD in the light of the government reform of the 1970–1980s

In the period from 1934 to the 1970s, DPOD consolidated its position as an interest organization in Danish disability policy. In the 1940s, DPOD took part in a number of committees established by parliament, and later in the 1960s participated in the preparation of legislation of importance to people with disability (Bengtsson 2001; Bonfils 2006). DPOD was still a minor organization when it came to the number of members. An evaluation from 1965 showed that it represented 10,000 disabled people (De Samvirkende Invalideorganizationer 1965). Membership was reserved for disability organizations representing people with visible physical impairments and the organization only increased from four to six member organizations from 1934–1960. The position of influence was based on a strong chairperson, who among other things became the head of the Committee on Social Reform in the period 1965–1972 (Bengtsson 2001). The position of influence was also based on political alliances and networks with the associations of elderly people, association of patients and the trade union. In the meantime, the number of associations of patients and disability organizations, representing among others people with learning difficulties and users of mental health services, increased and the associations gained influence in political matters of importance to their member group. Until the 1970s, DPOD was reluctant to open up membership for these organizations, as they were regarded as more

diagnosis-based and orientated towards health issues, whereas 'the old organizations' were formed as interest groups in the area of social policy.

Another tension concerned the members of the new organizations, which combined disabled and non-disabled people, and in this way challenged the old organizations' vision of disabled people as the only legitimate spokespersons of disabled people. However, the government reform of the 1970–1980s changed the political opportunity structure and challenged the 'old' DPOD strategy. The 1970 reform reduced the number of municipalities from approximately 1300 local authority districts to 275 municipalities, 25 counties to 14 counties and a number of public tasks were delegated to the county and municipal level. The regulation of the disability area was reformed in 1976. From separate legislation aimed at regulating the individual institutions of different impairment groups it changed to a law regulating social services collectively. In 1980, the state-run institutions were delegated to county level promoting a move away from institutionalized services towards normalization and integration of disabled people in society (Bonfils 2006; Bengtsson and Kristensen 2006). In 1980, the Danish Disability Council was established and replaced four former councils: the Council of Deaf People, the Council of Blind People, the Council of People Hard of Hearing and the Advisory Council for Mentally Disabled. At county level, social user councils were established and the Ministry of Social Affairs stipulated that users of municipality-based social services could also organize in user councils.

The government reforms in the 1970s challenged the position of DPOD in different ways. A general shift in the government's cooperation with interest organizations at national level privileged the Local Government Denmark and the County Council Denmark, established in the government reform of 1970, whereas DPOD was placed in a more marginal position as an advisory body, but outside the formal arenas of negotiation (Bonfils 2006). The process of decentralization placed the counties and municipalities as central actors in implementing disability policy with the opportunity to decide different levels of service provision and find solutions that fitted in with local conditions. DPOD was only organized at national level, leaving it in a powerless position when it came to influencing policy-making at county and local levels.

In the years from 1970 to 1980, DPOD transformed from being an interest organization representing the 'old' disability organizations to an organization representing the whole disability movement. In the beginning of the 1970s, different organizations representing patient groups, people with learning difficulties and mental health service users applied for membership of DPOD, and in 1974 the national board of DPOD decided to open up for membership of a wider range of disability organizations. New disability organizations applied for membership and by 1979 DPOD had 21 member organizations. The organizations that used to be part of the environment of DPOD became co-members of the meta-organization. The organizational change can be interpreted as a way of dealing with the potential threat that the patient organizations would establish an alternative meta-organization and by that challenge the position and monopoly status of DPOD as a representative for 'disabled people' in political settings. The organization change can also be seen as a way of strengthening the resources and action capacity of DPOD, as it by doing so, gains more members and economic resources that can be changed into political action in a governing structure under change.

From 1974 to 1978, the organizational structure was changed, and DPOD established local branches at county level and gained political influence here. Due to lack of resources, it was not possible to establish local branches at municipality level,

leaving it in a powerless position when it came to influence the policy at municipal level. In 1980, the formation of the Danish Disability Council at national level and user councils at county level opened up new opportunities for DPOD to gain influence. The political opportunity structure had changed and the strategy of DPOD was, as in 1934, to fit into the new government structure, by organizational adaption. The governance shift introduced the involvement of users of the welfare service as a means to opening up the decision-making process to a greater number of the public. As part of the New Public Management trend, a more responsive and effective public sector was developed, where users become consumers or customers in a market-based social service system (Newman 2001; Sørensen 2004). At the national level, the Danish Disability Council opened up the opportunity for DPOD to represent the interests of the community of disabled people in an advisory council, exclusively dealing with the transversal social issues of disabled people in different political areas. At county and municipal levels, the new opportunity structure placed DPOD in a position as a 'user' of social services both in alliances, but also in competition, with other social clients revealing the tension between the different social clients as regards attention to their specific problems and the struggle to influence issues of redistribution of welfare benefits and services.

DPOD and the local government reform of 2007

During the period from 1980 to 2006, the members of DPOD grew to 32 member organizations and DPOD became integrated in the political process in a wider range of government activities representing disabled people in more than 80 councils, committees and boards (Bonfils 2006). At municipal level the original voluntary user councils were replaced by voluntary councils consisting of elderly and disabled people or disability councils, and the number of municipalities with disability councils increased from 5% in 1991 to 22% in 2005 (Bonfils 2006).

In 2007, a local government reform reduced the number of municipalities from 273 to 98, and changed the government structure from 14 counties to five regions. Since 2007, the regions have been responsible for hospitals, including healthcare services. The regions cannot impose taxes, and the activities of the regions are paid for by subsidies from the municipalities and the state. The reform redistributed the work between the state, regions and municipalities, and the new municipalities now have full authoritative and fiscal responsibility in the disability sector. As part of the reform, disability councils became compulsory and DPOD became designated to recommend members from the disability organizations to represent disabled people. In order to fit into the new opportunity structure, DPOD went through an organizational change in 2005–06, closed down the branches at county level, and set up new local branches at municipal level. The challenge of DPOD has been to mobilize local members from the different member organizations to participate in political activities and the work of establishing a locally founded DPOD organization.

The local disability councils were organized as a parallel to the Danish Disability Council at national level and made up of an equal number of representatives from disabled people and from public authorities. The organizational set-up is based on the idea of governance by network, with the principle of sector responsibility as the foundation for dealing with the multiple problems and challenges that different people with impairment are facing today (Bengtsson 2005; Bonfils 2006, 2007). Participating in network-based policy processes demands a strategy based on cooperation and

creation of trust between the participants (Jensen and Sørensen 2004). The strategy of cooperation and dialogue between the disability movement and the public authorities has played a significant role in Danish disability policy, and the political activism of DPOD is historically based on this dialogue and consensus-seeking strategy (Wiederholt et al. 2002; Bonfils 2006). DPOD followed this strategy at local level, and the strategy has already shown its success, as the local disability councils in less than two years have shown their capability in placing disability issues on the political agenda at municipal level (Bendix 2008).

By looking at the history of DPOD, its political activities and organizational change, it is possible to see a strategy based on achieving dialogue and cooperation with the government and local authorities; a strategy that changed the organizational setup in order to make it fit into the present institutional settings of policy-making. The history also reveals how the leaders of DPOD have been powerful political actors, who have played significant roles in the development of the Danish welfare system, not only in the disability arena, but also by influencing the development of social policy in a broader sense. The historical approach reveals how the influence of DPOD previously was based on a strong chairperson seeking influence at national level. Today, DPOD is represented in multiple political settings as formal, institutionalized councils and boards as well as informal and more activity-based political settings. This involves that a growing number of people is appointed to represent DPOD as political actors and to be present in different political arenas at national and local level. DPOD has developed from a hierarchically-based top-led organization to a locally-based and more pluralistic organization. This is due to its strategy of adapting to the political opportunity structure and in this way gain political influence at national and local level. The historical approach also reveals some of the tensions and conflicts that became present, when disability issues became part of the political communication, institutional settings and process of policy-making. The following part will explore some of the tensions and challenges facing DPOD and the disability movement in general, as they become engaged in policy-making under new form of governance. The study of DPOD is used to highlight some analytical generalizations. DPOD represents a critical case study with strategic importance in relation to some general problems and tensions of meta-organizations and political representation in the disability field (Flyvbjerg 2001).

Recruiting political representatives

The very existence of an organization depends on members. Members are important as a resource along with economic resources and a professional secretariat in gaining political influence (Christiansen and Nørgaard 2003). The creation of a meta-organization is a way to mobilize resources that can be changed into political influence. Members are not only important as symbolic backing and a numerical expression of the mandate of the organization, but, in relation to DPOD, members are playing a new and more important role, as new forms of governance and network-based political processes are becoming more important when gaining political influence. In Denmark, the change in institutional settings of policy-making towards representation through formal disability councils at national and municipal level requires the mobilization of political active representations at different levels. Due to the increasing numbers of boards and councils, where DPOD is represented, DPOD is responsible for mobilizing more individuals to become active in promoting disabled

people's rights and interests. The challenge is not only a question of mobilizing a greater number of active members, but also about the skills, political competences and interest in politics of the appointed members. The representatives demand support and assistance from the meta-organization in developing their skills and knowledge about disability policy, the function of the political system and their role and mandate as representatives of disabled people. Their role is influenced by the ability of the meta-organization to shape them as political agents, but the role of the representatives is also shaped by the public institutions, which define the political space, norms and issues that can be expressed in these settings.

The case study of three disability councils reveals how the representatives of DPOD experience and develop their political roles due to the rules and norms expressed in the political culture and discourse of the disability councils. The councils are formal institutions, where achieving political influence and results may take time. The representatives conform to the role of being patient, seeking dialogue and building up relations of trust with decision-makers on a long-term basis. As an example, the DPOD members of the Danish Disability Council express their experience with the council as an institution 'where the tone and the way we present our interest is done in a very nicely manner and conflicts are played down', but they also emphasize their role as a 'watchdog' (Bonfils 2006, 184). The representative of DPOD must be willing to accept the dominant discourse of the network, that politics also is about presentation and legitimacy and that it may take a long time and hard work to make political changes. The representative must have the proper professional and social skills together with the proper personality to fit into the dominant political discourse and to become accepted as a worthy member of the network. The study shows that in order to become accepted as a political actor, the disability organizations are pointing out persons, who can fit into this common understanding of being a political representative of disabled people in Denmark. In an interview with the leader of the DPOD, he expresses the competence that is valued: 'The representative of disabled people must be both critical and cooperating. . . Therefore we have to be selective and point out those who have the proper skills and the proper personality' (Bonfils 2006, 204), and he points out that members who are consensus seeking and good at creating a relation of trust are preferred to members who are more critical and provocative (Bonfils 2006).

Influence through formal political institutions has become dominant and the disability organizations are therefore putting a lot of effort in influencing through these political arenas. Doing this, they may overlook the multiplicity of sites of political influence. Many of these are constituted outside the formally constituted political institutions. The question is if the disability organizations are concerned about how lack of interest of politics, especially among the younger members, may reflect an unwillingness to participate in officially defined political spaces. This unwillingness may be linked to a disillusion with formal political institutions (Newman 2001, 136). Moreover, young people may be reluctant to step into the dominant role of disability representatives as consensus seeking actors. The study of DPOD shows how young disabled people are challenging the conformity of the established DPOD and previous relations of power between the different disability groups.[7] The Association of Youth with Disabilities points out a lack of solidarity between the old and strong disability organizations and the organizations representing groups with cognitive impairment. They ask for a stronger commitment of DPOD to speak the voices of the most excluded disabled people in society. They also point to how young people may choose to live their political lives on the borderline between formal institutions and protest

and activity-based political forms of expression, and how this may be in conflict with the existing norms of being accepted as a worthy partner to other political actors in a network-based political setting. They call for new strategies that involve the young disabled people in non-hierarchical relations and activity-based political projects. The standpoint expressed by the Association of Youth with Disabilities underlines the dilemma of recruiting members who are willing to become engaged in the established policy networks and conform to a dominant consensus-seeking political role. The disability organizations' success in relation to being members of an established policy network may stand in the way of recruiting new and younger generations of disabled people.

Political representation and the tension between different kinds of disability organizations

The tension between organizations in the disability field is historically and politically connected to both recognition and welfare policy, but also to the formation of meta-organizations and the questions of political representation. The differentiation between organizations *for* and *of* disabled people is well known in several countries and finds expression in the tension between organizations controlled and run by non-disabled people and the organizations controlled and run by disabled people themselves. The tension has been located as an issue connected to the struggle between a paternalistic approach and dominance of disabled people, and the struggle organizations of disabled people have had to become recognized as legitimate spokespersons for themselves (Barnes 2002; Shakespeare 1993).

In Denmark, the tension between organizations *for* and *of* disabled people took place in a historical period of development, where the organizations of disabled struggled for recognition and development of the welfare state. As the welfare state developed and disability organizations became recognized as political interest groups, some of the charity-based organizations dissolved, and the conflicts and tensions between the two kinds of organizations have become minor and more or less non-existent. However, the tension between different kinds of organizations is not only a question of the difference between organizations for and of disabled people. The tension also exists between the different organizations of disabled people, e.g. between the old and new disability organizations. The old disability organizations have been designated as 'access organizations' and the new ones as 'patient organizations' (Hugemark and Roman 2007). This tension was reflected in the old disability organizations that dominated DPOD until the 1970s, when DPOD were reluctant to open up membership to these new 'patient organizations'. Where the members of the old organizations were disabled people themselves, the new organizations combined a membership of disabled people, relatives, professionals and anyone who supported the purpose of the organizations. The tensions between disabled and non-disabled members are reformulated as a question of members having personal experiences with disability or not. The relatives, professionals and supporters are valued for their personal experience from living or working together with disabled people. This gives them an experience, which they can express in political settings and use in the struggle to improve living conditions for disabled people. The old disability organizations were reluctant to let non-disabled people become official representatives of DPOD, but have accepted this difference as part of the rules of the game in DPOD.

However, a new tension seems to have come to light as the number of small and diagnosis-related disability organizations has increased since the 1990s. The new organizations are established for persons with rare diseases, specific diagnoses and as parent's organizations struggling to gain access to specific treatments for their children. Other organizations are formed as user organizations in relation to specific welfare services (Bonfils 2006; Jensen 2009). Common to these organizations is a narrow focus on the specific problems in a certain sphere of their members' lives, whereas the old 'access organizations' and 'patient organization' have a broader political agenda. In Denmark, DPOD has managed to gather the disability movement into one umbrella organization and avoided the development of rival meta-organizations. In this process, DPOD has set up rules that prevent small and new disability organizations and user organizations of disabled people from becoming members, inciting the new organizations to seek cooperation with the more established and old disability organizations. Jensen (2009) shows how an association based on members from different impairment groups, which have a common interest in improved disability pension and the need for flexible working arrangement, were excluded from becoming a member of a local disability council. The government has authorized DPOD to designate members to the local disability councils. By this, organizations and associations of disabled people not members of DPOD are excluded from the political arena. The point is that a meta-organization like DPOD has to deal with the tensions between different disability organizations, and they play a significant role in shaping the field of disability policy by their mandate to represent disability and disability related issues in political settings. DPOD then has the power to exclude specific groups and organizations of disabled people from the political arenas as they, to some degree, control the routes of access to arenas of influence.

Political representation and identity conflicts

Most disability organizations are founded around specific impairment groups, where the members identify with people with similar impairments. In the case of DPOD, the potential identity conflicts between the members of a meta-organization can be traced back to the formation of the organization in 1934 and the tension between the organization of the deaf people and the other organizations. The organization of deaf people opposed being categorized as an organization of disabled people, as the term 'disabled' in this historical period was associated with being unable to work.

Identity tensions are also seen between, for instance, the members representing physically disabled people and people with learning disabilities, as they find they have very few disability-related problems in common. The internal solidarity between the disability organizations has been seen as fundamental for creating a meta-organization, and so gaining a position of political power. The member organizations have to agree on who can be given the mandate to represent the organization in official and political settings. The representatives are given the mandate to speak on behalf of the whole group and are in this way obliged to represent each other and express each other's experience of disability-related problems and needs. In the study from 2006, three disability councils and the representatives of DPOD's political strategies were followed. The study showed that the representatives of physically disabled, blind and deaf people were in a position of power, placing their political issues high on the political agenda, unintentionally leaving weaker disability groups on the sidelines. In one case the question of accessibility for wheelchair users to

buildings, etc., dominated the agenda and the disability council appeared as a narrow 'accessibility-improving council' more than a broad disability council. In an interview with the head of the disability council, he explains how:

> . . . I know we have this tendency to focus on one specific group like the physical disabled and the problems of accessibility to buildings . . . leaving other groups like the needs of children and young disabled on a sideline . . . it is a process of exclusion that is going on, and it is important that we also take up issues related to those disabled people, who are not directly represented in the disability council. (Bonfils 2006, 223)

The study points to how the representatives of disability meta-organizations are in a position where they can in- or exclude political issues from the agenda. The representatives will often be laypersons and are typically placed in a position where they draw on their own experience with disability and struggle to improve the living conditions for their own impairment group. Therefore, dealing with internal identity-related conflicts is another challenge facing disability meta-organizations. The question is, whether meta-organizations like DPOD are taking the problem of identity difference seriously. They have to acknowledge the inescapable fact that representatives are identifying with their own impairment group in their political action and struggle. The acknowledgement that politics of present matters in disability politics is fundamental and shows that the representatives are not only representing the range of ideas, interest and beliefs, but also 'mirrors' a specific group of disabled people and the experiences of this group. The politics of present is essential for understanding the development in a democracy and political activism today (Phillips 1996). The studies of the representatives of DPOD indicate how the complexity of disabled people's voices and identities are regulated and marginalized by organizations and people, who have become legitimate spokespersons.

Concluding remarks

This article has focused on disability meta-organizations and their role in disability politics. The study of a single meta-organization, The Disabled Peoples Organizations – Denmark (DPOD), has been used to highlight some general tendencies and tensions that are revealed when disability meta-organizations become engaged in policy-making under new forms of governance.

The formation of a disability meta-organization like DPOD is in itself a symbol of political power, as the organizations unite to represent the disabled people as one interest group. The DPOD has developed into a political actor engaged in policy making at different government levels. Through the interaction with politicians and public officials, the meta-organization plays a significant role, as the organization 'speaks for', 'acts for' and can even 'stand for' disabled people in political settings in Denmark today. This position has been developed through a strategy of organizational adaption, and I have pointed out how this strategy can be seen as a means to place disability meta-organizations in a position of political influence. The position has also been reached by shaping the political identity of disability representatives as consensus seeking political actors with the competences of building up relations of trust with public officials and politicians.

Today, the participation of DPOD is institutionalized in policy making at multiple levels and through formal institutions such as disability councils. DPOD include and

exclude organizations of disabled people as members and by this shape the interests, opinions and perspectives of disability presented in politics. DPOD designate members to participate in disability councils and may exclude the most critical, provoking voices of disabled people from these political arenas in order to keep their political power. The conformity of a disability meta-organization such as DPOD may hinder recruiting younger disabled people and disabled people who define their political identity in other shapes and forms than the old 'access' and 'patient' organization. This makes the role of disability meta-organizations and their political representatives interesting areas to study, as it reveals the power and the bias of those organizations and disabled people, who have managed to place themselves in a position of political influence, and who have the resources, the time and the will to participate in politics.

Notes

1. The dissertation is based on both historical research in Danish disability policy, the history of DPOD and studies of three disability councils in Denmark. The historical research of DPOD is based on archive material from the Association of Physical Disabled [Dansk Handicap Forbund] and the archives of DPOD. The material consists of articles from newsletters and the minutes from the executive committee of DPOD from the period 1952–2004. The material reflects the discussions and interests of the leadership. The dissertation also includes a case study of three disability councils made in 2004. The case studies of The Danish Disability Council, The Disability Council of the Municipality of Århus and The Disability Council of the Municipality of Karlebo, took place in the period August–December 2004 and were based on studies of the minutes from the council meetings, observational studies of pre-meetings of members from the DPOD and the council meetings in the period and interviews with the members of the three disability councils.
2. The research from 2007–09 includes analyses of articles from the newsletter of DPOD 2008–09, and observations made at the 75th anniversary of DPOD on 22 April 2009.
3. The Rare Disorders Denmark is another alliance of 36 rare disease organizations.
4. The Danish population was 5,511,000 in 2009.
5. The Danish Federation of the Deaf is possibly one of the oldest disability organizations in the world.
6. The different quotations presented in this article are translated by the author. The original Danish quotations are to be found in Bonfils (2006).
7. Speech made by the head of the Association of Youth with Disabilities – SUMH, at the 75th anniversary of DPOD on 22 April 2009.

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