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# The role of disability groups in the development and implementation of the UN Convention on the Rights of Persons with Disabilities

Mario Levesque
Department of Politics and International Relations
Mount Allison University
malevesque@mta.ca

Brynne Langford
Department of Politics and International Relations
University of British Columbia

## Abstract

The neoliberal agenda has seen increased engagement of governments and disability organizations in policy making and implementation processes. Yet governments have been slow to address needed changes in disability policy over the last three decades questioning the role of disability organizations who have increasingly turned to rights-based claims on states. The UN Convention on the Rights of Persons with Disabilities, which reaffirms in article 29 the full political participation of persons with disabilities, is one such example. Unclear, however, is the role of disability organizations in the UN Convention's development, ratification and implementation. Were disability organizations active and central actors in this process? This article investigates this question in relation to three case studies: Canada, the United States and the United Kingdom. The story that emerges underscores the centrality of disability organizations in policy development during times of government disinterest or indifference.

## Keywords

Disability policy; Political participation; Disability rights; Disability groups; UN Convention, Canada; United Kingdom; USA

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Mario Levesque
Department of Politics and International Relations
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## Introduction

This article examines the government-nonprofit organization nexus in the area of disability. It accepts the neo-liberal turn over the last few decades where the focus is on governments retaining their policy making role while devolving policy implementation to civil society actors such as disability organizations through “partnerships” and “contracting” yet argues that disability organizations remain important actors throughout the policy development process to ensure the full inclusion of persons with disabilities in society. Governments have been slow to address needed changes in disability policy over the last three decades while changes that have occurred have been “not good enough,” with minimal gains won through long drawn out processes (Levesque & Graefe, 2013). What then is to be made of the minimal advances to date or “citizenship by installments” as Prince has characterized it (Prince, 2001)? For persons with disabilities, this is important given their late and continuing struggle for enfranchisement. While persons with disabilities, including those with mental and cognitive disabilities, have had the right to vote in Canada for over 20 years, the situation is bleak elsewhere such as in the United States (US) or the European Union (EU), where approximately half of the states ban or limit such rights (Valentine & Vickers, 1996; Davidson & Lapp, 2004; EU Agency for Fundamental Rights, 2010). This state of affairs exists despite the UN Convention on the Rights of Persons with Disabilities (hereafter "Convention") which reaffirms in article 29 the full political participation of persons with disabilities. Lost in these developments is the role of disability organizations. Far from being relegated to policy implementation, disability organizations may be significant actors in policy development, sought out for their expertise or to legitimate government decisions (Prince, 2010). Moreover, disability organizations remain important actors in the policy process, holding governments to account especially at times when governments are reluctant to move key files forward or attempt to backtrack on important decisions (Young & Everitt, 2005).

The central role played by disability organizations in the development and ratification of the UN Convention in 2006 and its subsequent implementation in Canada, the USA and the United Kingdom is probed in this paper. It proceeds in six parts. The first part questions the role of interest groups in the policy making process with a focus on disability groups and their late enfranchisement. While disability groups remain important actors, equality in rights remains elusive. Next, efforts to ensure the equality of disability rights within the context of the Convention are examined in the second part. The third, fourth and fifth parts examine efforts to ratify and implement the Convention by Canada, the US and the United Kingdom (UK) highlighting the role of disability organizations in the process. The conclusion then summarizes the similarities and differences across the three case studies. The story that emerges underscores the centrality of disability organizations in policy development during times of government disinterest or indifference.

**Disability groups and policy making**

Disability organizations remain an important part of civil society actors (Roberts, 2001; Graham & Phillips, 1997). Whether one has a disability or not, involvement in disability organizations remains an important way to facilitate learning and to become an engaged member of the community (Canadian Centre on Disability Studies, 2002; Eldson, Reynolds, & Steward, 1995; Putnam, 2000). It is through such organizations where a wide range of individuals come together to share their experiences and work out differences in order to ensure their effective representation to decision makers in the policy process. Disability organizations and community organizations more broadly are also important points of contact when people encounter challenges in their lives (Gouthro, 2010; see also Meadowcroft, 2004). They can either provide needed services directly or help one access such services, thus helping one maintain their independence and contribute to the broader community’s health (Bron, 2003).

Disability organizations also remain an important source of information which can both help and challenge governments. For example, governments often approach organizations in need of specific information on a policy area (expertise) and to enhance their legitimacy for decisions taken through consultations. In the process, disability organizations can challenge government approaches and information, as well as work to dispel myths and break down stigma and discrimination (Mansbridge, 1992; Prince, 2010; Hendriks, 2006). It is through this process of disability organization interaction with governments and other non-governmental organizations that the economic, social and community value of the organizations are realized and one mechanism from which persons within those organizations can work towards their full participation in society (Quarter, Mook, & Armstrong, 2009).

Such benefits are questioned in the current neoliberal period when the focus is on fiscal retrenchment, privatization and a continued push for a smaller and residual state role in social programming (Prince, 2012a). It is during these periods especially that the capacity of disability organizations is questioned. Do disability organizations have the capacity in terms of resources such as human, funding and infrastructure to be able to effectively partner with the state to carry out key policy implementation roles? As Levesque (2012) has documented in the Canadian context, disability organizations are increasingly challenged to fulfill this role, especially in economically challenged areas.

In such situations, the question of how to actualize one’s rights is a challenging endeavour, especially political rights such as voting. This is important because, for example, studies of US national elections reveal that persons with disabilities tend to be 10-21% less politically inclined than non-disabled persons. This also varies among persons with disabilities in that women, older individuals, those with severe disabilities, lower education and income tend to be even less politically inclined (Schur, 1998, 2003; Schriner & Shields, 1998; Shields, Schriner & Schriner, 1998; Schur, Shields & Schriner, 2005). Similar results are found in the United Kingdom where, for example, only one-third of people with learning disabilities voted in the 2001 election (UK Political and Constitutional Reform Committee, 2014). Significant barriers also exist to voting accessibility from inaccessible polling stations (67% in the 2010 election) to registration issues, as reports have revealed for the 2005 and 2010 elections (Sanders et al., 2005; Gilbert et al., 2010; see also UK Political and Constitutional Reform Committee, 2015). Such results are also found in the Canadian context. For example, D’Aubin and Stienstra in 2004 observed that persons with disabilities were underrepresented in local, provincial and federal elections and pointed to negative public attitudes, public awareness and funding issues that needed to be addressed. This is in contrast to a 2006 report on the 1997 Canadian Election Survey which found that persons with disabilities were more likely to vote than persons without disabilities. As the author of this study stated, this higher voter turnout is likely due to being part of the survey which raised their consciousness on the issue and prompted them to vote (McColl, 2006). Recent work by Levesque (2016) examined the political participation of persons with disabilities in Canadian provincial office. It found that only 1.2 per cent of candidates for the last three provincial elections in each province were persons with disabilities, which is far below the rate of disability in the Canadian adult population at 16 per cent. In addition, political parties and electoral management bodies were found to be significant barriers for the political participation of persons with disabilities. For example, recruitment efforts, party funding mechanisms and disability provisions were lacking in political parties. Campaign finance laws were also found to be in need of revision to address the added costs persons with disabilities face when seeking elected office (Levesque, 2016; for a broader Canadian comparative comparison, see Prince, 2012b).

Across the US, UK and Canada, a recurring theme is the cumbersome registration processes that have been found to be contributing factors to lower voter turnout among persons with disabilities (e.g., Dickson, 2002). The slow evolution of voting rights has not helped matters. For example, the majority of EU countries suppress the right to vote for persons with mental health problems and persons with intellectual disabilities (EU Agency for Fundamental Rights, 2010). This is contrary to the vast literature which has found this position to be untenable (e.g., Beckman, 2007, 2014; Karlan, 2007; Hamilton, 2012). Yet the problem persists and is rooted in societal attitudes and barriers—stigma and discrimination (Hahn, 1988). It is such challenges that the UN Convention can help overcome.

## Disability rights and the Convention

The 2006 United Nations (UN) Convention on the Rights of Persons with Disabilities follows the trend to rights restatement and reconceptualization as a method for providing tools for those disadvantaged seeking redress. Such conventions include the 1979 UN Convention on the Elimination of All Forms of Discrimination Against Women and the 1989 UN Convention on the Rights of the Child (United Nations, n.d.a).[1] To be sure, the rights elaborated in these conventions do not trump the 1948 UN Universal Declaration of Human Rights which are universal and inalienable, interdependent and indivisible, equal and non-discriminatory and which put forth both rights and obligations (United Nations, n.d.b). Rather, it is on this obligation to respect, protect and fulfill human rights that these newer conventions build so as to map out where actions are required. This is similar in nature to the entrenchment of political and equality rights for persons with disabilities in key constitutional documents such as Charters of Rights and Freedoms (see Chivers, 2008). To this end, while such Conventions or Charters run the risk of creating "special" rights for designated groups, they are nonetheless a welcome addition for those in the field (on this point see Mégret, 2008 and Harpur, 2012).

The specification of disability rights is important because of continued rights infringements by governments among others. For example, in Canada, the federal government had long discriminated against persons with disabilities in regards to website accessibility to the point that blind individuals often needed to rely on sighted persons to transact business via government websites. It was the Jodhan case in 2012 that forced the federal government to begin revamping their websites to ensure that they are truly accessible to all individuals (see *Jodhan v. Attorney General of Canada*). To date, the pace of the revamping, according to disability advocates, is comparatively slow and uneven across federal organizations. Cases such as Jodhan highlight the stigma and discrimination still at the root of many rights infringements (e.g., D'Aubin & Stienstra, 2004; Hahn, 1988).

But how to actualize rights and what is the role of disability organizations in this process? Rights actualization is the point the Convention addresses through rights pluralization, that is, the clarification of rights for particular groups (Mégret, 2008). It is through this process that incidental rights are created. Incidental rights are established positive rights, which require states to provide the resources for rights actualization, in turn granting citizens greater equality in accessing their rights.[2] This is important because without this clarification, states can choose to be inclusive or exclusive of disability when evaluating human rights (Harpur, 2012: 2-11). The point is that it is these incidental rights that can be used in litigation, a process for which persons with disabilities have often been marginalized (Quinn, 2009). For example, Keleman and Vanhala (2010) and Vanhala (2011) trace how a shift to a rights discourse has been increasingly pursued in Canada and the European Union (EU), and Canada and the UK respectively has aided the (legal) mobilization of groups seeking redress (see also Kayess & French, 2008). Beyond this mobilization, many point to the importance of the process followed in rights pluralization as power in itself to shift societal norms and break down stigma and discrimination (e.g., Lord & Stein, 2008) with some going so far as to suggest the need for the incorporation of notions of social justice in order to truly make progress (Parker, 2007; Lawson & Priestley, 2013). This is especially the case when persons with disabilities are directly involved in the policy making process such as through disability organizations thereby embracing the "nothing about us without us" philosophy of the disability movement (Chivers, 2008).

Yet a narrow focus on rights pluralization or processes may leave us blind to important contextual variables affecting disability organizations such as existing legal frameworks and policies and practices. As Prince reminds us in relation to the Canadian context, while many rights exist, current policies and practices fall far short of what is needed, leaving persons with disabilities marginalized in society (Prince, 2009). A similar situation exists in the UK as discussed below. Similarly, Steinstra (2012), drawing on the pluralist critique (e.g., Newton, 1969), argues that one also needs to examine an individual's resources for them to claim their rights. Simply put, one needs resources–money, expertise, time among other things–to claim rights without which they largely remain words on a page. In the same way, cultural interpretations of disability may affect disability rights actualization. Johnson (2013) argues that the Convention is western-centric and may negate rights actualization for those with intellectual disabilities in other cultures given the fact that they may not interpret capacity to reason as the basis of autonomy (see also O'Mahony, 2012).

But what is driving this shift to rights pluralization? One important factor is the gradual change in approach to disability in the last three decades from the medical to the social model of disability. The medical model of disability, long the mainstay of government disability policy, emphasizes the problematic and individualistic nature of the disability with the goal of rehabilitating or "fixing" the individual so they may integrate into mainstream society. In contrast is the social model that views disability as a social construct where disability is a product of the social environment and, as such, society needs to change to accommodate differences (Rothman, 2010; Mitra, 2006; Barnes & Mercer, 2004a, b; Hahn, 2002; Pfeiffer, 2001).

As disability organizations have noted, the Convention represents some initial yet imperfect steps in the transition to the social model of disability. For example, section 'e' of the preamble of the Convention recognizes that "disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others” (United Nations, 2008). This is consistent with the social model which represents a paradigm shift (Fraser-Butlin, 2011). Yet it also utilizes the term “persons with disabilities,” which is inconsistent with the social model which uses the term “persons with impairments.” This is significant given the former term does not necessarily include the latter, leading one to question exactly who the target group is (Kayess & French, 2008). This is why we term the shift to embracing the social model in the Convention “imperfect,” and underscore the role of disability groups in the development and implementation of the Convention to which we now turn.

## Disability groups and the Convention

What exactly was the role of disability organizations in the Convention’s processes? Our investigation finds that a significant role existed and continues to exist for disability organizations in the Convention’s development, ratification and implementation (Reiss, 2014; Justesen & Justesen, 2007; Lawson, 2007). As Kofi Annan, the former UN Secretary General stated on the Convention’s adoption, “It was the community of the disabled themselves that worked tirelessly and insistently to promote this Convention” (United Nations, 2006). Simply put, conventions alone do not develop nor implement themselves, and much concern exists that commitments made will be left to languish on the shelves of government indifference (MacKay, 2007). The 2010 UK *Equality Act* is a case in point, illustrating the time lag in policy translation given the UK agreed to the Convention in 2006 and ratified it in 2009 (Fraser-Butlin, 2011) yet the 2010 *Equality Act* continued to embrace the medical model of disability. This underscores the fact that signatory states possess significant latitude in the Convention’s implementation, thus creating an opening for civil society actors such as disability organizations to work with governments to address inequities, provided sustained, coordinated and effective pressure can be maintained on decision makers (Lord & Stein, 2008; MacKay, 2007). This calls into question the resources of disability organizations when pursuing legal, legislative and bureaucratic remedies and the role of the state in the provision of such resources (Levesque, 2012; Levesque & Graefe, 2013; Flynn, 2013). The danger is in disability organizations’ overreliance on state resources for their activities which may be undercut when changes in state funding formulas are made (Levesque & Graefe, 2013). At the same time, the converse is true. That is, the significant latitude states possess to implement the Convention provides them with considerable leeway to delay commitment, and to avoid or dilute/deflect pressure from civil society actors, especially when these countries have not signed the Optional Protocol and/or not designated a central monitoring body to oversee the implementation of the Convention. Whether or not this is the situation that occurred will be examined in the next three sections as we profile the significance of disability organizations in the Convention’s development, ratification and implementation in three case studies: Canada, the US and the UK.

## Canada, disability groups and the Convention

The Canadian disability rights movement dates back to 1976 with the founding of the Coalition of Provincial Organizations of the Handicapped and its successor in the early 1980s, the Council of Canadians with Disabilities (CCD), who worked to focus on the deinstitutionalization of persons with disabilities (Stienstra, 2012; Council of Canadians with Disabilities, n.d.). This movement advocated independent living and equality rights and won significant gains when non-discrimination against persons with “mental or physical disability” was guaranteed under s. 15

Equality Rights of Canada’s 1982 Charter of Rights and Freedoms (Chivers, 2008; Canada, Department of Justice, n.d.). To actualize these rights, groups were provided state funding under the Court Challenges Program to pursue legal remedies.[3] Legislative changes such as the 1986 *Employment Equity Act* also represented modest gains at a time when several studies revealed the significant gap that remained to have persons with disabilities fully included in Canadian society (for an overview of these studies, see Graefe & Levesque, 2010). By the late 1990s and on the domestic front, Canada was searching for how to address the recommendations contained in *In Unison: A Canadian Approach to Disability*, which sought the full inclusion of persons with disabilities in Canadian society (Graefe & Levesque, 2006). Internationally, Canada participated in the development of the Inter-American Convention on the Elimination of all forms of Discrimination Against Persons with Disabilities in the late 1990’s. This is a human rights agreement within the Organization of American States (OAS), which requires states to progressively adopt legislation in the areas of social policy, education and employment to reduce discrimination against persons with disabilities (Organization of American States, n.d.). It is this treaty that pushed Canada into the development of the Convention for which disability organizations played a significant role.

Of note were two Canadian disability organizations primarily involved in the negotiations of the Convention: the Council of Canadians with Disabilities (CCD) and the Canadian Association for Community Living (CACL). In the early stages of negotiations (2004 – 2005) the CCD held national consultations with the Canadian disability community. These meetings helped shape the approach of the delegation, bringing forth ideas of the disability organizations present and emphasizing important rights such as, duty to accommodate, which represent important rights wins for the disability community. Additionally, in these consultations it was agreed that there would need to be a strong method of monitoring in order to have significant impact. These points of views informed the arguments of the civil society members of the Canadian delegation negotiating the Convention.

On March 30, 2007, Canada signed the Convention, much to the excitement of the disability community. Perhaps these feelings were even stronger as “[m]embers of the disability community were included in the Canadian delegation that worked at the UN over a five-year period to draft this Convention” (Council of Canadians with Disabilities, 2004). However, once signed, the CACL and the CCD, in particular, became involved in pressuring the government to keep its commitment to Canadians with disabilities and ratify the convention. For example, the CCD sent letters to many Canadian politicians, including Prime Minister Stephen Harper, reminding them of their commitments. The letters pointed out that at a recent meeting between disability organizations and the government “there was unanimous support for ratification [in 2009]” (Council of Canadians with Disabilities, 2009a). Other disability groups were also active in this process with over 100 groups signing the National Action Plan on Disability, which asked the government to ratify the Convention within two years of signing (Council of Canadians with Disabilities, 2009b). The ongoing involvement of disability organizations was needed to keep disability on the political agenda and push for Canadian ratification of the Convention.

On December 3, 2009 it was announced that the government would table the Convention in parliament. Steven Estey chair of CCD’s International Committee stated “[d]isability has not been and is not a partisan issue. All parties in the parties in the House of Commons have supported the development of the CRPD” (Council of Canadians with Disabilities, 2009c). Despite this, the process was stalled when Prime Minister Harper prorogued parliament on December 30, 2009. However, the Convention was ratified on March 10, 2010, not long after parliament resumed sitting and was celebrated as a victory by the disability community (Council of Canadians with Disabilities, 2010).

Following ratification of the Convention, the CCD shifted its attention to educating the disability community about the Convention and ensuring its implementation. A number of disability organizations including the CCD and the CACL gathered together to produce a Call to Action letter to ask government to "take leadership on implementing [the Convention]" (Council of Canadians with Disabilities, 2011). The CCD and CACL also worked together to create a working paper on what they saw as important in the implementation process. They specifically noted the need for "mechanisms for reporting, monitoring and reporting; a participation strategy; a framework for implementation and a public and transparent review process" (Council of Canadians with Disabilities, 2011). The CCD has also been active in persuading the government to keep its commitments to the monitoring structure of the Convention. It is notable that the Canadian government submitted their first report late in February 2014.

As this brief profile demonstrates, Canadian disability organizations, especially the CCD and the CACL which are both national disability coordinating organizations, have played a large role in the Convention process internationally and domestically. Canadian disability organizations were involved in the negotiations and also transmitted the views of smaller organizations. However, this role did not end after the negotiations of the Convention concluded. These disability organizations were in many ways responsible for keeping the Canadian government accountable to the Convention and persons with disabilities, a task which is still ongoing today (see Walker, 2013; Council of Canadians with Disabilities, 2011).

## The US, disability groups and the Convention

The disability movement emerged in the United States (US) in the 1960s. It challenged hierarchical conceptions of disability and worked to establish disability specific rights (Nielsen, 2012). The work of those involved culminated in three significant pieces of legislation: the 1968 *Architectural Barriers Act*, the 1973 *Rehabilitation Act* and the 1975 *Individuals with Disabilities Education Act* (IDEA). This legislation addressed accessibility of public buildings, nondiscrimination in federal programs and employment and education needs (for an overview, see Nielsen, 2012) and was largely consistent with the independent living movement emerging in California at the time. Yet, issues related to equality remained for which disability organizations continued their lobbying efforts and which culminated in the 1990 *Americans with Disabilities Act* (ADA). This act ensures the civil rights of persons with disabilities are protected from discrimination through provisions in the areas of employment, accessibility, transportation, and public services by focusing on reasonable accommodation (Batavia and Schriner, 2001). It is also this Act that is at the heart of the US’s refusal, to date, to ratify the Convention.

US disability groups have long worked to ensure their government signs and ratifies the Convention yet have consistently faced a US government that is reluctant to do so. Early in the process, People Who, a national disability organization geared to exchanging information on emerging issues related to mental and social health, recognized that “the US position is to not sign treaties that provide rights without remedies, [and] hence hasn’t signed the ‘holistic’ treaties that assert social rights. This treaty process [Convention] will take several years at best” (emphasis added; Caras, 2003). This was no secret and came directly from the Bush Jr. administration much to the chagrin of the disability community (see also Percy, 2001).

At the heart of US resistance is its preference for national laws such as the ADA as the way to ensure rights for persons with disabilities. As a result, the US delegation was limited to a support role sharing information rather than acting as a leader in the field and, as People Who noted, it was clear that there was no intent on the part of the US to increase their involvement or to ratify the Convention (Caras 2003, 2004; Human Rights Watch, 2009). This frustrated other countries and disability organizations who were looking for stronger guidance and leadership from the US to guide this Convention through the UN process, especially in light of the US’s adoption of the ADA years earlier (Stein & Lord, 2009).

This was a formidable challenge for US disability organizations to address. Two stand out in particular:  the National Council on Disability (NCD) and the US International Council on Disabilities (USICD). The NCD, an independent nonpartisan federal agency charged with providing advice to Congress and the President on disability policy, has long been involved in the process and released several briefing papers and reports throughout the process (for an overview, see National Council on Disability, 2004a, 2006) including the hosting of panel discussions comprised of experts to investigate the issues involved. For example, in a July 2004 NCD panel discussion, Janet Lord saw the US’s position of continued “neutrality” as “extraordinary” given its typical role in multilateral treaty negotiations, and given the lack of members from the disability community in its delegation (National Council on Disability, 2004b). The NCD has been particularly active in examining the consistency of the Convention with existing US laws such as the ADA, and has found “no legal impediment to US signature and ratification” of the Convention and, as such, encouraged the US to adopt and ratify the Convention (National Council on Disability, 2008). This finding is also consistent with academic commentary on the subject (see Melish, 2007; Quinn, 2009; Lord & Stein, 2008). The NCD expressed their "disappointment" at the failure of the US Senate to ratify the Convention in 2012 (National Council on Disability, 2012) and worked to continually educate decision makers and the public alike (e.g., National Council on Disability, 2013). For example, in 2014, the NCD addressed misperceptions related to concerns over the loss of sovereignty, a weakening of the US federal system, reproductive rights, and burdensome regulations, among other items, and again encouraged decision makers to ratify the Convention (National Council on Disability, 2014).

Similarly, the USICD, a federation of non-governmental organizations (e.g., disability organizations), government agencies and Americans with disabilities, has long advocated for the signing and ratification of the Convention. For example, they applauded President Obama's decision to sign the agreement in 2009 and have continually encouraged decision makers to ratify the Convention (USICD, 2009, 2010a). In late 2010, the USICD submitted written testimony to US Senate Hearings on the issue of the Convention in terms of its need and fit with US laws arguing for its ratification as soon as possible (USICD, 2010b). Like the NCD, the USICD denounced decision makers for failing to ratify the Convention in 2012 (see USICD, 2012a) and recently encouraged decision makers for ratification now that the US Supreme Court has ruled that the Convention is consistent with the federal character of the US (see the USICD's overview of the Court's Bond case decision—USICD, 2014; USICD, 2012b). Such a ruling should put to rest challenges to ratification put forth by some organizations such as the Heritage Foundation, who questioned the loss of US sovereignty, and by parentalrights.org, who challenged provisions for children with disabilities (Groves, 2013; parentalrights.org, n.d.).

Other disability groups that were heavily involved in the process were the Landmine Survivors Network and People Who, while many other groups such as the American Association of People with Disabilities (AAPD), United Spinal Association and the AG Bell Association for the Deaf and Hard of Hearing have recently stepped up their support for the Convention’s ratification (see AAPD, 2013; United Spinal Association, 2013; AG Bell Association, n.d.a, n.d.b). These groups were not part of any US delegation per se. Unlike their Canadian counterparts, US disability organizations have faced challenges to the level of participation of their government in the Convention, and related to its signing and ratification which is unusual given the early adoption of the *Americans with Disabilities Act* (1990) and unlike other countries such as the UK who have a long history of disability rights.

To date, the US has not ratified the Convention despite the significant work done by disability groups. Such resistance to ratification runs deep and dates back to the 1950s when to defeat efforts by some Senators, who felt threatened by international human rights treaties, to preserve the US’s legislatively entrenched racism, the Eisenhower administration “promised not to accede to any human rights treaties”, a position and legacy which largely continues to this day (Lord, 2015; Note that the US has also not ratified the UN Convention on the Rights of the Child which they signed in 1995. See United Nations, 2015a; and, Attiah, 2014). In response, disability groups have broadened their approach. While continuing to pressure decision makers to ratify the Convention, groups are working on strengthening existing disability legislation such as the *Rehabilitation Act*.

## The UK, disability groups and the Convention

The disability rights movement in the UK originated in the 1960s much like the US. By the 1970s, the tenets of what would become the social model of disability were elaborated thus thrusting the UK into the forefront of the disability rights movement (Vanhala, 2011). The result has been to polarize disability organizations into either organizations “of” or “for” persons with disabilities. The difference is that "of" organizations are largely led by persons with disabilities in pursuit of their rights embracing the social model of disability while the reverse was true for "for" organizations (largely led by non-disabled persons and embraced the medical model of disability). The British Council of Organisations of Disabled People (now the UK Disabled Peoples Council) would be an example of an "of" organization while "for" organizations included some of the largest disability organizations in the UK at the time such as Scope, the Royal National Institute for the Blind (RNIB), Mencap and Leonard Chesire Disability. Some of these charities have since undergone a transformation, embracing the social model of disability and changing their name once a significant number of persons with disabilities were able to attain senior positions within them such as was the case with the RNIB. In 2007, they changed their name to Royal National Institute *of* Blind People (RNIBP) (Vanhala, 2011: 156-173). This distinction is important and led to the 1995 *Disability Discrimination Act* (DDA) and subsequently the 2010 *Equality Act*, with disability organizations playing significant roles in their development and passage into law (Vanhala, 2011).

The 2006 Convention's development, adoption and ratification occurred between these Acts for which several disability organizations were actively involved. Such organizations included the British Council of Disabled People previously mentioned; Leonard Cheshire International, which largely focuses on disabled children's rights and the move to independent living; People with Disabilities in Ireland with a broad focus on disability rights; Scope, which promotes the full equality of persons with disabilities in society; and The National Society for Children and Adults with Learning Disabilities (RESCARE). These organizations were also involved either individually or as part of the UN Convention Campaign Coalition (UNCCC), an alliance of 29 disability organizations, the aim of which was to ensure UK ratification of the

Convention without reservations.[4] With UN treaties "[a] reservation is a declaration made by a state by which it purports to exclude or alter the legal effect of certain provisions of the treaty in their application to that state" (United Nations, N.D.c.). In some ways this process may undermine the principles fought for in the negotiation of the treaty. For example, the UNCCC was formed after it became clear that the UK government was tepid to the Convention's ratification and had several reservations (which perhaps explains the 2010 *Equality Act*'s embrace of the medical model). The result was a significant advocacy campaign including numerous memorandums to the UK Human Rights Joint Committee (UN Convention Campaign Coalition, 2009; on the range of submissions, see Parliament of the UK, 2008a).

For example, Leonard Cheshire Disability's Memorandum stressed the Convention's ratification while outlining the case that it was consistent with the EU's confirmation process (Parliament of the UK, 2008b). Yet, such a response to the Convention by the UK government should have come as no surprise to disability organizations given that Scope had months earlier raised concerns with the UK's stance (BBC News, 2008). Such action underscores the work disability organizations have done in the development of the Convention, but also in holding the UK government to account for its ratification.

Despite the efforts of disability organizations, the UK placed four reservations on the Convention at the time of ratification. The first was applied to Article 12, section 4, which outlines the need for the state to put safeguards in place to prevent the abuse of power when persons with disabilities are supported in exercising their legal capacity. With this reservation the UK reserved the right to keep in place a program it had for supported decision making, which at the time did not include a safeguard (United Nations, 2015b). This reservation has since been removed following a change in the program. Additionally, with regards to Article 18 the UK reserved the right to introduce legislation that may limit the "liberty of movement" as defined in the CRPD "for those who do not have the right under law to enter or remain in the UK" (United Nations, 2015b). In response to Article 24 the UK also reserved the right for parents to have the option of sending their child to an integrated school or a specialized school (United Nations, 2015b). Finally, with regards to Article 27 the UK reserved the right to consider disability in the employment of those in the armed forces (United Nations, 2015b). Following ratification of the CRPD in the UK, disability organizations have been active in pushing the government to remove these reservations and ensuring the UK follows through with their monitoring commitments to the Convention.

It is this monitoring role that disability organizations have continued since the Convention's ratification. It is on this point that Inclusion London and the UK Disabled People's Council have worked to monitor and aid governments in the difficult process of translating the Convention into "on the ground policy" (Inclusion London, 2012). This has included constantly reminding governments of the need for the rights and holding them to account by publishing reports when they fail (see, for example, Inclusion London, 2013). Inclusion London has also worked with other disability organizations in evaluating the progress of the UK government to implement the Convention by participating in a joint submission to the UN Universal Periodic Review Committee.[5] This critical review identified several aspects in need of attention, including the need for the UK to withdraw its reservations to four of the Convention's clauses, the lack of the UK government to incorporate the Convention into domestic law, a lack of government leadership on the disability file, and the problem of the government's partial retreat from aspects of the Convention, among other things (Disability Rights Watch, 2012). Similar concerns were elaborated by the Sisters of Frida in early 2013, a co-operative of disabled and allied women who share their experiences, mutually support and build relationships with each other, who focused narrowly on the disastrous effects this had on women (Sisters of Frida, 2013). As a result of the UK’s actions and the voices of disability organizations, the UK is the first country to face a UN inquiry into disability rights violations. These violations are in relation to Article 19, on living independently and being included in the community, and Article 28, on providing an adequate standard of living and social protection of the Convention (Inclusion London, 2014).

As the UK situation reveals, disability organizations have played a significant role in holding the UK government accountable. Not only were they significant actors in the Convention’s development, they worked with the UK government to ensure its signing and ratification, especially when the UK government seemed to pause or retreat somewhat from its commitment. It is this pause that has caused great concern for disability organizations and led to the current UN inquiry into disability rights violations.

## Conclusions

The story that emerges underscores the centrality of disability organizations in policy development, especially during times of government disinterest or indifference. Disability organizations remain significant civil society actors increasingly involved in policy development and service delivery functions. In the Canadian case, disability organizations partnered with the federal government in developing and elaborating its positions in the Convention process. In effect, the organizations were “embedded” in the delegation and were able to effectively put forth their positions. Such collaboration or partnering has since receded given the Convention’s signing and ratification, thus calling on disability organizations to renew efforts to work with the

Canadian government and hold it to account to ensure its implementation–something which organizations have so far been slow to do for various reasons, including funding challenges.

The US case is more complex. Disability organizations there have been marginalized in the Convention’s process, with the lack of representation in the US delegation, and have had to combat a leadership vacuum on the part of its federal government. This is significant given state and non-governmental actors from other countries repeatedly questioned the absence of disability leaders in the US delegation. US disability organizations have also had to address potential conflicts with US domestic law, which has taken until 2014 to be clarified. Even so, ratification remains elusive given the United States’ historically institutionalized position of not ratifying international human rights treaties. A fractured disability community as to the merits of the Convention has also not helped matters.

The UK case demonstrated great promise for the advancement of rights for persons with disabilities. The UK was already a leader in the shift to adoption and implementation of the social model of disability long before the Convention began. It also had one of the largest delegations throughout the Convention process incorporating ample disability organization representation in its delegation. However, such leadership soon evaporated when ratification of the agreement neared and the medical model of disability proved difficult to let go as evidenced with the 2010 *Equality Act*. The fact the UK government is now facing a UN inquiry for disability rights violations is also of much concern and suggests a backsliding of commitment by the UK, suggesting the ineffectiveness of disability organizations to sustain recently won gains. We disagree with this interpretation and point to the consistent and vocal work of disability organizations in the UK to uncover challenges and problem areas and to hold their government to account. This suggests that a robust civil society actor sector can play a significant role in monitoring processes, as well as policy development and implementation, which bodes well for potentially overcoming current challenges that they face, however difficult they may be.

Collectively, Canada, the US and the UK are at different points in the Convention’s ratification and implementation. In all countries, disability organizations have played a central role in the Convention–roles which have been mediated by their respective institutions and political culture. Even so, the fact remains that disability organizations are now and have been “at the table” as central players working to navigate social change while earning every incremental gain. This reveals the existence of a politically active and vibrant disability community, and a need to broaden our view of political participation beyond elected office and voting for persons with disabilities to include policy development and implementation.

At a broad level, our review of the situation in Canada, the United States and the United Kingdom is reflective of the neoliberal turn where an opening has been afforded non-governmental actors in policy development and implementation. In all of our cases, a range of disability groups have taken advantage of such opportunities with mixed results. As they have learned, participation in policy development and implementation does not ensure that meaningful changes are made or implemented. Furthermore, significant resources are needed to ensure their continued participation given the long time lines involved, resources—financial and human capital (often voluntary)—which must come from their supporters given the retrenchment of government funding for disability groups’ core operational services. This cacophony of disability actors has also afforded governments additional latitude and the opportunity to play groups off of each other and to keep them engaged while governments pursue their agenda of limited changes (Canada), no changes (the US) and conflictual changes (the UK) (on the nonneutrality of governments, see Bachrach and Baratz, 1970). This suggests that disability groups have been co-opted by the neoliberal state to do governments' work, thus further entrenching incremental changes. While seemingly negative, this may simply be a reflection of their new role as policy entrepreneurs in the development of the Convention and as watchdogs in its implementation. Simply put, their participation comes at a cost and expectations and timelines need to be managed accordingly to reflect their arrival in the policy process.

## Notes

1. One can also point to the recent examples of the UN International Convention for the Protection of All Persons from Enforced Disappearance (2006) and the UN Declaration on the Rights of Indigenous Peoples (2007).

2. Negative rights are seen to be non-interference on the part of others in an individual accessing a right, whereas positive rights are seen as including the support of others in accessing a right.

3. For an overview of the Court Challenges Program, see Coalition of Child Care Advocates of BC, n. d.; Brodie, 2001; on legal remedies, see Vanhala, 2011.

4. Other disability organisations who were part of this Coalition were: DAA, UK Disabled People's Council, Inclusion Scotland, NCIL, Alliance for Inclusive Education, Disability Equality in Education, Scope, RADAR, SIA, CSIE, Challenging Perspectives, National Federation of the Blind, Equalities National Council, APDA, LC Disability, Centre on Human Rights for Disabled People - (NI), Disability Action Northern Ireland, Capability Scotland, GADCIL, Preston Disc, ADD, Group of Solicitors with Disability, IDEA, Treehouse, and EqualAbility.

5. These organizations included: Disability Rights Watch UK, UK Disabled People's Council, Norfolk Coalition of Disabled People, Alliance for Inclusive Education, Inclusion London, The Guide Dogs for the Blind Association, Disability Alliance, Disability Equality North West, Equalities National Council, Action on Hearing Loss, Disability Action Northern Ireland, Mencap, Royal National Institute of Blind People, Radar, Scope, Sense, Learning Disability Coalition, Capability Scotland.

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