



Nothing about us without civil society: The role of civil society actors in the formation of the UN Convention on the Rights of Persons with Disabilities

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Abstract: In the past two decades civil society has increasingly played a role in global policy making. The UN Convention on the Rights of Persons with Disabilities is one such instance. This Convention represents a new model of involvement between nongovernmental organizations and multilateral policy making bodies at the global level. The unparalleled access that NGOs had to the delegates during the Convention and their participation in the drafting process created a legally binding, human rights-based Convention for Persons with Disabilities that is contextually different than it would have been absent civil society involvement. This is evident in three primary outcomes of the Convention: a human rights agenda for persons with disabilities; a definition of persons with disabilities; and the inclusion of gendered language establishing human rights for women with disabilities.

Key Words: Civil society participation, UN Disability Treaty, Multilateral consensus building, Global policy making

Introduction

The first human rights treaty of the 21st Century was adopted in December 2006. This treaty, the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), is also notable as it included remarkable participation from civil society actors such as nongovernmental organizations (NGOs), international nongovernmental organizations (INGOs), and disabled persons organizations (DPOs) in the drafting process (“Convention on the Rights of Persons with Disabilities,” 2011). It has been noted by some that the UNCRPD was the most expediently negotiated UN convention due to the participation of nongovernmental organizations and the involvement of persons with disabilities (Price, 2011). While this may be the case, the real value of civil society actors is demonstrated in the unique outlook they provided during the debate and the differing perspectives with which they approached the issues being deliberated. The participatory involvement of NGOs in policy creation at the global level has been on the rise in recent years and it is inferable that this has resulted in policy creation that has been more human

rights focused. Thus, given the unprecedented access that NGOs, INGOs, and DPOs experienced during the formation of the Convention, it is likely that their involvement is not only demonstrative of a paradigm shift in the way civil society interacts with multilateral institutions of global governance, but is also evident in the negotiated outcomes of the treaty.

The increased partnership between civil society and the United Nations leading up to the past few decades has been well documented¹. Participation guidelines for civil society were outlined at the founding of the United Nations in Article 71 of the UN Charter, which granted NGOs consultative status with the United Nations Economic and Social Council (ECOSOC). Allocating this level of participation to NGOs was significant because while it permitted NGOs to make recommendations to delegates - an action that observers were not permitted to take - it strictly prohibited NGOs from partaking in the deliberative process (Willets, 2000).

Literature review

Much has changed since 1945 and civil society actors have gradually gained further contributory rights in governance. Based on findings in the *World Development Report*, Sollis (1992) indicates that NGOs gained a standing in multilateral agencies through their involvement in the execution of development projects, but for the most part these organizations were not identified as companions for policy creation (Martens, 2006). It was not until a number of years later that NGOs were taken seriously at the decision-making table – a participatory status that is still hotly contested by some states (Alger, 2002; Willets, 2000). The advent of NGO participation was particularly noticeable in the 1990s when NGO and civil society collaborated in the creation of global environmental policy, specifically during the Rio Conference on Environment and Development in 1992 (Donini, 1995; Willets, 2000). Nonetheless, this involvement is discounted by some theorists. Willets, for example, argues that while NGOs have the ability to be recognized and speak to their areas of expertise before the UN, they lack the ability to partake in voting and are likewise are not supposed to negotiate or craft the creation of policy within the UN (2000).

Franklin (2007) points out that in the case of the World Summit on Information Society, the involvement of NGOs in a participatory fashion indicated the United Nation's new approach towards nongovernmental agencies by incorporating these valuable knowledge units into the

¹ Alger (2002), for example, writes at length about this phenomenon and the repercussions of NGO involvement at the UN.

policy making dialogue. This rise of the so-called ‘Third UN’ is, as Franklin says, an example of the UN’s embracement of a multi-stakeholder participatory model of governance. This model can encompass a variety of stakeholders including, but not limited to, NGOs, businesses, and thought leaders. While this model might be more readily used to view other types of civil society/governance interactions, it does provide a good basis from which to view the UNCRPD, as NGOs regularly attempted to negotiate and increase their clout, to varying degrees of success within multilateral institutions.

The involvement of civil society actors in issues of global governance has, as Holzscheiter (2005) asserts, “shaken up the state-centric picture of international decision making” (p. 274). Putnam’s concept about civil society and governmental interactions, as summarized by Kim (2009), emphasizes the give and pull that exists between these two sectors as agreeable outcomes in spite of sometimes contradicting goals are sought. The role and participation of civil society, it is argued, creates better governance, as it tempers a government-centric perspective.

Some theorists have speculated that increased civil society involvement in global policy making occurred as a result of citizen disenchantment in political parties that failed to represent the desires of various constituencies on a global scale. Van der Heijden (2002) makes this argument in regards to the formation of the aforementioned global environmental policies. The impetus for the existence of many NGOs is to either advocate for governmental change or to fulfill functional roles that governments are failing to perform or do so adequately, argues Gordenker & Weiss (1995). Kamat (2004) makes a similar argument, but claims instead that this phenomenon results from states experiencing motivation from “private interests.” Hence, NGO membership rolls are increasingly benefiting from the erosion of other traditional forms of civil society organizations such as unions or religious groups (p. 158).

Teegen, Doh, and Vachani (2004) make a similar argument through the utilization of an international business lens to view this problem, wherein actors provide governance and value through their participation. They also argue that NGOs fill a representational void that is not adequately being met by state or market players. In doing so, NGOs are undertaking the tasks that were previously ascribed to nations (Raustiala, 1997). A dearth of hope in one’s government is what Courville & Piper (2004) describe as a motivating factor in citizens seeking out social justice through nongovernmental means. This framework of NGO involvement arising from a

failure of other resources or governance bodies is instrumental in providing a powerful foundation upon which to examine global advocacy NGOs. This is particularly true of the case of NGO involvement in the crafting of the United Nations Conventions on the Rights of Persons with Disabilities (UNCRPD) as global initiatives had, for years, attempted to meet the needs of persons with disabilities with very little success.

The participation of NGOs and other civil society actors in policy making and implementation at the multilateral level has resulted in much discourse about what constitutes balance between the two, sometimes conflicting, aims of these bodies. Gordenker & Weiss (1995) write that oftentimes the power within group negotiations favors one body over another even though both may desire collaboration and cooperation. This concern is well articulated by Kim (2009) in the description of the “danger of participation” being one in which NGOs and civil society oftentimes fear that “cooperation will degenerate into co-option” (p. 875). Willets argues that there should be a collaborative role between NGOs and nation-states as both have a vested interest in global governance. This is achieved in different manners by governments and civil society due to the former possessing the deliberative power of the pulpit compared to the latter, which Willets refers to as ‘powerless’ (2000, p. 199). On other hand, proponents of the multi-stakeholder approach to governance, such as that articulated by Franklin, would argue that the inclusion of multiple vested parties at the discussion has leveled the scales of power (Helmerich & Malets, 2011). The more idealistic of theorists argue that this approach has also led to the type of selfless deliberation that is championed by Mansbridge et al. (Matz & Ferenz, 2005; Mansbridge et al., 2010). The equality of deliberation and lack of self-interest may be the norm in ideal governance circumstances; however, it is unlikely that this is often, if ever, achieved in normative governance negotiations at the global level. The value implicit in civil society being granted a voice is that, generally speaking, NGOs and civil society actors are representative of their membership and don’t have the same propensity to bow to outside interests². As such, Kamat (2004) generalizes that civil society driven policy is indicative of a bottom-up approach to development.

The involvement of nongovernmental organizations and international nongovernmental organizations in other global areas of concern has also been increasing in recent years as the

² At the same time, one of the criticisms that is levied against NGOs is that their outside interests are more easily disguised than those experienced by governments. This may well be the case in some instances, but the financial incentives experienced by government officials are much greater and well documented.

United Nations has attempted to gain knowledge from outside sources in a bid to appease those who oppose their top-down development schemes. This has been true in the negotiations around establishment of the UNCRPD as well. NGOs and DPOs were permitted to participate in the Ad Hoc Committee meetings, their consultation was encouraged, and a fund was created to ensure that financial restrictions would not prohibit the participation of experts on these issues from developing nations (Melish, 2007). Much remained the status quo within the drafting of the UNCRPD, but there were many positive outcomes included in the final document that would likely have not been realized had there not been an active force within the meetings advocating for outcomes desired by members of civil society.

Despite the varying perspectives on the causal factors for increased NGO involvement in global governance, it is probable that the outcomes of the Convention on the Rights of Persons with Disabilities would have been different had civil society actors and NGOs been excluded from the drafting process. After all, the UNCRPD was not the first initiative undertaken by the UN to address the needs of the disabled. The year 1981 was dedicated as the International Year of Disabled Persons (“The International Year,” 2003-4). One outcome of this was the creation of the World Programme of Action Concerning Disabled Persons, adopted in 1982, which included guidelines for responsive action (“World Programme of Action,” 1982; “World Programme of Action,” n.d.). It was decided the 1983-1992 would be the United Nations Decade of Disabled Persons which saw the adoption of guidelines for educational equality for persons with disabilities and a declaration outlining rights due persons with cognitive illness or disabilities (“United Nations Decade,” n.d.). There have since been numerous other initiatives that included provisions for persons with disabilities, but none have been so significant as the UNCRPD³.

The case for development for persons with disabilities

Individuals with disabilities are routinely acknowledged as the world’s poorest population for a variety of circumstantial reasons (Barnes & Sheldon, 2010). Globally, people with disabilities and their families inherently face greater challenges than their able-bodied peers. These challenges impact them for life. Children with disabilities are more likely to have untreated illness, not learn basic social skills due to reduced interactions with others, and lack

³ The UN enable website has a detailed timeline devoted to the first fifty years of development initiatives and policymaking. This can be viewed at <http://www.un.org/esa/socdev/enable/dis50y00.htm> and is recommended for any scholar interested in this topic.

proper schooling due to poor attendance or a lack of resources to meet their needs should they attend (Moore & Yeo, 2003). Without resources and support structures, those who are born with disabilities are less likely to achieve success and more likely to stay impoverished. These and additional challenges set them up for difficult lives as adults, and these adversities are compounded for individuals who face so-called double discrimination for other identity features in addition to their disability, such as their gender or religious affiliation (Moore & Yeo, 2003; Price, 2011; Reina, Adya, & Blanck, 2007). A household with a disabled family member is economically less secure than their neighbors either due to additional expenses or less income. In Tanzania, for example, households that fit this description have both a 20 percent greater likelihood of being poor and a mean consumption rate of up to 60 percent less than their neighbors (Masset & White, 2004). In urban slums, the lack of opportunities can be even more stark, as Barnes & Sheldon (2010) state, “between 65 and 80% of India’s estimated 60 million disabled people live in areas where public amenities such as clean water, electricity and sanitation are almost non-existent” (p. 77). It is likely that these living conditions are the standard rather than the exception for many disabled people the world over.

Similarly, it has been determined that poverty can lead to disability through the lack of adequate shelter, medical treatment, or suitable food and water sources (Masset & White, 2004; Moore & Yeo, 2003). An estimated 100 million people suffer from disabilities that have been caused by malnutrition or lack of sanitary environments (Moore & Yeo, 2003). Additionally, Moore & Yeo (2003) cite a World Health Organization study from 1992, which determined that significant blindness and hearing loss exhibited in children in Africa and Asia was preventable or treatable. Of the estimated 650 million people with disabilities worldwide, the majority are poverty-stricken (Rasmussen & Lewis, 2007).

It is generally accepted that 15 percent of the global population is disabled; however, due to discrimination and exclusion in the developing world, little is known about the living conditions of those who need to be lifted out of poverty (World Health Organization, 2011; Lord, Suozzi, & Taylor, 2010; Yeo, 2001). What is known, according to Lord et al. (2010), is that “in all countries disability rates are significantly higher among groups with lower economic status, underscoring the link between poverty and disability...one of every five of the world’s poorest persons is disabled” (p. 565). The cycle of poverty and disability is argued by Yeo (2001) to be a product of discrimination, which propagates a life of poverty. In the worst instances this leads to

chronic poverty. This issue is of grave concern for organizations involved in development, and it presents a strong argument for the creation of a multilateral convention seeking to increase the agency and reduce the discrimination of disabled persons.

Civil society involvement in the formation of the UNCRPD

The needs of the disabled have been addressed in various ways at the state and global level; however, most of the global initiatives failed to meet the needs of this people group. At the national level, legislative initiatives to establish equal rights for persons with disabilities have been notably sparse. According to Karr (2011), equal access legislation had been adopted by only 39 member states prior to the adoption of the UNCRPD (p. 68). It is important to note in light of the lackluster previous legislative initiatives that civil society was allowed unusual access and drafting privileges during the deliberative proceedings of the UNCRPD (Lord et al., 2010; Rasmussen & Lewis, 2006). The involvement of NGOs may have increased the complexity of the political wrangling during the drafting of the UNCRPD, but the outcomes were better as a result. The organizations who represented persons with disabilities during the drafting were able to utilize their collective voice to create policy which, while far from complete, demonstrated that allowing a minority group the faculty to act as determinants in the policy that shapes their lives can result in powerful and meaningful outcomes. While the UN largely remains a top-down organization, the sanctioning of these minority voices as valid is a step in the right direction. From the perspective of the DPOs, the UNCRPD should be representative of an inclusive approach to disability – an approach that mandates the participation of persons with disabilities in the formation of policies going forward (Lang, 2005).

During the first session of the Ad Hoc Committee on a Comprehensive and Integral International Convention on Protection and Promotion of the Rights and Dignity of Persons with Disabilities (hereafter referred to as the Ad Hoc Committee), Chairman Luis Gallegos proposed, and the committee agreed to, NGO participation in the Ad Hoc Committee process through attending meetings, making statements, receiving documents, and distributing their statements (“Report of the Ad Hoc,” 2005). The committee also recommended to the General Assembly during this first meeting that steps be taken to improve the accessibility of the United Nations facilities and encouraged adoption of a draft resolution which not only emphasized the value of NGO participation in the Committee, but encouraging member states to include disabled

person's NGOs and persons with disabilities in their delegations ("Report of the Ad Hoc," 2005).⁴

The rosy outlook with which the Ad Hoc Committee embraced the participation and voice of NGOs in the creation of the proceedings would not last, and a tension was demonstrated, as NGOs desired more clout while state delegations believed themselves to be sufficiently accommodating for the NGOs. During these initial Ad Hoc Committee meetings, according to Lang (2005), few persons with disabilities were present for the deliberations, which resulted in the initial approach towards the Convention representing the ideology of the medical model – the significance of which will be later explored.

To leverage the expertise of the various DPOs and NGOs involved, the International Disability Caucus was established (Lang, 2005). This caucus, representing approximately 50 NGOs, INGOs and DPOs, was driven by consensus, predicated on mutual respect, and sought to present a cohesive agenda that would be both applicable and beneficial to all with disabilities (Minkowitz & Kovary, 2008; Rasmussen & Lewis, 2006; Reina, 2008). These goals were marginally successful and the influence the caucus exerted during the proceedings and the outcomes they negotiated are regularly cited in literature on this issue.

The second Ad Hoc Committee meeting took place in June 2003 and a working group was established to draft the text of the international convention. This working group included 12 NGO representatives (from a diverse selection of accredited NGOs). Lines of funding were established through the Voluntary Fund to assist with the cost of travel to New York for NGOs and persons with disabilities from economically disadvantaged nations ("Ad Hoc Committee," 2005). After this second Ad Hoc Committee meeting, *Ability* magazine noted that continued involvement of civil society actors was being contested by some state delegates. This contributed to a sense of discontentment within the DPO community regarding the lack of adoption of their proposals (Sabatello, 2004).

The Working Group for the creation of the draft text convened in January 2004. Of the 12 non-governmental organizations represented, one was from the Middle East (Jordan), one was from Latin America (Costa Rica), one represented Africa (South Africa), and India and the Philippines each had a representative present. The remaining seven were from the global North

⁴ It is important to note that most of the NGOs that were classified as accredited for the Ad Hoc Committee were those that enjoyed consultative status with ECOSOC. Exceptions were made for 24 NGOs that did not have consultative status with ECOSOC ("Ad Hoc Committee," 2003).

or a developed country (New Zealand) (“Working Group,” 2007). There were 27 governments and one human rights institution that were also involved in the Working Group (Lang, 2005). The International Disability Caucus had a role in the selection of the NGO representatives in the Working Group, and the seats were first allocated to seven members of the International Disability Alliance.⁵ Geographic location was the decisive factor in deciding the allocation of the remaining five positions on the Working Group (Lang, 2005).

Nongovernmental organizations that were involved but not members of the Working Group were disproportionately represented by the West (Lang, 2005). Even within NGOs that represent the globally disabled there are biases inherent in the perspectives of the cultural background of the NGOs involved in the convention.⁶

Later, in the spring of 2004, the Ad Hoc Committee met for its third session. During this session there was some debate about limiting the continued involvement of civil society actors within the Ad Hoc Committee. This debate was not resolved during the third session nor prior to the fourth session. Much of the conflict pertained to if, and how, NGOs should be permitted to participate in the informal sessions where many policy decisions were deliberated and decided (Light, 2004). Early on in the third session, states reached an agreement pertaining to the policies guiding NGO participation during informal sessions. It was established that accredited NGOs would continue to be able to participate during the formal sessions, as was already the case. It was also determined that they could observe the informal proceedings, which had been previously prohibited. The International Disability Caucus is credited with lobbying for this decision; however, as pointed out by Light (2004), the so-called ‘open informals’ created the opportunity for some discussion to occur in closed-door, off-the-record meetings. This reduced the transparency of these the decision making negotiations, but it did not seem to greatly inhibit the ability of NGOs to influence Convention outcomes on the aggregate.

During the fourth session in August and September of 2004, the participation of these groups at this level was upheld, but they did not receive the full range of benefits granted to the state participants (“Timeline,” 2011). The International Disability Caucus at the conclusion of the fourth Ad Hoc Committee meeting issued a statement indicating that they wished to be

⁵ Interestingly enough, the International Disability Alliance, an umbrella organization for DPOs, claim to have championed the creation of the International Disability Caucus (Lang, 2005; “Who we are,” 2009).

⁶ It is, however, important to note that the unequal participation of citizens from the global south has been noted within NGOs as well and is relatively systemic to the international NGO community (Edwards, 2005).

further utilized and included in the process. Specifically, this statement indicates that the Caucus wished for more accessible proceedings and continued contributions to the UN Voluntary Fund to provide for travel expenses for NGOs from developing nations to attend the meetings. Finally, the statement demanded the implementation of a “consultation mechanism with the International Disability Caucus” (“Disability Caucus Closing Statement,” 2004: 3).

The fifth Ad Hoc Committee session occurred in January and February of 2005. The majority of the meetings held during this session were informal in nature, resulting in states purportedly being the only participants who could offer interjections. Exceptions were made for three of these sessions that were opened to NGO statements (Doherty, 2005). Reina (2008) mentions that the prohibition on active participation by NGOs during the informals was not always upheld as occasionally they were permitted to comment in these sessions. Additionally, Reina (2008) mentions that sessions would occasionally temporarily adjourn to allow for NGO intervention. The chair of Disabled People International, on behalf of the International Disability Caucus, issued a statement at the conclusion of the fifth session again expressing a desire to be more fully utilized during the proceedings (Ilagan, 2005). Requests were additionally made at this time for documentation to be provided in an accessible manner and done so in a timely fashion (Ilagan, 2005). The subsequent sixth and seventh Ad Hoc Committee meetings did not demonstrate any noteworthy changes to the involvement of civil society actors; however, it is of significance that negotiations pertaining to the language referencing women with disabilities, which represented a great victory for civil society involvement, occurred during the sixth session of the Ad Hoc Committee (Arnade & Haefner, 2011). During the eight session, the final draft was adopted and the UN General Assembly subsequently adopted the convention in December 2006 (“Timeline,” 2011).

Without the contribution of civil society actors within the context of the creation of the UNCPRD, states would have been unlikely to implement policies that required them to critically examine their own practices (Melish, 2007). The power that NGOs and DPOs leveraged and the engagement of citizens was vital in the realization of an outcome that was more agreeable to both states and civil society actors. NGOs involved in the drafting of the UNCPRD were capable of guiding the final Convention towards objectives that would have been unfulfilled otherwise. This is not to say that they achieved any, or most, of their goals; however, it is demonstrative of the beneficial role that civil society involvement can have on global governance deliberations.

Outcomes negotiated by civil society involvement

Human rights-based model implementation

In recent years there has been a systemic shift in the way that development agencies have thought about how to best serve the needs of the disabled. Previously, rights discussions for these individuals were primarily concerned with meeting disabled persons' basic needs from the perspective of individual deficiencies (Lord et al., 2010). Rather than continue to implement development strategies from this so-called medical method, a human rights approach towards the disabled has brought forth the social model of disability, which views disability as a product of "socially constructed barriers" (Lord et al., 2010, p. 564). As such, persons who have a disability are able to claim an entitlement to the rights that are afforded the able-bodied in society.

The medical model is described by de Búrca (2010) as the model "in which disadvantages are generally viewed as intrinsic to the condition of the person" (p. 2). The person who has a disability, according to this model, is categorically lacking an ability or capacity compared to a person without a disability. This was the foundational ideology toward disability upon which most relevant policies globally had been based prior to the UNCRPD. Some nations had implemented laws that were more reflective of the social model, but for many governments, particularly those representing less developed nations, thinking about disability through the lens of the social or biopsychosocial model was a departure from their domestic practices⁷.

The social model of disability has been defined in a variety of ways, but most theorists agree to a number of overarching themes. For example, it is mostly agreed that the social model is human rights driven and socially constructed. According to Moore & Yeo, this results in a definition of disability as "the loss or limitation of opportunities to take part in the everyday life of the community and on an equal level with others due to physical or social barriers," and thus an approach towards realizing equality for those who are disabled must be based on "societal change" (2003, p. 572). Albert & Hurst state that "impairment is seen as normal for any population" and the utilization of the social model is helpful to understand how the "complex web of discrimination," provides fewer opportunities and greater difficulties for those with

⁷ It is particularly important to note at this juncture that there was a schism between countries who passed legislation reflective of the social model, and nations who enforced this legislation to the fullest extent. Furthermore, while the UN made an effort to promote a human rights based agenda for persons with disabilities through the Standard Rules on the Equalization of Opportunities for Persons with Disabilities in the early 1990s this, and other bureaucratic steps, toward equality for persons with disabilities were more symbolic than practical and representative of a moral argument for rights rather than a concrete legally enforceable one (Standard Rules, 1993).

disabilities (Albert & Hurst, 2005, p. 2). As such, the social model mandates a societal response, such as legislative initiatives to correct the discrepancies (Jette, 2006).

Another framework utilized for conceptualizing disability is that of the biopsychosocial model. Within this model, disability is understood as a phenomenon resulting from the combination of “biological, personal, and social forces” (Jette, 2006, p. 727). The World Health Organization agreed upon the *International Classification of Functioning, Disability, and Health* (ICF) in 2001. This model includes varying degrees of bodily functions, activity, and participation (Jette, 2006).

Bickenbach (2009) describes the difference between the medical and biopsychosocial models in the following manner:

Disability is most validly conceptualized, not merely as a problem or abnormality in how a person functions or behaves (the medical model) but as a multi-dimensional outcome of complex interactions between features of a person’s physical and psychological condition and the physical, human built, socio-cultural, attitudinal and political environment. (p. 1112)

This definition is logical and convincing. Yes, societal change is a component of attempting to increase the equality of access for those with disabilities, but the physical limitations associated with disability must be approached with a viewpoint of acknowledging the diversity of environmental and societal actions that create the boundaries that are the basis of discrimination. In speaking about assigning a human rights approach toward persons with disabilities, Bickenbach also states that the values a human rights perspective seeks to provide are those which are foundational to a good life – freedom, health, and opportunities (2009, p. 1115). This list is reminiscent of the human capabilities outlined by Martha Nussbaum. These capabilities, such as life, bodily health, affiliation, and bodily integrity, cannot be met for marginalized populations without the active involvement of government and civil society actors alike (Nussbaum, 2007)⁸.

Powerfully, for persons with disabilities, despite the fact that some governments argued that a human rights convention was not necessary, this ideology supports the case made by DPOs

⁸ The universality associated with the application Nussbaum’s capabilities to persons with disabilities is contested; as such, this comprises one of many difficulties in forming a human rights convention on the subject. This is one of the shortcomings of the biopsychosocial model– that this model is difficult to use as a policy-making framework as benchmarks pertaining to conditions of ability or disability are not globally equal (Barnes, 2011; Clements & Read (eds), 2008).

that a model of disability assistance cognitive of the complex dynamics associated with disability and a human rights agenda, must be implemented by states if these capabilities are to be met. Albert and Hurst (2005) make this case in arguing that human rights equality for persons with disabilities entails the state protecting these people from the discrimination that could prevent them from achieving the values that they have a right to as a result of their humanity. This is the case even if a physical or mental condition may make achievement of those freedoms more difficult.

It was through the lens of such a model that the UNCRPD was established⁹, and this focus primarily came about due to the involvement of DPOs & NGOs (Lang, 2005). Mexico was instrumental in the formation of the Convention on disabilities, thus there was much conflict when the delegation from Mexico introduced a draft that neglected a human rights framework (de Búrca, 2010; “History,” 2011). NGOs actively protested this draft, and it is extremely probable that without the involvement of civil society the Convention would have proceeded without the human rights framework (de Búrca, 2010). Within the contextual framework of the Convention, the social model is evident in the phraseology that is utilized. For example, the Preamble acknowledges “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” (“Convention on the Rights of Persons with Disabilities Text,” n.d.) The social and biopsychosocial model is particularly evident in the following components that were negotiated by NGOs.

A definition of disability

According to de Búrca (2010), one of the most significant debates about language in the Convention pertained to the insertion of a definition of disability or person with disability. The state delegations, in general, preferred to not include a definition of disability in the Convention. For the most part, this opposition was constructed due to concerns that the language included would contradict their current narrowly-defined state laws. The cultural perspectives implicit in describing and defining disability also varies greatly. Thus, even if national delegations would

⁹ It is important to note that a model acknowledging that these progressive models previously guided some UN initiatives. The International Year of Disabled Persons, for example, focused on creating culture of “fairness and equality” for persons with disabilities (“The International Year,” 2003-4). However, initiatives prior to the UNCRPD lacked the brevity that is associated with a human rights convention.

have wanted to include a definition of person with disability it was unlikely that a consensus on the definition of that term would be reached (Schulze, 2009).

Civil society and NGOs, on the other hand, generally lobbied for an explicit definition of disability or person with disability. For NGOs, the campaign was grounded in the belief that due to systemic discrimination against persons with disabilities, the inclusion of a definition would limit the possibilities of this discrimination occurring in the future. The specifics of the definition were debated heavily and in some regards the NGOs involved did not see the victories that they desired. The International Disability Caucus, for example, opposed the definition of a person with disability as someone who is described as having a “long-term” impairment (Schulze, 2009). This group also advocated for a definition that listed more types of impairments including psychosocial and neurological (Schulze, 2009). They did not achieve their desired outcomes on either of these accounts, but ultimately, NGOs did succeed and a definition of a person with disabilities was included; however, it was not unanimously agreed upon (de Búrca, 2010)¹⁰.

Rights for women with disabilities

Disabled women are particularly vulnerable and oftentimes face prejudice based on both their gender and their disability (Reina et al., 2007). States such as Kenya and South Korea were advocates for the insertion of a stand-alone component addressing this issue, whereas civil society actors argued that this would not sufficiently protect women with disabilities, particularly those residing in developing countries and more likely to be the victims of double discrimination (Reina et al., 2007; Hershey, 2006)¹¹. While most states acknowledged that women’s rights should be addressed in some manner within the UNCRPD, there was some antagonism toward the adoption of a gendered perspective on the grounds that women – both with and without disabilities – were protected under the Convention on the Elimination of All Forms of Discrimination Against Women (Arnade & Haefner, 2011).

For civil society actors during the drafting of the UNCRPD, attempting to determine how best to establish a human rights agenda that also met the unique needs of disabled women represented an area of conflict with states. Within civil society, this resulted in conversations

¹⁰ The definition of a person with disabilities reads, “Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction as with various barriers may hinder their full and effective participation in society on an equal basis with others.” (“Convention on the Rights of Persons with Disabilities Text,” n.d.)

¹¹ Doherty (2005) writes that Korea was especially involved in advocating for the inclusion of language pertaining to women’s rights due to the lobbying efforts of Korean civil society groups.

relating to the different perspectives that women from nations of differing stages in development brought toward disability. The experience of living with a disability varies greatly for women from developing countries compared to those who reside in first-world countries; as such, they wanted very different outcomes from the inclusion of a gendered perspective (Hershey, 2006). For civil society and state delegations, the deliberation consisted of determining if the circumstances faced by women with disabilities should be included in the preamble, a standalone article, or through gendered language employed throughout the whole document (Reina et al., 2007; Hershey, 2006).

The aforementioned International Disability Caucus and the women's caucus within Disabled People's International argued for the implementation of the ultimately agreed upon two-track approach with an article on disabled women and gendered language in certain articles throughout the rest of the Convention (Hershey, 2006). Arnade & Haefner (2011), among others, write that there was great consternation over how women should be included. The twin track approach was clearly a hard fought success¹². Without the involvement of civil society in general, and women within civil society in particular, the inclusion of women's rights in this manner may not have occurred.

At the same time, it is worth noting that certain articles within the UNCRPD do not include a gendered perspective despite this advocacy. These articles include those pertaining to familial rights (Article 23), education (Article 24), rehabilitation services (Article 26), and employment (Article 27) (Reina et al., 2007). The lack of specific language pertaining to the rights of women in these articles are of concern and are representative of areas in which women face additional discrimination compared to their male counterparts. Women in developing nations believed that greater benefit would be achieved due to gendered language throughout the Convention, so it is of concern from a development perspective that these articles, which are important components of development, lacked such particulars (Hershey, 2006).¹³

Critiques & conclusions

¹² Civil society's ownership of this success is evident in that the proposal for the twin track approach was drafted by civil society and adopted by the state delegates, rather than the other way around (Arnade & Haefner, 2011).

¹³ Interestingly, there have been struggles within DPOs as to how to include female voices within the advocacy of rights for women with disabilities and the adoption of feminist ideology for women with disabilities to see equal representation with their male peers (Price, 2011). It is thus, important to note that the rights of women were debated at the multilateral level, even though the struggles for women are still occurring within their own advocacy organizations.

In general, criticisms about NGO involvement in global governance focus on the lack of accountability and transparency of NGOs. Marginalized groups might not be represented within NGOs, such as the instance of women within disability NGOs. Similarly, in a study conducted by Flower & Wirz (2000) on the participation of persons with disabilities within NGOs, it was determined that NGOs incorporate persons with disabilities into the organizational structure through information sharing. Organizational roles that entail decision making and leadership are too often filled by persons without disabilities. Certainly, this was also seen at the global level during the sessions informing the creation of the UNCRPD, and it remains an area of growth for organizations that seek to represent this marginalized population. As with the state, concerns relating to policy decisions being driven by financial incentives from powerful influences, rather than constituency interest do exist.

Within the drafting of the UNCRPD, NGO representation was primarily from organizations based out of the West (Lang, 2005). Because disability is approached from different perspectives based on cultural assumptions (Bickenbach, 2009; Karr, 2011), the perspective, participation, and lobbying of a majority of Western or global North NGOs during the creation of the UNCRPD may have resulted in skewed outcomes as result of cultural beliefs or norms. The lack of involvement of NGOs from the South and developing nations, despite the financial assistance provided to attend, might present an area of further research. Additionally, valuable research might entail attempting to understand if North/South power dialogues were present within NGO deliberations. The creation of the International Disability Caucus meant that in some instances NGOs that were not members or held differing opinions were silenced. Did this occur along these cultural divisions as well? Furthermore, Light (2004), contends that some NGOs, which were not disability advocacy organizations, were able to utilize the procedural benefits of NGO participation to further their own aims. What was the influence of these organizations on the proceedings?

Overall, as Lord et al. argue, civil society and NGO involvement in the drafting process was instrumental in ensuring that the UNDCRP utilized a holistic approach towards establishing rights for individuals with disabilities, and DPOs played an important role in bringing the perspective of those most impacted by the Convention to the forefront of the negotiations (2010). Likewise, Rasmussen & Lewis (2007) state “the CRPD was the first UN Convention with

significant civil society input in its drafting process. In fact, much of the final text incorporates that drafted by civil society” (p. 441).

The UNCRPD demonstrated a monumental step towards the establishment of a human rights lens to apply to the rights of persons with disabilities, but it remains to be seen if the Convention will result in economic advancement for these persons. Undoubtedly, raising awareness about the realities of life for many with disabilities and drawing attention to their economic and social needs globally has been valuable. The UNCRPD has yet to be tested and demonstrate that it can assist in meeting the MDGs for persons with disabilities. Criticisms have also been levied about the significance of the Convention due to the failure of the United States to ratify. While the US argues that ratification is not necessary based on current US law dedicated to increasing equality for persons with disabilities, the lack of US support is notable. Future research dimensions on this topic may focus on the role of NGOs in the implementation process and determining if continued NGO involvement at the state level extends the value of the UNCRPD beyond the initial guidelines established in the convention.

Ultimately, the rallying cry of the international disabled persons movement of “Nothing about us without us” should reflect the power of their organizational alliances in the creation of the UNCRPD. Without NGO involvement, the collective voice of the globally disabled may not have been heard and the final Convention on their behalf would have severely lacked the human rights framework and outcomes that were necessary. Despite the fact that disabled persons organizations and nongovernmental organizations did not achieve all their goals, they were successful in facilitating the creation of a legally binding, human rights-based Convention for Persons with Disabilities. The involvement of disabled persons in the process reflects the sentiment from Courville & Piper that “hope can be used to mobilize various marginalized groups to find a collective voice, eventually leading to empowerment” (2004, p. 39). This case demonstrates that the engagement of discriminated populations in advocacy through nongovernmental organizations must continue as these partnerships with organizations of global governance yield better governance and policies for the most relegated members of society.

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