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### Publication Date

2014

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UNIVERSITY OF CALIFORNIA, SAN DIEGO

Human Rights and Grassroots Organizations:  
Localizing the United Nations Convention on the Rights of Persons with Disabilities  
in Nicaragua

A dissertation submitted in partial satisfaction of the  
requirements for the degree Doctor of Philosophy

in

Sociology

by

Stephen Meyers

Committee in charge:

Professor Amy Binder, Chair  
Professor Gershon Shafir, Co-Chair  
Professor Kwai Ng  
Professor Nancy Postero  
Professor Richard Feinberg

2014



The Dissertation of Stephen Meyers is approved, and it is acceptable in quality and form for publication on microfilm and electronically:

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University of California, San Diego

2014

## DEDICATION

I would like to dedicate this dissertation to persons with disabilities in Nicaragua and all that they do to make their own world and all of our worlds better.

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## ACKNOWLEDGEMENTS

I would like to acknowledge Professor Amy Binder and Professor Gershon Shafir. Together, as my Chair and Co-Chair, they guided me through this dissertation with wisdom and, I believe, love (if not for me, at least for sociology). Both of you provided me a guiding hand on my shoulder (and another hand firmly pushing me back). I would also like to acknowledge Professor Kwai Ng for reminding me why I chose to do this (i.e. for people not for publications). I would like to acknowledge Professor Nancy Postero, for her questions about my approach to human rights, and Professor Richard Feinberg, for his interest in Nicaragua. Rafel Lucea, thank you for your kindness and interest these years, especially when we were together in Washington D.C.

There are, of course, teachers of theory, research, and method, and then there are teachers of life. I would like to acknowledge Santiago Castellon for his wisdom and partnership for more than a decade in creating opportunities for people with disabilities in Nicaragua. His generosity, however, as he will admit, pales in comparison to the acceptance and insight provided to me by the leaders and members of the various grassroots associations I worked with. You inspire me.

I would also like to acknowledge the constellation of friends that have kept me sane (or at least kept me company in my insanity). First, there was Shark Night. While all evidence points in a different direction, I believe all of you Thursday night loyalists actually enjoyed those movies we watched week in and week out for more than three years. Secondly, there is TwoME (Muscle Mass Explosion). We are now back up to bench pressing our body weight, which is good as we do not want the size of our

brains to exceed the size of our chests. Lastly, and most recently, I would like to acknowledge EMRAQ (Embracing MiddleAged-hood Racquetball). It is amazing none of us have sustained major injuries, but I assume that is because our stress relief is focused on the ball and not each other. There are individuals, of course, who I want to name directly. Hugh Erik, ever since our mothers threw us in the same playpen while they Jazzercised, you have been my one, constant friend. Milda, my soul mate, we only have forty-eight years to go. Negin, my little sister, I assume more almond cookie/sugar bombs are on their way. Ian, do not think that just because my dissertation is over I am going to stop getting up at 5:00 a.m. and making coffee. Zoe, Play Club will never have a final act. Cristina, you and I will both make it in the end, whether in the UN or academia, I do not know. Tad, you were the sounding board for my initial ideas. Valerie, we will take over the world together (and then, in the end, you will take it over from me). Other people, fill your name in here and come up with something witty to say about it.

Chapter 1, in full, is a reprint of the material as it will appear in *Research in Social Science and Disability* 2014. The dissertation author was the sole author of this paper.

Chapter 3, in full, is a reprint of material as it will appear in *Qualitative Sociology* 2014. The dissertation author was the sole author of this paper.

Chapter 4, in full, is a reprint of material as it appears in the *International Journal of Politics, Culture, and Society* 2014. The dissertation author was the sole author of this paper.



## VITA

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- Meyers, S. (2014). "Global Civil Society as Megaphone or Echo Chamber?: Formalizing voice in the international disability rights movement." *International Journal of Politics, Culture, and Society*.
- Meyers, S. (2014) "The Past Dividing the Present: Nicaragua's Legacy of War Shaping Disability Rights Today." D. Mitchell and V. Karr (Ed.s) *Crisis, Conflict, and Disability: Ensuring Equality*. (Routledge). Pp. 195-201.
- Meyers, S., V. Karr, and V. Pineda. (2014). "Youth with Disabilities in Law and Civil Society: Exclusion and inclusion in public policy and NGO networks in Cambodia and Indonesia." *Disability and the Global South Journal*. 1(1): 5-28.

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- Karr, V.L., Meyers, S. (2013). "Acceptance or acceptability: Youth inclusion in today's schools." In Azzopardi, A. (Ed.) *Youth: Responding to lives - An international handbook*. (Boston: Sense Publishers): 123-136.
- Pineda, V.S., Karr, V.L., Ali, C., Meyers, S. (2011). *Ensuring rights in development: Implementing the UN Convention on the Rights of Persons with Disabilities with select case studies from the MENA region*. (Open Hands Initiative).
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ABSTRACT OF THE DISSERTATION

Human Rights and Grassroots Organizations:  
Localizing the United Nations Convention on the Rights of Persons with Disabilities  
in Nicaragua

by

Stephen Meyers

Doctor of Philosophy in Sociology

University of California, San Diego, 2014

Professor Amy Binder, Chair  
Professor Gershon Shafir, Co-Chair

The passage of the UN Convention on the Rights of Persons with Disabilities in 2006 was hailed by the international disability rights movement as “giving voice” to millions of persons with disabilities around the world. The Convention institutionalizes a role for Disabled Persons Organizations (DPOs) in monitoring their rights. As such, international disability NGOs, networks, and funders have initiated capacity building projects that organize persons with disabilities for advocacy in local

communities around the world. A central tension, however, has emerged. While the international disability movement is interested in mobilizing grassroots groups, it is also interested in ensuring that those DPOs reflect global priorities. As such, the international movement is engaged in promoting a very narrow organizational model that corresponds to membership-based, human rights advocacy that conflicts directly with the self-help, social support model that is the basis of many local disabled persons organizations, especially in the developing world.

Using qualitative data drawn from fieldwork with grassroots disability associations in Northern Nicaragua, this article shows that international and national organizations have utilized a number of methods, including providing advocacy training, establishing new organizations, formalizing reporting procedures, to bring DPOs together around a human rights advocacy agenda. Program implementation, however, revealed a narrow concern with political empowerment that did not resonate with a local focus on addressing material needs and the instillation of a strict hierarchy and bureaucratic procedures that did not allow local DPOs to deviate from pre-determined, top-down agendas. This case study provides insight into the way global civil society legitimates itself through outreach directed at the grassroots, yet does not allow their full participation in interpreting and implementing their human rights. When local groups resist, it is understood as the result of a lack of consciousness or clear understanding rather than the strategic response of associations embedded in cooperative relationships and focused on addressing the material needs of their members.

## **Introduction**

### **Sociological approaches to human rights and civil society**

Sociologists have struggled with the idea of human rights for more than twenty years (Turner, 1993, 2006; Waters, 1996; Stammers, 1999; Freeman, 2002; Woodiwiss, 2005; Morris, 2006; Somers and Roberts, 2008). Despite two decades of grappling with the issue, the basic problem persists: human rights is an inherently normative concept that is seemingly ill-suited for sociological investigation. Theories of human rights are often paired with the equally moral concepts of the “good,” the “just” (Henkin, 1990, p. 1), human dignity (Donnelly, 1982), and natural rights to basic needs (Shue, 1996). Sociology’s aspiration of producing (Weberian) value-free knowledge rooted in objective (Durkheimian) social fact (Turner, 2006, p. 6-12; Morris, 2006, p. 2-7) has put the discipline in a weak position vis-à-vis legal studies and the humanities in terms of developing a theory of human rights. Despite these challenges, Bryan Turner has argued that sociology can offer ontological grounding for human rights through a sociology of the body and the universal “precariousness” of our social institutions (Turner, 1993, 2006). This attempt, however, has met stiff opposition on the basis that it not only offers a very narrow conception of human rights as only those claims relevant to the physical body, but makes little use of sociology’s core strengths (Waters, 1996). More recently, Amitai Etzioni has offered a normative, yet non-ontological, theory of human rights on the basis that human rights are simply “self-evident moral claims” that only “closed minds” or “closed societies” could ignore (Etzioni, 2010, p. 194). Etzioni’s explicit goal of justifying “cross-

cultural moral judgments” (Ibid., p. 197), however, is even more problematic than Turner’s in terms of guiding objective social scientific research.

The solution for developing a sociological approach to human rights, however, is seemingly simple. It is to focus on the fact that human rights have become the “lingua franca of global struggles” (Somers and Roberts, 2008, p. 385). In the present era of globalization, human rights has become one of the most useful tools in the toolbox of social movement organizations (Stammers, 1999), whether in terms of local protests or transnational campaigns. To wit, the Universal Declaration on Human Rights was all but a dead letter in the context of a post-World War II system premised on non-intervention and sovereignty until the South African anti-apartheid movement chose it as the corner stone of its 1950s campaign (Klug, 2005). From that time forward, the meaning of human rights and its associated practices “have been socially constructed in the context of social movement challenges” (Stammers, 1999, p. 981). To put things another way in an era wherein transnational movements are carried forth by a World Polity (Boli and Thomas, 1997), the “rights explosion” (Epp, 1998) is tied to the “NGO boom” (Hershey, 2013; See also Sikkink, 2002). In many ways, legal theorists, UN agencies, and heads of state are continually playing catch-up with civil society with the human rights theory, law (i.e. conventions), and policies they produce or enact.

While sociologists of citizenship have challenged the notion of human rights on the grounds that the “sovereign nation-state still remains the sole institution that administers and enforces rights, even those conceived to be universally held” (Shafir, 2004, p. 11), Somers convincingly argues that citizenship and human rights are built

upon the same foundation: human recognition. Furthermore, in both cases, that recognition requires membership within both political and civil society (Somers 2008; Somers and Roberts 2008, p.414). It is the latter form of inclusion—civil society—where sociology has an opportunity to make its biggest contribution, but also faces significant barriers.

Civil society, like human rights, has become a conceptual terrain riddled with problems, in large part because of its current link to human rights. Since the late 1980s, when the study of civil society was rejuvenated by grassroots, anti-Communism campaigns in Eastern Europe (Cohen and Arato, 1992), civil society has been paired with the value-laden notions of democratization (Putnam, 1993), “strength” (Waisman, 2006), “voice” (Kaldor, 2003, p. 11), freedom (Rudolph, 2000), and empowerment (Chapman, 2009). The net result has been that civil society is either so narrowly defined that its non-conventional forms are dismissed (Lichterman, 2011) or it is so universally celebrated that its basic organizational characteristics are ignored (Watkins, Swidler, and Hannan, 2012).

Somers herself exemplifies the biggest problem: by linking civil society and rights together, she argues that only those forms of civil society engaged in political advocacy are good, and therefore should be supported, and those falling outside of that model are deemed as bad, and should therefore be opposed. In *Genealogies of Citizenship* (2008), she identifies the type of civil society promoted by social capital theory (i.e. voluntary associations premised on communal responsibility) as a socially and politically marginalizing force, going on to endorse “democratic associations of rights-claiming citizens” as the singular route towards inclusion (p. 253). Somers’



advocacy of a certain type of civil society is not only reflected in her own research and the research of other social scientists, but in the practices of UN agencies and international NGOs. The recently published *UN Handbook on Civil Society* defines civil society as those associations that “scrutinize the implementation of human rights, report violations [of human rights abuses]... and campaign for the development of new human rights standards” (UN-OHCHR, 2007, p. iii) and international NGOs dedicated to a “rights-based development” paradigm only identify “people’s organizations and social movements in a collective struggle for change” (Chapman, 2009, p. 180) as potential allies, designating all other voluntary organizations as either ineffectual or actual barriers to change.

The result of this merging of civil society with human rights advocacy is that many forms of associational life, especially those found in the Global South, are deemed “backward” (Lewis, 2001), traditional, “weak” (Waisman et al., 2006), “bad” (Chambers and Kopstein, 2001), or otherwise illegitimate. What this means is that those service organizations, religious groups, social support networks, and other forms of voluntary life that the world’s poor not only benefit from, but oftentimes create and contribute their time, energy, and resources towards, are categorized as part of the problem and therefore in need of change. Ironically, while Somers argues that “the right to have rights” (2008) depends on membership in civil society, she and many others do not extend those rights-bearers the right to define the mission and practice of their own associations. In the end, civil society and human rights conflate: both are about rights claims. And claims-making in the name of human rights—getting out into the street, publishing reports, raising awareness—has increasingly become the only

legitimate action that a civil society association can take, whether its members believe it serves their needs or not.

In order to step back from the normative, prescriptive, and *ought*-based rather than *what-is*-based nature of most sociological approaches to human rights and civil society, I have taken an organizational view of both. Interpretations of human rights are made within organizations and many organizations are structured on the basis of dominant interpretations of human rights. Quite simply, global civil society is populated with formal organizations and informal associations that are just as susceptible to environmental pressures (Watkins, Swidler, and Hanna, 2012) as any other organization is (i.e. corporations, states, schools, etc.), whether they are claiming to be “doing good” (Fisher, 1997) —i.e. claiming to promote human rights—or not. Sociological institutionalists have been helpful in this regard by developing a research agenda focused on the way institutions, or formal and informal “rules and belief systems” (Scott, 1992), are promoted within organizational environments (Meyer and Rowan, 1977; DiMaggio and Powell, 1983). As such, human rights are just another “global model” (Boyle, 2002; Meyer, Boli, Thomas, and Ramirez 1997) or organizational ideology that can be used to pressure organizations to change. Institutionalists have also highlighted the role that a “world polity” (Boli and Thomas, 1997) of international and grassroots NGOs plays in promoting human rights and the importance that the local integration into global civil society (Hafner-Burton and TsuTsu, 2005; TsuTsu and Shin, 2008; Cole, 2012) can play in promoting specific human rights instruments. Typically, institutionalist or World Society (Meyer, 2009), which is the name institutionalism typically goes under when applied globally,

approaches to worldwide organizational change, however, fail to follow the organizational chain all the way down to the local level in order to understand how grassroots actors integrate global models in their everyday lives.

To figure out what human rights are in the lives of real people, I decided to not only approach the issue organizationally, but also ethnographically. I decided to take a backseat and let the world's most marginalized, who are the presumed beneficiaries of human rights, speak and act for themselves. What that has produced is an institutional ethnography wherein I have sought to record what the "inhabitants" (Hallett and Ventresca, 2006) of institutions say and do in regards to their rights and their organizations. That has meant keeping a close eye on the everyday interactions that take place in small, voluntary associations in one of this world's far-flung hinterlands: Segovia (a pseudonym), Nicaragua.

### **Disability rights as product and producer of civil society**

I chose to focus on the international disability rights movement because of personal familiarity with the field, but also because of the force by which it has been expanding in recent years and the universality of disability around the world (the World Health Organization estimates 15% of the world's population experiences some level of disability; WHO, 2011). Due to the recent passage of the UN Convention on the Rights of Persons with Disabilities (2006), grassroots groups of disabled persons, many of which have organizational histories dating back decades, have been forced to reckon with human rights, whether they have wanted to or not. The UNCRPD and the

international organizations associated with its promotion have created new, global, environmental pressures that have forced local civil society organizations to “electively and strategically adapt” (Maines, 1977, p. 250) and diversify as their old organizational models clash with new ones (Lounsbury, 2007). My decision to take a grassroots perspective on the international disability rights movement has allowed me to go below the “surface similarities” (Hallett, 2010, p. 55) found between disabled persons organizations (DPOs) worldwide, such as missions statements and various activities (i.e. annual marches), and to instead highlight the context and group-specific interpretations of disability rights made by local actors and expose tensions that get to the very essence of how individuals define themselves and relate to the outside world.

The international disability rights movement offers an unprecedented opportunity for exploring the relationship between civil society and human rights and the meaning-making and everyday practices that define them. The 2006 UN Convention on the Rights of Persons with Disabilities (UNPRD) is both a *product* of civil society and a *producer* of civil society. It is the celebrated achievement of a collection of international NGOs and global disability activists (Sabatello, 2014; Lord, 2008) as well as their impetus to enlarge and enhance their networks and take their message out of New York, Geneva, and Washington D.C. and into the cramped offices, dusty streets, and living rooms of persons with disabilities and their grassroots associations spread throughout the world, especially in the Global South.

The passage of the UNCRPD in 2006 was a watershed moment for the advancement of disability rights globally. The hope of the backers of the UNCRPD is that, as an international human rights instrument, countries around the world will be

forced to address the social marginality of disabled persons within their societies. While implementing the rights outlined within the Convention is first and foremost an obligation of the states that have signed and ratified it, a very specific role for civil society groups representing persons with disabilities is contained within its articles (Sabatello, 2014, pp. 23-24). The General Obligations of the UNCRPD state that “Persons with disabilities are actively involved in the definition and implementation of their rights, through their representative organizations” and Article 33 states that disable persons organizations (DPOs) “shall be involved and participate fully in the [treaty’s] monitoring process.” As the first major international human rights instrument of the 21<sup>st</sup> Century, the UNCRPD represents a significant advancement in the formal institutionalization (i.e. written into the law) of civil society into the rights monitoring process. This is, in many ways, a reflection of the fact that international NGOs and global networks of DPOs in North America and Western Europe were at the negotiating table and included in the Convention writing process (Lord, 2008; See also Sabatello, 2014), a process that heretofore had been left to UN agency staff and representatives of states.

As such, addressing the social, political, and economic marginality of persons with disabilities around the world has been reframed through the “macro-logic” or “global model” (Boyle, 2002; Meyer, Boli, Thomas, and Ramirez, 1997) of human rights. The problems persons with disabilities face are no longer understood to be the result of their individual physical, sensory, or intellectual impairments, but the result of a discriminatory society that refuses to recognize their rights. While this social model (Oliver, 1986) or rights-based paradigm (UN-ENABLE, 2010) of disability has

been present in the West since the 1970s, it is predominantly new in the less developed world.

The rights-based approach to disability is inextricably linked to persons with disabilities advocating for themselves. This, in turn, means that membership-based disabled persons associations doing rights advocacy is the only legitimate form of civil society recognized by the international disability movement. In the pages that follow, I will look at the way in which this organizational model has been exported around the world, which includes my field site in Segovia, Nicaragua.

### **A map to the chapters ahead**

The following dissertation is somewhat unorthodox for a doctoral candidate in sociology at the University of California, San Diego. Rather than produce a “book-like” dissertation of integrated chapters, each of which builds upon the other, I have produced separate essays, four of which were written as journal articles and, thus, designed to be self-contained “worlds of their own.” Chapter 3, which outlines theory and methods, and this introduction and the final conclusion, are the exceptions as they were written solely for the purposes of the dissertation. All four article essays, however, utilize data from the same source—eighteen months of participant observation of a grassroots coalition of disabled persons organizations in Segovia, Nicaragua over the summers of 2009, 2010, and an eleven month period during 2011-2012—and attempt to highlight intra- and inter-organizational change as local disability associations are integrated into the international disability rights movement.

To a certain extent, the articles are repetitive, in that they must provide background on the international disability rights movement, give an overview of my field site in Nicaragua, and summarize data and methods. But they are each different, taking a slightly different view on the movement and marshalling different aspects of my data in order to make an original argument. The strength of the dissertation is that I have been able to open up many fronts and engage in many debates. The weakness of the dissertation, however, is that I may be speaking to too many audiences rather than fully and consistently engage one, specific academic debate. The conclusion, however, seeks to identify the most important implications of my research in total and to sketch a route ahead by which I can continue using my data, including data I have not yet analyzed or used in any of my existing articles, to produce one, book-length monograph that makes a singular, yet impactful, argument.

As a reader, you can quite literally read the following chapters in any order you wish. You can or will soon be able to find several of them in published form. Chapter 4, “Global Civil Society as Megaphone or Echo Chamber?: Formalizing voice in the international disability rights movement,” is currently available online and will be published in a forthcoming print edition of the *International Journal of Politics, Culture, and Society*. Chapter 3, “The Social Model under the Shadow of the Revolution: Ex-combatants negotiating disability identity in Nicaragua” has been accepted for *Qualitative Sociology*. Chapter 1, “Disabled persons associations at the crossroads of two organizational environments: grassroots groups as part of an international movement and a local civil society” is currently under its second review as a “revise and resubmit” with *Research in Social Science and Disability*. Chapter 5,

“The Problem of ‘Pretty Little Programs’: Disability consciousness and intra-movement conflict,” however, is the outlier in that it was rejected by *Mobilization*. I, however, plan to rewrite Chapter 5 in the near future and submit it elsewhere. There are also three additional works that are based upon my dissertation research, which I am not including here in the dissertation because they were written expressly for an interdisciplinary or policymaking audience. These three additional works are “Wounded Warriors or One of the Crowd?: Civil War, Citizenship, and Disability in Nicaragua” in *Peace Studies Journal* (2013); “The Past Dividing the Present: Nicaragua’s Legacy of War Shaping Disability Rights Today” in the edited volume, *Crisis, Conflict, and Disability: Ensuring Equality* (2014); and “A Tale of Two Civil Societies: Expectations regarding public resources and disabled persons organizations in Nicaragua and Uruguay,” which was co-authored with Elizabeth Lockwood and is forthcoming in the July, 2014 issue of the *Disability Studies Quarterly*.

As a guide to the following chapters, I am providing a brief summary of each, specifying their particular contribution towards the overarching dissertation project.

*Chapter 1: Disabled persons associations at the crossroads of two organizational environments: grassroots groups as part of an international movement and a local civil society*

This chapter provides a broad overview of my research by arguing that by analytically situating grassroots DPOs as “caught” between two different organizational environments, we can better understand why some DPOs embrace the rights-based advocacy model promoted by the international disability rights movement



and others reject or reinterpret it in relation to the norms of their local civil society. Organizational environments are defined as all those organizations providing or associated with the provision of a specific product or service (Meyer and Rowan, 1977; Scott and Meyer, 1992, p. 129; DiMaggio and Powell, 1991, p. 65). Using the analogy of a Venn Diagram, I describe local disability associations in Segovia as struggling between meeting the expectations of international disability NGOs and global DPO networks and meeting the expectations that their members and the broader Nicaraguan have for voluntary associations to provide concrete services, often in cooperation with the government. By taking this approach, I am able to describe the structuration processes (DiMaggio, 1991) that took place over the past ten or fifteen years to create an international disability movement and compare that to the structuration processes which occurred during the Nicaraguan Revolutionary Period (1979-1990) that yielded the expectations for civil society that most Nicaraguans hold today. I am then able to provide a series of examples showing how and why particular DPOs either embraced, resisted, or innovated upon the rights advocacy organizational model promoted by international disability NGOs active in Nicaragua.

*Chapter 2: Inhabiting grassroots civil society: Organizational theory and small group method.*

Political theorists and social scientists have increasingly narrowed the scope of what is considered to be civil society and inserted normative language regarding what constitutes the “right” kind of civil society for democratization and economic development. It is therefore necessary to take an organizational approach towards

voluntary associations in order to understand their basic features. Sociological institutionalism and World Society Theory offer that opportunity. These approaches, however, only look at superficial similarities, requiring an “inhabited” approach wherein group style and intra-organizational interactions can be studied in order to understand how organizational models are reinterpreted and put into practice.

*Chapter 3: The Social Model under the Shadow of the Revolution: Ex-combatants negotiating disability identity in Nicaragua*

The social model of disability, which defines disability as the product of social discrimination rather than the physical, cognitive, or sensory differences of individuals (Oliver, 1983), became the dominant logic of the international disability field with the 2006 passage of the UN Convention for the Rights of Persons with Disabilities (Sabatello and Schultz, 2014, p. 2). As such, international NGOs have sought to enlist grassroots disability associations around the world to advocate for their new rights. These campaigns promote a new identity frame of disabled persons as a globally and universally oppressed group (Sheldon, 2005, p. 126). This identity, however, does not benefit all groups equally, and actually threatens some. Using qualitative methods, I compare the usage of the disability identity by two grassroots associations in Nicaragua. Ex-Contra soldiers with disabilities use the identity to obfuscate their discredited history as “traitors” and, instead, represent themselves as unjustly discriminated against disabled persons deserving special benefits and human rights

protections. Ex-Sandinista soldiers with disabilities also make claims, but only reluctantly as disabled, preferring to self-identify as war wounded. Because of changes in law, however, Ex-Sandinista soldiers increasingly are unable to make claims as “war heroes” (Bruun, 1995), but must instead access benefits as persons with disabilities “in general.” This case demonstrates how actors strategically use the social model of disability in relation to local political culture and group identity.

*Chapter 4: Global Civil Society as Megaphone or Echo Chamber?: Formalizing voice in the international disability rights movement*

Using two seemingly contradictory depictions of transnational human rights campaigns as “multiplying the voices heard in domestic and international politics” (Keck and Sikkink, 1998, p. x) and only effective when they are able to “cue, commend, or curtail the proliferation of speakers” in order to maintain a “core message” (Brysk, 2013, p. 211), I challenge the notion that the international disability rights movement is “giving voice” to millions of persons with disabilities around the world simply because the UNCRD institutionalizes a role for DPOs to monitor their rights. Instead, I point to a central tension that has emerged within the movement. While international disability NGOs and global DPO networks are interested in mobilizing grassroots groups, they are also interested in ensuring that those grassroots DPOs reflect their global priorities rather than local concerns.

Using qualitative data drawn from my fieldwork, I show that international and national organizations have utilized a number of methods, including providing

advocacy training, establishing new organizations, formalizing reporting procedures, and so forth to bring DPOs together around a human rights advocacy agenda. Program implementation, however, revealed a narrow concern with political empowerment that did not resonate with a local focus on addressing material needs and the instillation of a strict hierarchy and bureaucratic procedures that did not allow local DPOs to deviate from pre-determined, top-down agendas.

*Chapter 5: The Problem of 'Pretty Little Programs': Disability consciousness and intra-movement conflict*

Fostering group consciousness has served as an important means for mobilizing groups for collective action. The Western disability movement is an exemplary consciousness movement (Groch, 1994; Barnartt, 1996; Barnartt and Scotch 2001), having mobilized persons with disabilities to confront discrimination and advocate for change. Since the passage of the UN Convention on the Rights of Persons with Disabilities in 2006, international activists have been promoting disability consciousness throughout the Global South, where they often encounter resistance from grassroots disability associations, especially those providing rehabilitation services. Disability activists have interpreted this resistance as a “false consciousness” (Charlton, 2000, p. 70) caused by persons with disabilities internalizing negative beliefs about themselves. Using data collected at international meetings and a youth center in Segovia, Nicaragua, I demonstrate the way activists use the perceived lack of disability consciousness in developing countries as justification

for forcing fundamental change in the policy and practice of grassroots organizations. In this case, first a German NGO and then a national office of a network of grassroots associations, attempt to force a day program for youth with developmental disabilities shut down, replacing it with consciousness-raising workshops meant to empower the youth. The parents, youth, and larger community rebel and reinstate the old organizational model. This article contributes towards a greater understanding of the negative and often unexplored disempowering aspects of consciousness movements (Mansbridge 2001, p. 250).

*Conclusion: “Obras, No Palabras!” – Works, Not Words!: Rights, Resources, and Relevance*

I conclude by discussing the vulnerability of persons with disabilities and their precariousness. The current rights-based model is rooted in a discursive approaches to the public sphere that is inappropriate when applied to societies that lack resources to redistribute public goods in response to political action. Instead, the culture of solidarity demonstrates an alternative approach to realizing rights through social support and self-help. Nicaragua nor disability, however, are unique. The relationship between human rights and civil societies should be examined in relation to other rights-bearing identity groups (i.e. indigenous or the “aged”) and other cultural and economic contexts.

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## Chapter 1

### **Disabled persons associations at the crossroads of two organizational environments: Grassroots groups as part of an international movement and a local civil society**

#### **Introduction**

During the National Disability Day rally that took place in Segovia (a pseudonym), Nicaragua in the summer of 2010, the leadership of the *departemento's* (or province's) seven disability associations sat in a row on the community center's stage. Off to the side stood a representative from Handicap International, which is one of several international nongovernmental organizations (NGOs) providing technical assistance to disabled persons organizations (DPOs) in town. Above the grassroots leaders hung a banner, which had just been carried the length of Segovia's main street at the head of a march. The banner proclaimed "25 Agosto: *Día Nacional de la Persona con discapacidad*" along the top, *Comisión Departmental de incidencia y sensibilizacion de personas con discapacidad* (Departmental Commission for Advocacy and Awareness—CDIS, a coalition made up of the seven associations) in the middle, and—untranslated from English—the logo for the "Disability Rights Fund" along the bottom. In front, stood the Mayor with a microphone in hand, ready to respond to a short series of speeches from each association in the coalition concerning the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). Miss Deaf Nicaragua, a local member of the Nicaraguan Association of the Deaf, had just signed an impassioned speech, demanding the municipality put a sign language interpreter in every classroom; the Association of the Physically and

Motorly Disabled had just pointed out all of the inaccessible buildings that needed to be changed; and the president of the Association of the Blind and chair of CDIS, announced the coalition's new objectives for 2010-2011 as placing more members in local cigar-rolling factories and encouraging the city hall to establish the nation's first municipal office for disability affairs. Each demand utilized the language of human rights.

The Mayor began his response slowly by listing a few of his office's accomplishments: wheelchair ramps had been added around the central plaza and more children with disabilities were now going to public schools. The Mayor then announced that these accomplishments were insufficient, paused dramatically, and took his speech in a very different direction. Rather than renew promises, make excuses, or outline future plans, the Mayor explained that the government *could not*, and, in fact, *should not* do everything that needed to be done. Appealing to the grassroots associations sitting behind him, he explained that the people and the government were "brothers." He went on to begin a short civics lesson, not just for the benefit of the disability rights commission, but for the two or three hundred people gathered that afternoon in the gymnasium. The Mayor appealed to three words: "*Cristiana, Socialista, Solidaria*" (Christian, Socialist, Solidarity) and explained that in Nicaragua, since the Sandinista Revolution thirty-one years earlier, everyone had their part to play in contributing towards the common good. The Mayor went on to say that the rights of persons with disabilities could only be fulfilled if everyone worked together, hand in hand. He was referring to a long history of civil society, government, and even business sharing responsibility for promoting a better life for all

Nicaraguans. The members of CDIS, sitting below the banner and behind the Mayor, nodded in agreement...the Handicap International representative did not (Field Notes: August 25, 2010).

The tension on the community center stage four years ago is emblematic of how Segovia's disability associations are caught at the crossroads of two organizational environments: 1.) the international disability rights movement—NGOs, foreign donors, and transnational networks focused on promoting the UNCRPD—which pressures them to engage in political advocacy; and 2.) Nicaraguan civil society, a collection of hundreds of “mass” organizations, which mobilize citizens in “solidarity” work and pushes them to provide basic services. In short, DPOs in Segovia sit at the intersection of a Venn diagram, where opposing organizational environments uncomfortably overlap, each claiming the DPOs as theirs alone.

The place where DPOs in Nicaragua find themselves is not unique, yet few researchers or activists recognize the different organizational environments that lay claim upon grassroots disability associations. Sociological institutionalism (Meyer and Rowan, 1977), however, provides some basic tools for conceptualizing the situation. An organizational environment is composed of all the organizations that provide “a given product or service” (Scott and Meyer, 1992, p. 129) plus other “relevant actors” (DiMaggio and Powell, 1991, p. 65). The organizational environment for automobile manufacturing, for example, would not only include GM, Toyota, and so forth, but also their suppliers, unions, and regulators. As such, institutionalists, who focus on the social and cultural mechanisms that govern behavior (i.e. institutions), depict organizational environments as arenas where its members are pushed “toward

homogenization” (DiMaggio and Powell, 1991, p. 64) and adopt “scripts” (Jepperson, 2002) based upon the expectations of others in something analogous to organizational “peer pressure.” In a quest for legitimacy, organizations model themselves off of others and conform to both formal and informal “rules and belief systems” (Scott, 1992) regarding their field. In the era of globalization, many organizations, ranging from voluntary associations (Hwang, 2006) through to governmental agencies (Kernaghan, 2000), reflect global models promoted by worldwide organizational environments, even when those models do not reflect local needs or effective practices. More recent institutional theory, however, shows that the members of organizations on the ground, or the “inhabitants of institutions” (Hallett and Ventresca, 2006), respond to external environmental pressures in diverse ways.

The international disability rights movement, defined in this article as those organizational actors whose primary mission is to promote the ratification and implementation of the UN Convention on the Rights of Persons with Disabilities (UNCRPD), is an organizational environment actively drawing grassroots disability associations in the Global South into its fold. Part of this worldwide expansion consists of technical assistance programs meant to “empower” local DPOs as rights activists. In Segovia, however, many of the members of local DPOs do not see their groups as part of a larger movement, but instead expect them to act according to the norms of a local civil society populated by self-help and social support groups.

By focusing on this organizational environmental “crossroads” where the global meets the local, I am offering an alternative analysis to disability studies scholars and activists who dismiss local resistance to the human rights-based model of

disability as signifying a backwards “culture” (Ingstad and Whyte, 1995; Phillips, 2009) or “false consciousness” (Charlton, 2000). Instead, I am arguing that the diverse responses of local DPOs in Segovia to the international model of disability rights advocacy can better be understood in terms of opposing organizational environments wherein grassroots associations are simultaneously pressured to look and act one way by international organizations and to look and act another way in response to local civil society. Understanding the position DPOs are in is not only important for analysis, but also policy development.

### **The international disability movement promoting a new organizational model**

The passage of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) in 2006 was a watershed moment for the international disability rights movement. The hope is that the UNCRPD, as an international human rights instrument, will force states around the world to rectify the marginality of disabled persons. Governments, however, are not the only actors being asked to change: grassroots DPOs are too. The international disability rights movement constitutes an organizational environment composed of UN agencies, global DPO networks, international NGOs, and others who are pressuring local DPOs to adopt a new organizational model. In this section, I will review literature indicative of “structuration” processes (DiMaggio, 1991) within the international disability rights movement that have made advocacy DPOs a global standard.

The organizational model of DPOs promoted around the world is a product of the disability movements in North America and Europe. In the 1960s and 1970s,



Americans with disabilities involved in civil rights protests began to see their own marginality in terms of the systemic discrimination (Barnartt & Scotch, 2001) and Western Europeans with disabilities began to utilize the Marxist-materialist language of oppression (Finkelstein, 2001) and exploitation (Abberley, 1987, p. 8). Soon, Western activists sought to effect social change through collective action (Groch, 1994; Barnartt, 1996). Establishing advocacy DPOs was seen as an important means for displacing medical experts and traditional charities as the spokespersons of persons with disabilities and thus giving persons with disabilities power over their own lives (Oliver, 2004, pp. 22-23).

Over time, Western disability activists began to turn their attention towards developing countries. A movement coalesced around the call for a UN human rights convention specifically for persons with disabilities. The drivers for the UNCRPD in the late 1990s and early 2000s were individual activists, international NGOs, and DPO networks primarily based in the West (Lord, 2008; See also Sabatello, 2014). As a result, they were instrumental in shaping the UNCRPD and inserting language within it that specifies DPOs as advocates (Sabatello, 2014, pp. 23-24). The General Obligations of the UNCRPD state that “Persons with disabilities [should be] actively involved in the definition and implementation of their rights, through their representative organizations” and Article 33 states that DPOs “shall be involved and participate fully in the [treaty’s] monitoring process.” This language, in essence, is a mandate for persons with disabilities to form organizations that do rights advocacy. The UNCRPD, thus, acts as a blueprint for what grassroots disability associations should look like and how they should act.

While international disability rights actors identify local groups as allies in promoting the UNCRPD for their potential to exert pressure on government from below, they also, paradoxically, depict these same grassroots groups as a barrier towards the advancement of rights for being service providers. Ubiquitous amongst comparisons between Western disability movements and those in developing countries is the observation that while DPOs in the North are concerned with rights, “In Southern countries, the groups themselves often feel that the most immediate needs are for practical programs of rehabilitation” (Ingstadt & Whyte, 1995, p. 24) and “meeting their survival needs” (Turmasani, 2003, p. 3). In regards to Post-Soviet states, Phillips (2009) asserts that local DPOs are “plagued by socialist legacies,” “have a narrow focus on shoring up social programs,” and should therefore pursue international partnerships that can teach them a new model (p. 283). The author of an earlier survey of DPOs that spanned Latin America and Africa argued that many DPO members have internalized negative cultural beliefs about disability and therefore have a “false consciousness” that constitutes a “major barrier faced by the disability rights movement” (Charlton, 2000, p. 70).

Perhaps most importantly, the international working group of UN advocates and experts who wrote the UNCRPD itself, also saw DPOs as problematic for not being advocacy organizations. In 2002, while reporting on progress made on the convention, the authors lamented that DPOs in developing countries “often fail to engage with the human rights system” and then argued that “there is therefore a need for a new kind of disability NGO – or amalgam of NGOs – with a clear mandate to monitor human rights developments around the world” (Quinn & Degener, 2002,

p.179). As a result of this concern, international disability NGOs, global DPO networks, and various funding agencies and foundations began to implement programs with the specific purpose of transforming grassroots disability associations into rights-advocates.

There are several central actors within the international disability rights movement who are actively reshaping grassroots disability associations around the world. The Disability Rights Fund (DRF), Handicap International (HI), and CBM International are some of the most important actors structuring the global organizational environment, including my field site in Nicaragua. To that end, each has programs based upon the UNCRPD's civil society mandate. DRF, for example, explains its funding philosophy as "DRF grants strengthen local stakeholders who can hold governments accountable for fulfilling the rights of persons with disabilities. By supporting civil society efforts at country level to ratify, implement, and monitor the [UN] CRPD, DRF seeks to make a more direct impact on improving the conditions of [persons with disabilities]" (DRF, 2013). HI, a European-based NGO, launched its *Making It Work* campaign several years ago to provide technical assistance to local DPOs in order to "strengthen their advocacy to influence social change" (HI, 2010). CBM International (originally Christian Blind Mission before secularizing), explains its *International Advocacy and Alliances* partnership program for rights advocacy as promoting disability inclusion "within the guiding frameworks of the UNCRPD" (CBM, 2013). In each instance, these initiatives influence grassroots disability associations to prioritize rights advocacy as their primary function.

### **The tradition of mass organizations in Nicaragua**

While grassroots disability associations in Nicaragua are being incorporated into the international disability movement, they also continue to be a part of a local organizational environment and that promotes different expectations and assumptions about the role of civil society associations should play, including DPOS.

In 1979, a revolutionary coalition toppled the Somoza regime, a US-backed dictatorship. While led by the socialist Sandinista Front, the coalition was broad and inclusive, drawing together Catholic base communities, student groups, trade unions, business associations, farming cooperatives, and neighborhood organizations (Everingham, 1996; Fruhling, 1992). As a result of such diversity, the ruling junta that took the place of the dictatorship was built upon compromise, assuaging the fears of participants who opposed the establishment of a Cuba-style communist state. As an alternative, Nicaragua pursued a homegrown vision of democratic socialism (Brentlinger 1995; Ruchwarger 1987) centered on “participatory forms of democracy” (Vanden & Prevost, 1993, p. 68). What this meant in practice was a rejection of a state-run economy and large welfare state in lieu of a mixed economy of small businesses and worker-run cooperatives and a civil society sector oriented towards self-help and social support. These civil society associations, known as *organizaciones de masas* or “mass organizations” (Anderson & Dodd, 2005; Babb, 2001), provided many of the services that would commonly be expected of a welfare state. During the Revolutionary 1980s, more than half of the population belonged to at least one mass organization and many had multiple memberships (Ruchwarger, 1987).

In the beginning, the Nicaraguan government provided some financial support to the mass associations, but had to end doing so when the the US Reagan administration began funding *contra-revolucionarios* (“Contras”) in a CIA-backed counter-insurgency (Kinzer, 2007, pp. 136-148) and pressured its allies to stop providing Nicaragua foreign aid (Biekart, 1999, p. 182-193). The US also imposed an economic blockade that prevented Nicaragua from exporting goods and effectively dried up the government’s tax base.

During this period, mass organizations, which were already aiding the populace in its “struggle for economic survival” (Vanden & Prevost, 1993, p. 66), became all the more important. The government in partnership with the mass organizations, however, was still able to achieve some astounding goals. For example, the Minister of Education, who was also a priest, Fr. Fernando Cardenal, initiated the *Cruzada Nacional de Alfabetizacion* (National Literacy Crusade) to address rural illiteracy rates, which were above 80% (Brandt, 1989) at the time. By organizing an estimated 90,000 university students and young professionals into small voluntary groups to teach basic skills in villages, rural illiteracy dropped by 37% in a few years (Hirshon, 1984). The campaign is emblematic of Nicaraguan identity (Hanemann, 2005; Brentlinger, 1995) and continues to serve as a model for mass organizations operating today.

It was within this context that many of Nicaragua’s first disability associations were founded in the 1980s. The Association of the Deaf was created to educate its members (Polich, 2005); the Organization of Disabled Revolutionaries was formed to provide rehabilitation to wounded Sandinista soldiers (Bruun, 1995); and *Los Pipitos*,

an association of parents of children with disabilities, was founded by Omar Cabezas, a Sandinista revolutionary, politician, and father of daughters with developmental disabilities. Each of these groups and other disability associations are founded on self-help principles and as allies of the state.

Despite the end of the Revolutionary period in 1990, mass organizations continue to thrive in Nicaragua and are a major focus of recently re-elected President Ortega, who was the leader of the Sandinista Front in the 1970s and 1980s. In 2007 and 2011, Ortega's campaign explicitly promoted mass organizations as a way of promoting the "Common Good" by addressing social needs (*Compana Solidaria*, 2011, p. 24).

### **Data, methodology, and field site**

In order to understand the way grassroots disability associations respond to their joint membership in the international disability rights movement and local civil society, I embedded myself within a network of local DPOs in Nicaragua. Over two summers (2009 and 2010) and an 11 month period spanning 2011-2012, I acted as a daily participant observer within the member organizations of the Departmental Commission for Advocacy and Awareness (CDIS) in Segovia. Segovia, which is a pseudonym meant to protect the identity of my research subjects, yet preserve some regional specificity, is truly "local" in the sense of being a hinterlands. *Nueva Segovia* is a region with several sizable cities, each of which has a disability coalition. Calling my field site "Segovia" is akin to calling it "Mountainous North City." In terms of disability and civic tradition, this region of Nicaragua is important for having been the

major battleground during the *Contra* War and being a Sandinista stronghold. In the 2011 elections, almost two-thirds of the population voted for the Sandinista Front and the local government maintains strong ties with local, mass organizations. Segovia is typical of Nicaragua in that the economy is dominated by agriculture and low-skilled manufacturing. In Segovia's case, tobacco is the major cash crops and cigar rolling factories the largest employers, which pay workers approximately \$130 a month, close to the country's average real GDP of about \$1,700 per person. Nicaragua is the second poorest country in the Western Hemisphere next to Haiti.

On a daily basis, I attended meetings, workshops, and other events organized by or for local disability associations. I also joined local organizations' leaders and staff in their daily activities, spending time in their offices or visiting their members or meeting with various government agencies and/or businesses. At the beginning of my field work, I provided each association with a description of my research project, the intended use of the data collected (i.e. academic publications), and their rights as associations to operate discretion over the activities I observed. In turn, each association provided me with a formal invitation stating that they understood my research objectives and their rights. My participant observation was supplemented with semi-structured interviews. Interviewees were provided with consent forms and explained their rights as research subjects. I also provided them pseudonyms. Over the three years, I recorded 69 formal interviews and attended dozens upon dozens of activities.

The use of qualitative methods to study organizational environments is particularly important. Sociological institutionalists, who normally theorize

organizational conformity, typically rely on large “field” studies that identify “surface similarities” between organizations (Hallett, 2010, p. 55). While important, this practice overlooks the way change is negotiated within organizations (Hallett & Ventresca, 2006). Members of organizations, often attempt to “interpret change in the institutional environment based on how they have defined their prior experience within that environment” (Everitt, 2012, p. 205) and often create as much diversity as they do similarity when the old clashes with the new (Lounsbury, 2007).

### **Responding to two organizational environments**

Grassroots disability associations and international disability NGOs have co-existed in Nicaragua since the beginning of the Revolutionary Period in 1979. From the 1980s through to early 2000s, however, these NGOs focused on humanitarian rehabilitation, such as the provision of artificial limbs and wheelchairs (ICBL, 2003, p 289-290). Their engagement with local DPOs in Segovia was primarily to identify landmine survivors and others in need of their services. On the local side, grassroots disability associations in Segovia occasionally received support from international actors, but never on a permanent basis. Equally important, local groups, such as the Organization of Disabled Revolutionaries (ex-Sandinista soldiers) and the Association of the Blind, which ran a Braille school, were often more tightly aligned with other veterans or education initiatives than with *disability* associations. International disability NGOs did not begin organizing Segovia’s grassroots DPOs into a distinct disability sector until the UNCRPD was adopted by the UN in 2006. These new activities represented structuration processes in an organizational environment



(DiMaggio, 1991). Local organizations, however, have responded differently to the international environment's promotion of a new organizational model, with responses ranging from conformity through to resistance and creative innovation.

*The international disability movement restructuring the local environment*

In 2008, Handicap International (HI) initiated the Departmental Commission for Advocacy and Awareness (CDIS) by bringing together Segovia's five existing local associations and then later including two entirely new DPOs created soon after. HI's local Coordinator for Social Participation in Segovia explained that at that time the European office, which had just launched their *Making It Work* global campaign to promote the UNCRPD, had determined that "people [with disabilities around the world] by themselves cannot and will not make demands, so they need an organization to make demands for them" (Interview: August 16, 2009).

Once brought together, HI began educating the organizations about the UNCRPD and encouraging them to engage in local political advocacy. The seven participating member organizations in CDIS, included the Association of the Blind, *Los Pipitos*, the Association of the Deaf, the Organization of Disabled Revolutionaries, the Association of the Disabled Resistance (wounded ex-Contra soldiers), the Association of the Physically and Motorly Disabled, and the Organization for Disabled Women. Along with HI's initial investment and coordination, CDIS began receiving small grants from the Disability Rights Fund (DRF) in 2009, which supports "civil society efforts at country level to ratify, implement, and monitor the [UN]CRPD," and began participating in trainings

provided by other international NGOs and a newly established national *Federación de Asociaciones de Personas con Discapacidad* (Federation of Associations of Persons with Disabilities—FECONORI), which was also a product of international NGOs.

During my fieldwork, I regularly sat in on CDIS monthly meetings. The meetings included all of the DPO leaders in Segovia and occasional guests, including observers from HI, FECONORI, or other, outside disability organizations passing through town. The meetings were largely focused on planning the following month's activities, which included awareness events, marches, and meetings with the local government. Each of these activities was outlined in CDIS' grant agreement with DRF, which they used as a checklist, often sending an email to DRF's headquarters in the US in order to get approval for changing something as small as the date of an activity specified in the grant (Field Notes: September 29, 2011). The original 2009 grant for \$12,000 was "to promote alliances [CDIS] at the municipal level to disseminate and implement the [UN]CRPD" and the 2011 grant (\$20,000) was "to provide DPOs the tools for effective advocacy for their rights."

Despite already having received advocacy training from HI and others, CDIS was continually being invited to participate in rights advocacy trainings hosted by other groups. In October, 2011, I observed a local training in Segovia sponsored by FECONORI. The trainers were Nicaraguans based in FECONORI's Managua office who had been "trained as trainers" by an international NGO and were currently funded through an international grant. The course took place in a small conference room at a local motel and included members from six of CDIS' seven DPOs. The Organization for Disabled Revolutionaries was absent. The training was called "Organizational

Development for Directors” and was entirely devoted to rights advocacy, with daily modules on topics such as “Introduction to Political Advocacy” and “Laws for the Protection and Benefit of People from Disabled Persons Organizations.”

The overarching theme was that disability groups needed to be united in their advocacy. The trainers’ lectures and slides routinely defined strategies and declared objectives that CDIS should pursue. For example, political advocacy was defined as demands for rights “organized by groups and directed at institutions [public agencies]” and their final Powerpoint slide of the first day declared that “Everyone needs to be together and united to participate and fight (*luchar*)” (Field Notes: October 3, 2011). The following day, we were told that it was our job as disabled persons to “investigate and study the law” [UNCRPD] because “Knowledge is power.” In small groups, we read sections of the UNCRPD and then presented summaries to the larger group. The group I participated in was assigned the “right to communicate” rights violations to the UN (Article 1 of the Optional Protocol of the UNCRPD), but when our group leader summarized it as a right of “individuals,” he was corrected by the trainers, who explained to the rest of the participants that it was a right for “*DPOs and coalitions*”, not individuals, and then drilled us on the organizational hierarchy in Nicaragua, which ran from the local DPOs in Segovia, through CDIS, and up to FECONORI (Field Notes: October 4, 2012; See also FECONORI, 2013).

In very explicit ways, HI and the internationally-backed FECONORI were working to define the “form and function” (DiMaggio, 1999) of grassroots disability associations in Segovia. Through their technical assistance and training, these outside organizations were imposing their own understandings of disability and their own

solutions. The original diagnosis that persons with disabilities need a coalition to make claims on their behalf was made half a world away, in HI's headquarters in France, and DRF's mission of promoting advocacy was drawn up in a boardroom in the US. Yet, these beliefs and practices were now creating real change in Segovia. DPOs were now in regular contact with one another and implementing advocacy initiatives.

*Conforming to the international organizational model*

Of the seven participating associations in CDIS, only three fully embraced the rights advocacy model espoused by the international disability movement. Two of the associations, the Association of the Physically and Motorly Disabled and the Organization of Disabled Women, however, were products of the international organizational environment itself, having been founded by international NGOs. The third grassroots association to embrace the rights advocacy DPO model was the local chapter of the National Association of Disabled Resistance, which had failed to gain legitimacy within Segovia's local civil society over its twenty year history because it was an organization made up of former *contra* soldiers, who were largely considered to be traitors for having waged a guerrilla war on behalf of the US during the 1980s.

The Association of the Physically and Motorly Disabled (ADIFIM) was established in 2008 as a result of a local workshop held in Segovia by Dansk Handicap Forbund, a Danish international disability NGO (Interview: July 17, 2009). ADIFIM-Segovia was established as a chapter of a national network based in Managua, which was also organized by Dansk Handicap Forbund. In 2008, ADIFIM-Managua won a \$25,500 grant from DRF to support expansion. ADIFIM's mission was "to develop

actions geared towards compliance with human rights by implementing technical capacity strengthening processes for local leaders, raising awareness, disseminating information to the population at large, exchanging experiences and doing advocacy work leading to reforms of laws that affect the rights of persons with a disability.”

ADIFIM, whose members were predominantly amputees and wheelchair-users, was designed to be self-supporting through membership fees of 20 cordoba (about \$1.00) per month. Once Segovia’s City Hall had recognized ADIFIM-Segovia as a mass organization, it was provided with free office space in a building owned by the municipal government.

ADIFIM’s activities were all rights-oriented. What this meant in practice was that the leadership visited persons with disabilities in Segovia and provided them with copies of the UNCRPD and invited them to come to monthly meetings where they “studied the law,” meaning the President, Alfonso, would read passages of the UNCRPD and discuss what Segovia’s government should be doing differently.

ADIFIM also recorded *denuncias* (“denouncements”) of rights by recording incidents of persons with disabilities not being provided benefits they had claim to according to the UNCRPD or cataloging inaccessible public buildings.

I regularly spent time in ADIFIM’s office, where community members would occasionally stop by, looking for assistance. In July, 2012, for example, a middle-aged woman visited, seeking help for a very poor family in her *barrio*. She described the family’s teenage son as “being two persons, sometimes fine and sometimes out of control”—stealing things, pulling the laundry off of the neighbors’ lines, and screaming. She occasionally provided food for the family and had offered to look for

help for the son. She had already contacted *Los Pipitos* and the police, looking for *medicina* (medicine) or therapy. Alfonso explained that mental health problems were a disability and covered by the law and therefore the responsibility of the state. He also explained that there were no psychiatrists working for Segovia's government, which was a violation of the UNCRPD. The woman kept asking if there was anything he could do, to which he responded "*que lastima*" (It's a shame) (Field Notes: July 11, 2012). Other people came looking for concrete help, such as crutches or wheelchairs, and also advised it was the state's responsibility, not ADIFIM's. Alfonso would sometimes privately complain that people only wanted "benefits" rather than to learn how to fight for their rights and once publicly chastised a member during a meeting who asked for help on how to use her wheelchair. He explained they were there to "study the law," and "not therapy" (Field Notes: October 30, 2011), which seemingly drove her away permanently.

Besides holding office hours, participating in CDIS activities, and facilitating monthly meetings, the leadership team also spent significant amounts of time attending workshops on disability rights advocacy in Managua and elsewhere in Nicaragua. Alfonso, the vice president, and the secretary each reported attending "six or seven" workshops in 2010-2011 alone.

Despite initial success in attracting several dozen members in the early years, ADIFIM's Segovia chapter experienced a dramatic slide in membership from a high of close to a hundred in 2009 to barely a dozen active members a few years later. In early 2012, ADIFIM was in crisis because it could only muster 15 members for its monthly meetings, yet needed 50% plus one to elect (or re-elect) a board. At that time,

it had 70 members on the books, yet only a handful were still attending meetings or paying dues. After several attempts to bolster attendance, Alfonso announced that he was going to start asking inactive members to officially withdraw in order to bring their ranks down low enough that they could ensure a quorum. He explained that some members were “Sick and cannot leave the house” and then joked that others might simply be “sick in the heart,” which drew snickers over a failed romance between two of the members (Field Notes: June 3, 2012). When my field research ended in August, 2012, ADIFIM was still purging its ranks, trying to get it below thirty.

Segovia’s Organization of Women with Disabilities (ODIFOM) was established close to the same time as ADIFIM with the help of Handicap International, which had decided that women with disabilities needed their own association within CDIS to ensure that women’s issues were addressed. To that end, the majority of ODIFOM’s support in the early years was in the form of workshops conducted by international NGOs on self-esteem, consciousness, and self-advocacy. ODIFOM, however, suspended meetings in 2012 because less than five members were attending meetings. Others were not participating because of a lack of mobility or because they had joined other organizations, such as a women’s self-help group that ran a sewing cooperative (Interview: June 6, 2012).

Both ADIFIM and ODIFOM reflected the model of civil society associations spelled out in the UNCRPD and the program objectives of international organizations such as HI and DRF. In many ways, these groups had survived as long as they did because they received international support. But, they also seemed to lack resonance with the very people they were meant to represent. The local chapter of the National

Association of Disabled Resistance (ADRN), however, offers the counterexample of an old organization thriving by adopting the organizational model promoted by the international movement's organizational environment.

ADRN was founded in 1990 as demobilized *contra* soldiers returned to Nicaragua under a blanket amnesty that brought an end to the civil war. Its primary purpose was to help disabled *contras* reintegrate into civilian life. In the early years, their main activities were distributing wheelchairs and crutches normally donated by *contra* sympathizers in the US and administering a rotating fund that provided small, interest-free loans for members. For many years, ADRN remained a low-key organization, with few public activities in Segovia, where residents remained hostile towards *contras*. For this reason, ADRN members had trouble finding jobs. In fact, Humberto, the President of Segovia's chapter, explained that disability discrimination was not a problem for his members, but instead political discrimination. He illustrated his point by recounting a time when he was fired as a night watchman on the basis of his *contra* past:

Sometimes you have to hide your political beliefs, because in the government, I was working at the INSS [National Institute of Social Security], and Pablo [another member] too. We worked as security guards and one time we arrived and an official told us that we could no longer work there... We had been given the assignment and objectives, we were fulfilling them, but this government lady told us "No, I'm sorry, you can't be here." (Interview: June 7, 2012)

While Humberto and his colleague were unable to protect themselves from political discrimination, they and ADRN's members had found that the local disability rights campaigns provided them a non-partisan language for advocating for



themselves. One member explained: “Currently, I no longer [encounter discrimination] because I am really defending my rights—which say that I should not be discriminated against for having a disability” (Interview: July 13, 2012). As a disability association, they had also found they could gain resources. For nearly two decades, the city had done nothing for them, but once they joined CDIS, they were now seen not as a *contra* organization, but a disability association and the Sandinist-run City government allocated them a parcel of land to build an office on because they were serving a priority population. The newly built office and meeting hall were completed just in time for their end-of-the-year meeting in December, 2011. ADRN’s national office had also begun receiving support from the Disability Rights Fund for \$20,000 a year after having changed their official mission to statement to:

“Contributing to the process of the integration of persons with disabilities in social life and the nation’s productivity, in a framework of respect for their human dignity,” which no longer specified disabled *ex-contra* soldiers as members. This did not, in any perceptible way, change the make-up of Segovia’s seventy members, many of whom were openly anti-Sandinista, referring to the Nicaraguan people as “stupid” for their overwhelming support of the Sandinista government, which was “garbage” in their minds (Field Notes: December 4, 2011).

ADRN, which historically had little to do with the other disability associations in Segovia, had become one of CDIS’ most active members by 2011. Humberto spoke positively about the coalition’s work, stating that: “We are strengthening here in Segovia, when we started an alliance [CDIS] with all the organizations of people with disability, we found common objectives to fight for, for example, health, education,

accessibility... Already the City Hall has recognized us” (June 7, 2012). ADRN had also managed to integrate its members into a job placement service led by the Association of the Blind and supported by the city government.

In describing the structuration of an organizational environment, sociological institutionists predict that “This process permits many new organizations to spring up and forces existing ones to incorporate new practices and procedures. That is, organizations are driven to incorporate the practices and procedures defined by prevailing rationalized concepts of organizational work and institutionalized in society. Organizations that do so increase their legitimacy and their survival prospects, independent of the immediate efficacy of the acquired practices and procedures” (Meyer and Rowan, 1977, p. 340). In this case, however, the outcomes are predicated on the existence of another organizational environment, that of a local civil society of mass organizations. The first two associations (ADIFIM and ODIFOM) sole focus on rights were foreign to potential members, driving them away. But the ADRN, which had previously been a local pariah, was able to gain new legitimacy in both environments through its adoption of the international model.

#### *Resistance to the international organizational model*

Two organizations actively resisted organizational change. *Los Pipitos* (officially, the Association of Parents of Children with Disabilities), a prominent member of CDIS and one of the most respected mass organizations in Segovia, became a target for outside intervention in 2012, only to result in a renewal of its original mission. The Organization of Disabled Revolutionaries (wounded ex-

Sandinista soldiers) experienced less dramatic intervention, but came to view the expansion of the international disability rights movement into Segovia as a threat to their special status as war heroes who had sacrificed for the community.

*Los Pipitos* is a national network made up of dozens of local, self-governed and self-financed chapters throughout Nicaragua. The association dates back to the Revolutionary era and continues to have strong ties to the Sandinista ideology of “solidarity.” In Segovia, *Los Pipitos* consists of a small complex of offices, classrooms, a physical therapy building, and workshops. During the day, youth with disabilities rotate between learning piñata, candle, and furniture-making and group activities ranging from dance to discussing feelings. Many parents, who send their children there, describe it as initiating a “powerful transformation” in their children’s lives by bringing them out of isolation, imparting new skills, and raising their self-esteem (Field Notes: October 28, 2011). Nevertheless, Segovia’s Youth Center became a target for change.

CBM International, a German disability NGO, began pressuring *Los Pipitos* to change following the launch of CBM’s global “International Advocacy and Alliances” initiative, which promotes the UNCRPD in conjunction with grassroots DPOs. In September, 2011, I was invited as a participant observer of a workshop Gretchen, CBM’s regional representative, was conducting for *Los Pipitos* staff members, parents, and youth on the right to “inclusive employment” (Article 27 of the UNCRPD). The centerpiece of the workshop was based on clearly defining the concepts of employment and inclusion. The point being made was that the youth at *Los Pipitos* were not really employed (they were not paid) and were working in a

segregated facility (disabled-only). When she explained that *Los Pipitos* was out of step with disability rights, participants protested, arguing “This is a really nice place to work. It is clean, friendly, and safe!” To which she explained that people with disabilities have a right to inclusive employment and the Youth Center was against their rights. Later that day, I interviewed Gretchen and we discussed the workshop. She explained “*Los Pipitos* needs to change” and discussed the UNCRPD as the opportunity for that change. Gretchen’s workshop had little, immediate effect. Change, however, did come. (Field Notes: September 23, 2011).

Segovia’s Youth Center was not only a target of Gretchen’s, an international disability expert from Germany, but also the *Los Pipitos* national office in Managua, which had become more integrated into the international disability movement, including receiving funding from international disability NGOs. A revamped national website now stated that their mission was “to promote the Human Rights of people with impairments and/or disability, so that together, we can organize, define, legislate, and implement policies, programs, strategies and services” by raising awareness and advocating for “legislation, public policies, and [change in] institutions of the State.” Little of the original mission of parents supporting parents was left. *Los Pipitos* in Segovia, however, continued to operate as it had before, as a service organization.

After months of the national office pressuring Segovia to change, things came to a head in 2012 when the *Los Pipitos* national office decided to dissolve Segovia’s local board and appoint a new executive director, a professional woman from Managua who had run a women’s rights NGO. Her first act was to close the Youth Center and replace it with a series of “consciousness-raising” workshops for the youth

themselves and to begin organizing marches where the youth were given placards demanding respect for human rights. At one point, the gates to *Los Pipitos* were chained shut and a guard installed to prevent the parents from holding a meeting, where they planned to publicly protest the national office's actions.

Rather than the intended changes resulting in the youth becoming politically conscious, the majority stopped attending the weekly consciousness workshops. The larger community was equally upset. For example, the local family that I lived with during my field work announced that they would no longer fundraise for *Los Pipitos*, something they had done for years, because they no longer believed it was serving people with disabilities or doing Segovia any good.

After several months, the national office allowed the local chapter to elect a new board, which was required by law in order to remain recognized as a mass organization. The old board, which had been dismissed, was elected back into office. Their first act was to fire the new executive director. Their second act was to begin planning a reopening of the Youth Center through a scheme to begin manufacturing wooden cigar boxes in the carpentry workshop for businesses in town and to begin working with local *pulperias* (corner stores) to sell bread that volunteers and the youth could bake on premises (*Los Pipitos* had an industrial kitchen). With the profits, they believed they could offer even more social and educational programs than before. The Vice President of the Board framed these activities as "solidarity." She explained, "I always say it is a blessing to have a child with a disability, and we have that child but we do not have the resources, therefore we respond with solidarity" (Interview: August 12, 2012).

Despite attempts to pull the local *Los Pipitos* fully into the organizational environment of the international movement according to the advocacy organizational model, the local parents who retook control and dragged it back into the center of Segovia's civil society.

The *Organización de Revolucionarios Discapacitados* (Organization of Disabled Revolutionaries—ORD) was founded in 1982 as a national organization. It represents ex-Sandinista soldiers wounded in battle, about 70 of whom belong to Segovia's chapter. In the 1980s, it worked with the Sandinista government to support soldiers disabled in the war, celebrating them as “war heroes” (Bruun, 1995) for their service and sacrifice. In contradistinction with the ADRN, ORD members always described themselves as *lacerados de la guerra* (war wounded) rather than “persons with disabilities” (Field Notes: April 29, 2012). Even though more than two decades had passed since the end of the fighting, ORD members continued to take pride in their service. Denis, the local president of Segovia's chapter, who lost his arm in the war explained to me why he and other volunteered to join the Sandinista People's Army in the 80s:

We never said we are going to fight for you [the community] to give us shelter, we never said we are going to fight for you to give us a pension, we never said we are going to fight so that my family is well—nothing of the sort. You think about it, we only believed in defending the Revolution so that today we [Nicaraguans] would be better off... If you go by us in the organization [the ORD], we are seen here [in Segovia] as having been born of the Revolution... We are the dead, the wounded, and the wounded ex-soldiers who participated in the war—that is the Revolution. Those of us who are the Revolution: the mothers of heroes and martyrs that, thanks to this [Sandinista]

government today, are eating a little better. I am glad that I gave.  
(Interview: March 14, 2012)

The patriotic altruism given voice by Denis, however, did not mean that members did not want to be recognized for their service in both symbolic and material ways. One of the local members of the ORD explained to me that “Because we have acquired our different disabilities while contributing to the country, I think they [government] should give us special attention” (Interview: June 24, 2012). In 2011, however, the only formal benefit the ORD received was free office space, which they got on the basis of being a mass organization. The members, however, benefitted in other ways. While CDIS was promoting the right to employment in their advocacy, Denis confided that unemployment was not a major issue for ORD members, a fact I confirmed by surveying the members. Even the least educated and most severely disabled members worked, often for local businesses and public agencies ran by other Sandinista veterans. A common job was as a night watchman. They also benefited from access to a wheelchair workshop operated by ORD’s Managua office. That workshop, which was self-supporting by doing for-profit metalwork on the side, had been started in the 1980s with help from Whirlwind Wheelchairs, a US group that shared the Sandinista Revolution’s goals (Interview: July 12, 2010).

The group, however, saw CDIS and the disability rights movement more generally as a threat. Under the UNCRPD, Nicaragua was obligated to set up a National Disability Council to monitor disability policy. In the Spring of 2012, however, Denis showed me a copy of a petition the ORD was circulating, asking the government to reconsider the plan to create a Disability Council and to ensure that

there is “the attention and respect that is deserved by persons with disability resulting from the war” (ORD, 2012, p. 1). Their concern was that the council, as it currently stood, gave a seat to FECONORI, the national federation of all of Nicaragua’s DPOs. As a national federation, FECONORI was focused on promoting the rights of all persons with disabilities equally, whereas the ORD wanted to make sure that disabled Sandinista veterans received special attention. A few weeks later, I met with a national board member of the ORD in Managua to better understand their position. He portrayed the rise of FECONORI and the decline of the ORD’s influence as a zero sum game:

In the last two years, the [national, cross-disability federation] movement of persons with disabilities has grown. They have strengthened a lot, they are organizing—fighting and defending their rights... The Federation is working, planning, and anticipating the [new] laws that are coming out... In the last few years, they have grown into a strong organization... For the ORD, however, the problem is ugly. It is a horrible future for us. (Interview: August 21, 2012)

This loss of influence seemed to be taking a psychological toll on Segovia’s members. One member explained: “It is clear that we need [more] support, especially because a lot of times we [ORD members] *are forgotten, or not remembered—the sacrifice that a person who fought in the war has made*” (My emphasis; Interview: June 24, 2012). As a result, ORD representatives sometimes skipped CDIS events, refused to go to workshops on the UNCRPD, or publicly voiced reservations about the issues the disability rights movement was pressing for. FECONORI and other organizations’ reactions, however, were to dismiss them for not falling in line with their goals and objectives. When I asked a representative from FECONORI during a



meeting being held in Segovia about the ORD's absence, he simply shook his head and told me they were "showmen" (Field Notes, Oct. 10, 2011) and not team players.

Both the ORD and *Los Pipitos* resisted the pressure to adopt an international model as a rights advocacy DPO pushing for the UNCRPD. In the case of *Los Pipitos*, the parents felt that their duty as an organization was to provide concrete services to the youth. For the ORD, the case was different. As defenders of the Revolution, they had the most to lose with the changes. Their status as war heroes is entirely local and context-bound. The more that people with disabilities are presented as a homogenous group of rights-bearers, the more likely they are to lose their special recognition and privileges as exemplars of servants of the Revolution.

*Innovation at the crossroads of the international and local organizational environments*

The Association of the Blind offers a third way between the path of total embrace and complete resistance to the international disability rights movement. As co-chair of CDIS, Luis, the president of the Association of the Blind, had developed a nuanced view. He was skeptical of organizations like the Disability Rights Fund and the entire notion of rights advocacy, but he also recognized opportunities for advancing programs developed under the local, solidarity model.

Luis explained that DRF was quite involved in CDIS by directing what should be put into grant proposals and monitoring the coalition's activities. He expressed frustration over the incongruity of the goals DRF laid out and the needs of DPOs. In Luis's words: "Their [DRF's] ideas of what they want us to do are—Sometimes, we

find that we are financed for certain objectives in a particular way that is a bad use of the money, you understand? That is to say they want to pour more into promoting awareness, but we want to strengthen the associations internally... There is no logic [to DRF's funding]" (Interview: August 17, 2012). He was particularly concerned that his involvement coordinating the DRF for CDIS was distracting him from pursuing the goals members of the Association of the Blind had identified.

The Association of the Blind had been established in 1988 by Luis, who had been blinded in combat during the *Contra* War as a Sandinista soldier. Following the initial injury from a mortar explosion and several years of rehabilitation and then university education in Cuba, Luis returned to Segovia and opened a legal practice, catering to the poor. During that time, he realized that many Nicaraguans, especially those without sight, needed far more basic things than legal services, such as learning to use a white cane, read Braille, and find employment. At that point, he contacted other visually impaired people and formed the Association, eventually establishing a Braille school, where literate members taught uneducated members how to read and other skills and a sighted staff member helped place and train members in jobs. All of this was funded through a bicycle repair workshop where some of the Association's members as well as local, sighted citizens, volunteered. Recognized as a mass organization, the Association was provided with free office space and an additional building for the workshop, courtesy of the City Hall. Luis now had plans to expand the bicycle workshop in order to increase services the Association provided its 200 members, but as of 2012, no international NGO had shown interest.

As chair of CDIS, Luis had made several advances in terms of working with the municipal government. He had made sure that persons with disabilities were included in various social programs and that all new construction was built accessibly. But he saw political advocacy as having real limitations in terms of helping persons with disabilities.

I believe that the Mayor's Office alone does not have a sufficient budget for all [the needs of persons with disabilities]. They have a list of priorities, for example, people with unemployment, single mothers, children in the street, the people with AIDS, and people with disabilities. But it is a lot, I believe that they do not have sufficient financing for the streets, for the trash, for all...

Luis went on to explain that the expectations of international NGOs were unrealistic and based on their experiences in wealthy countries and not poor ones such as Nicaragua.

I believe that in the perspective of the international organizations, their professionals and the people and the leaders with disabilities that are in America and Europe—that in the United States when they have a new benefit, they have a Government with the sufficient funds and then the law does not only have the meaning of a desire. I believe that here the law is a desire or an objective for the future because you need to wait for the capacity... When an American person is thinking about the meaning of a new law, for example in Nicaragua, they believe that the words are a reality. But that is not [true] here. Right, it is impossible, yes? (Interview: March 21, 2012)

According to Nicaragua's national Ministry of Finance, Segovia's municipal government was allocated 139 million cordobas (\$5.7 million dollars) for 2012 for a population of 130,000. The Vice Mayor explained to me that the budget includes

investments, such as paving roads, putting in sewers and running water, and dredging the river, which periodically bursts its banks, and the city's administrative expenses (i.e. municipal employee salaries and facilities). A small amount is also set aside for "special initiatives" funding in public health, education, sports, culture, and vulnerable populations (i.e. the elderly, single mothers, street children, and, persons with disabilities) (Interview: July 25, 2012). It was this "special initiatives" pool of just a few thousand dollars that CDIS was being trained to advocate for. This budget may seem paltry by Western standards, but is a simple reality in country where 80% of the population lives on less than \$2.00 a day and the government lacks a tax base (UNDP, 2009).

The lack of budget, however, did not prevent CDIS and the municipal government from working together to advance rights. For several years, the Association of the Blind had operated a job placement service, with a local coordinator soliciting employment opportunities from local businesses, including tobacco factories, Segovia's main source of formal employment. After having been exposed to the UNCRPD, they recast the program in rights language, citing it as advancing Article 27 ("right to work and employment") of the Convention. The Article itself states that the right is to be promoted by States Parties enforcing nondiscrimination legislation and promoting access to employment through its own initiatives, but Luis decided that a better route was to expand the Association of the Blind's initiative and make it available to members of all the DPOs participating in CDIS, which he did in 2010. He then used it as a "conversation starter" with a new employment initiative launched by the municipal government.

In 2011, the Mayor's Office in Segovia launched the Agency for the Promotion of the Local Economy (APROE). The initiative consisted of a full time director and two staff members crammed into an office in the City Hall. Together, however, they had been able to attract a small grant from Delft, Netherlands, Segovia's "sister city," to be used for microcredit. When CDIS arranged a meeting with APROE, Sonia, APROE's director, was excited to have a partner experienced in promoting opportunities for a marginalized population and invited CDIS to join the initiative's board along with the head of the Chamber of Commerce and others. APROE's first order of business was to implement the microcredit fund, which Sonia made sure was available to persons with disabilities, but she expressed even more interest in promoting the Association of the Blind's job placement program. Using APROE as a platform, Sonia and CDIS began convening community meetings, where the leaders of member DPOs presented themselves to an audience of potential employers and educated them about their obligations to include persons with disabilities within their workforce (Field notes: October 4, 2011).

APROE and CDIS decided that rather than threaten businesses with sanctions, which the local Ministry of Labor had little capacity to enforce, they would achieve better results by convincing local employers that persons with disabilities can be good workers. On July 25, 2012, APROE and CDIS put together a "study tour" of 28 employers, government officials, and members of DPOs to go on site visits around Segovia. As a participant observer, I joined one group which visited a workshop where three people with visual impairments and one with Kyphosis (curvature of the spine) were making cigar boxes, another factory where half a dozen beneficiaries of CDIS

were sorting, drying, and rolling tobacco, and the Ministry of Agriculture, where one of the directors used crutches. At each site the manager and Julia, the Association of the Blind's jobs coordinator, answered questions (Field Notes: July 25, 2012).

Julia reported a dramatic shift in her job placement activity. Before the partnership with APROE, she only placed three or four people a month, but now regularly placed a dozen persons with disabilities in new jobs, oftentimes with employers calling her and inviting persons with disabilities to apply for vacancies (Interview: August 17, 2012).

The jobs initiative represents a case of “bricolage (Binder 2007) or “translation” (Haedicke 2012) where the rules and beliefs of two separate organizational environments are blended. The international disability rights movement sees contentious politics and rights advocacy as the best route for DPOs to promote their members' rights. Nicaragua's local civil society, however, has been built on partnership between government and civil society, with civil society often doing the bulk of the services. By reframing the job placement service in human rights language and using APROE as a platform to promote it, the Association of the Blind was able to justify their decision to continue promoting services and APROE was able to promote opportunities for persons with disabilities without the resources that would have been necessary if they wanted to do job placement themselves. In the past, the job placement program might have been framed in terms of “solidarity” rather than the UNCRPD, but the more important end result remains the same: more persons with disabilities are working.

**Discussion and Conclusion:**

The passage of the UNCRPD in 2006 helped solidify the international disability rights movement and spur its outreach into developing countries. Incorporating grassroots DPOs into their movement by promoting a very specific model of DPOs as rights advocates became central to that expansion. This meant, however, that local disability associations were being asked to adopt practices that often ran counter to civic tradition or made little sense in local context. Both the international disability movement and Nicaragua's local civil society can be viewed as organizational environments where the behavior of members is shaped by leading actors within the field whether or not the promoted practices solve on-the-ground problems (Meyer & Rowan, 1977). The fact that Segovia's DPOs had to straddle both environments meant that rather than "homogenize" across the field (DiMaggio & Powell, 1983), the CDIS' member organizations diversified. Some embraced the rights advocacy model, others resisted it, and one managed to blend it with its existing practices.

By taking an "inhabited approach" (Hallett and Ventresca, 2006) in my investigation of the organizational environmental pressures grassroots DPOs face, I hope that rather than simply promote a mode of analysis, I have exposed what is really at stake: people.

The international disability movement, which is dominated by the West, has recently begun to be criticized for ignoring complexities on the ground in the developing countries and attempting to homogenize approaches to disability along the lines of Western thinking (Grech, 2009). The "globalizing campaign" promoting the

UNCRPD currently does little to redistribute resources from North to South or otherwise address the concrete needs of persons with disabilities (Meekosha & Soldatic, 2011). While political advocacy is important, it often remains, in Luis' words, a "desire" rather than a reality in a local context where the government lacks capacity. It also strikes many Nicaraguans as ignoring their tradition of "solidarity," wherein people work together to address the community's needs.

Rather than being viewed as a barrier, Nicaragua's history of mass organizations offers an opportunity. If grassroots associations are given the flexibility to innovate with and create their own organizational model, they may be able to put something together that bridges the UNCRPD's overarching goal of promoting the full participation of persons with disabilities in their respective communities while also remaining effective at helping people meet their day to day needs. Since the Revolution, Nicaragua has found ways to address the needs of its populous despite its poverty. Initiatives such as the Literacy Crusade, which originally mobilized volunteers in the 1980s, but continue in various forms today, have helped Nicaragua achieve a primary school enrollment rate 20% higher than the average for countries with a similar level of economic development. In a recent report, the World Bank accredited Nicaragua's "pioneering strategies to fight poverty" to projects that "leverage local initiatives that stretch limited resources further and deliver sustainable results" (World Bank, 2013). Persons with disabilities in Nicaragua have many needs and many unrealized rights. By helping DPOs in Nicaragua take the best from both organizational environments rather than force them to choose one over the other, there



are ways to help Nicaraguans address their needs and advance a local, yet relevant, understanding of disability rights.

Chapter 1, in full, is a reprint of the material as it will appear in *Research in Social Science and Disability* 2014. The dissertation author was the sole author of this paper.

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## **Chapter 2**

### **Inhabiting grassroots civil society: Organizational theory and small group method**

#### **One Pope, two tarmacs, and a big misunderstanding**

One of the most famous photos from the Sandinista Revolutionary period (1979-1990) illustrates Western angst regarding alternative forms of civil society and expansive interpretations of human rights. “A Scolding on the Tarmac” depicts Pope John Paul II having just landed in Managua during his 1983 papal visit. In front of him, kneeling, is Ernesto Cardenal, an ordained Catholic priest, poet, and, not least, cabinet member in the Sandinista government. The Pope, in full papal vestments, is holding up a finger to Cardenal, reportedly saying “*Usted tiene que arreglar sus asuntos con la Iglesia* (“You must fix your affairs with the Church”). From the ground, Cardenal, in a simple, collarless shirt, is looking up and smiling (Dodson and O’Shaughnessy, 1990: 187-190). He would remain Minister of Culture for another four years.

The Pope’s admonishment of Cardenal is only the more significant because they were both engaged in very similar projects: using civil society to promote human rights. A couple of years before, John Paul II had landed on another tarmac, this time 6,000 miles away, to put the first chink in the armor of the Iron Curtain. The Cold War began to thaw when he took on a far more humble posture. On that visit, rather than attempt to reorder the life of a single, rogue priest in Nicaragua with a wagging finger, Pope John Paul would begin to reorder the lives of tens of millions when he got down on his hands and knees and “kissed the ground at the Warsaw airport [and] began the

process by which communism in Poland – and ultimately elsewhere in Europe – would come to an end” (Gaddis, 2006, p. 193). It was at that moment in 1980 that the *Solidarność* (Solidarity) movement, ostensibly a labor union, was born. The Catholic Church in Poland, which was one of the only civil society organizations intact and independent in the Soviet Empire, used the Polish Pope’s gesture as permission to begin providing both moral and material support to a protest movement that eventually restored democracy and market freedom (Kennedy, 2002). Equally significant, John Paul II chose human rights, rather than Catholic theology, as the idiom by which he would not only address the Soviet Union, but other repressive states (i.e. apartheid South Africa). John Paul not only embraced the largely secular language of universal rights in his homilies, encyclicals, and public addresses, but he specifically rooted himself in the United Nations’ Universal Declaration of Human Rights, declaring it “a true milestone on the path of humanity’s moral progress” (AAS 71, 1979, p. 1147-1148) and “one of the highest expressions of the human conscience of our time” (L’Osservatore Romano, English edition, 11 October 1995, p. 8.). Astutely, he used human rights to mobilize people (i.e. civil society) to stand up to their governments and advocate for Western-style democracy and a market-based economy.

At the time that the famous photo was taken, Cardenal was involved in a very different project that was alarming to John Paul II and his closest advisors in the Vatican. Nicaragua had launched a solidarity movement too, but rather than meaning civil society standing shoulder-to-shoulder *against* government, Nicaraguan *solidaridad* meant civil society standing hand-in-hand *with* government. In fact, any distinction between the two—civil society and the state—had collapsed. As a legacy

of the broad based revolutionary coalition of Catholic base communities, trade unions, agricultural cooperatives, student groups, neighborhood organizations, and business associations (Everingham, 1996; Fruhling, 1992) that joined the Sandinista Front in overthrowing the Somoza dictatorship, Nicaragua had developed a constitution that institutionalized “participatory democracy” by creating a National Assembly composed of “mass organizations” (civil society associations) rather than district-bound, elected representatives (The National Assembly would later be reformed to provide proportionate representation of political parties to appease opposition parties beginning in 1984; Lobel, 1987; see also Ruchwarger, 1997; Vanden and Prevost, 1993). This meant that mass associations proposed, voted on, and implemented legislation. In a sort of odd syllogism, civil society was the government and, to Cardenal, because he and the Church were part of civil society, it was only natural that he too be part of government.

Latin American liberation theology, which Ernesto Cardenal and his brother, fellow priest, and governmental minister, Fernando Cardenal, promoted, also used the language of human rights. But when liberation theologians framed the (local or “popular”) Church as being a part of the “fight for human rights” (Boff and Boff, 1999 p. 7), it did so by emphasizing social and economic rights through a novel combination of Marxism and Catholic social teaching on the common good and the “preferential option for the poor” (Gutierrez, 1973). A few months earlier, when Cardenal had learned of Papal concerns that Nicaragua’s “Popular Church” was developing into a “parallel church,” he and his brother responded with an open letter that stated “We make ourselves Christian by acting as Christians” and “The Gospels



are going in one direction, the Pope in another” (quoted in Sabia, 1997, p. 190). Simply put, the Cardinals were calling for a more active Church and active civil society, which did not limit itself to the watchdog role of monitoring political and civil rights, but actually got its hands dirty by trying to fix the everyday problems their members faced. The outcome in Nicaragua was an odd mix of mass organizations implementing health and education “solidarity” campaigns (Lobel, 1987) and other initiatives oriented towards survival needs (Anderson and Dodd, 2005; Babb, 2001). Government officials and civic leaders were in constant contact, working together to identify problems and mobilize the populace to implement their chosen solutions. The irony is that rather than fulfill Western fears that it would become a Soviet or Cuban-style totalitarian state, Nicaragua’s government remained small and civil society thrived.

To this day, Nicaragua’s welfare state remains small and the importance of its voluntary organizations remains large. Despite the end of the Revolutionary Period in the 1990s and various opposition governments hostile to civil society, mass organizations continue to represent “the best prospects for confronting the nation's need for economic and social justice” (Babb, 2001, p. 10) and act as the site where “Nicaraguan citizens continue to ‘learn’ a very specific form of democracy” (Anderson & Dodd, 2005). The current president and former leader of the Sandinista ruling *junta* in the 1980s, Daniel Ortega, continues to marshal the language of solidarity and liberation theology in his campaign to “finish the unfinished revolution” (Morris, 2010), using slogans such as *Unidad por el Bien Común* (United for the Common Good) and “*con todo y por el bien de todos!*” (with everyone and for the

good of everyone). Rejuvenating mass organizations and drawing the country together as “one big family” has been one of the Ortega administration’s most important goals (*Compana Solidaria*, 2011, p. 24). As such, the government continues to launch initiatives based on the universally celebrated Literacy Crusade and Popular Health Campaign of the 1980s by enlisting grassroots associations in programs meant to address poverty. This means that when the state is unable to effectively implement its own social services and fulfill its promises of economic and social rights, it relies on civil society to fill the gap.

In many ways, what the Pope was wagging his finger at in 1983 and what many international policymakers and NGO professionals worry about today, is not so much a reinterpretation and reorientation of Catholic theology, human rights, or even democracy, but an organizational model. By and large, theorists, policymakers, and practitioners currently “promote one vision of civil society as *the* vision” (Howell and Pearce 2001, p. 11 [their emphasis]). Anything that deviates from a very narrow understanding of civil society as membership-based associations engaged in rights advocacy is a problem. Since the birth of the Solidarity movement in Poland, which resulted in civil society being “rediscovered” as a concept (Oxhorn, 2006, p. 59), there have been a number of schools of thought regarding what civil society is and what it should do. Ultimately, the narrow definition evangelized by Pope John Paul II is now the model proselytized by social scientists and international development workers.

Just a few years ago, the UN published its most recent *Handbook for Civil Society*. In it, civil society is defined as those actors that “give voice to the powerless” when they “scrutinize the implementation of human rights, report violations [of human

rights abuses]...and campaign for the development of new human rights standards” (UN-OHCHR, 2007, p. iii). If this narrow definition were to be used as a starting point, Nicaragua’s civil society, including its grassroots disability associations, would be deemed either indecipherable or illegitimate (Lewis, 2001) from the very beginning. This narrow definition, however, is useful for identifying the organizational model promoted by the international disability rights campaign specifically and global human rights and development campaigns in general. Therefore, following a brief history of the modern definition (and redefinition) of civil society and its specific application to international development, I will outline an organizational approach to civil society based on sociological institutionalism and World Society theory. Finally, I will move from an examination of this overarching organizational approach to a more limited, grounded approach focused on capturing those processes that take place within small groups, the building blocks of civil society wherein local practices are initiated and global ideas, such as human rights, are interpreted.

### **Narrowing the definition of civil society and applying it to development**

Civil society is a broad concept that suffers from “extreme fuzziness” (Waisman 2006, p. 18). Perhaps the simplest way to define civil society is by what it is not: neither government nor business. It is the “third sector” (Corry, 2010; Etzioni, 1973) of non-profit, voluntary associations that range from churches to trade unions to the Boy Scouts. Cohen and Arato (1992) have provided a commonly cited definition of civil society as “a sphere of social interaction between the economy and state,

composed of actors and organizations that self-organize to advance collective goals” (p. 143). Over the years, however, civil society has increasingly been conceptualized as a social sphere that not only stands firmly outside of the state, but holds it accountable. Whereas theorists ranging from Tocqueville through to his intellectual descendent, Robert Putnam, have portrayed associational life’s democratizing influence as an almost accidental outcome of citizens coming together to do things as wide ranging as “to give entertainments, to found seminaries, to build inns, to construct churches, to distribute books” (Tocqueville, 2003, p. 596.) or to simply go “bowling” (Putnam, 1995), that accidental outcome of civil society is now increasingly defined as its main purpose, especially in “good governance through civil society” literature (Roy, 2008) . The supposed benefits of that democratization, however, now go beyond ensuring access to the public sphere or preventing corrupt, irresponsible, or unresponsive governance. A healthy civil society is now seen as a prerequisite to economic development and addressing the material needs of the poor. Today, legions of well-meaning, non-governmental organization professionals are descending on countries like Nicaragua to evangelize a very narrow conception of civil society as human rights advocates. Pope John Paul was an early forerunner of these efforts. Perhaps, even more worryingly, social scientists have fed into this evangelism by framing debates, outlining ideas, and defining models of civil society and human rights that provide the justification, if not motivation, behind many rights-based development policies and “empowerment” programs.

While civil society as a concept has been around for decades, it was only recently “rediscovered” (Oxhorn, 2006, p. 59) in the 1980s when the Polish

*Solidarność* (“Solidarity”) movement sprang up in opposition to the Communist state (See Cohen and Arato, 1992 for a definitive statement on this). As such, civil society was seen as a democratizing force capable of no less than bringing down the Soviet Regime. Whereas the anti-communist Solidarity movement was explicitly about democracy, others were also looking at forms of voluntary life that seemingly lacked any sort of political agenda, such as sports leagues and book clubs. Robert Putnam, while certainly celebrating this expansive view of civil society’s democratizing power, went one step further with social capital theory, arguing that “norms and networks of civic engagement [civil society] seems to be a precondition for economic development as well as for effective government. Development economists take note: Civics matter” (Putnam 1993, p. 37). Francis Fukuyama quickly picked up upon this theme, publishing *Trust: The Social Virtues and Creation of Prosperity* (1995), to explicitly promote this connection between civil society and the necessary norms for economic development. Civil society was quickly hailed as the “missing key” (Habeson, 1994, p. 1) to all that ailed both the developed and the developing world. In the case of the latter, it was quickly seen as a solution for poverty, autocratic government, and even civil war (Marchetti and Tocci, 2011). By strengthening civil society, developing country governments would become accountable and economies would thrive, creating a “virtuous circle” (Archer, 1994) of growth, equity, and stability. These academic ideas were quickly enshrined in public policy. In 1999, for example, the Secretary of State for International Development in the United Kingdom was arguing that civil society in the Global South “can help ensure greater equity in resource allocation, with resources focused on the priorities of the poor and other excluded

groups” (quoted in Howell & Pearce, 2011, p. 99). Soon, Western countries and multilateral organizations began providing funding and technical assistance to existing grassroots associations throughout the Global South or were implementing programs with the specific intention of founding more such organizations under the general understanding of “the more civil society, the merrier.”

No sooner had civil society been declared the remedy to every ill than its theorists began to raise the specter that civil society itself may be what makes a country sick. Putnam had famously cited bowling leagues (1995) as equally beneficial as any other type of group because all forms of associational life teach cooperation and instill trust. Critiques, however, soon followed. Nancy Rosenblum (1998) pointed out that according to Putnam’s theory, even the Ku Klux Klan generates social capital, a clear problem. Kaufman (2002), examining seemingly more benign fraternal organizations, such as the Masons and Knights of Columbus, declared that these civic associations were actually “anti-social,” having deepened religious and racial divides in turn-of-the-Century America. Chambers and Kopstein (2001) crystalized this line of research by coining the phrase “Bad Civil Society,” arguing that rather than focus on the density of voluntary associations, social scientists should instead focus on the “type” of organizations (p. 839). In relation to developing countries, Waisman, Feinberg, and Zamosc declared that rather than a silver bullet promoting development, Latin American civil society could potentially be “the gravediggers of democratic institutions... social organizations could be either part of the solution or part of the problem” (2006, p. 3).

Separating the wheat from the chaff quickly became an exercise of declaring much of associational life in developing countries a problem. Civil society was described as “sparse, weak, and dependent,” “operat[ing] as channels for clientelism or state corporatism” and as too service-oriented (Waisman et. al., 2006, p. 3). Greater autonomy from the state, especially populist regimes, became an ubiquitous prescription. Another problem identified is that in the face of weak states, civil society organizations often fill the gap left by an absence of the rule of law and provision of public services resulting in internal divisions being perpetuated through unaccountable “alternative systems of self-help and tribal justice” (Marchetti and Tocci, 2011, p. 49). Putnam (1993) himself, began to specify that true civic associations not only need to be separate from the state and market, but also be devoid of any ties of kinship, marginalizing many traditional forms of associational life in Latin America and Africa (Lewis, 2001). While service oriented and other voluntary groups were increasingly identified as a problem, linking civil society to human rights quickly became a shorthand solution. Margaret Somers (2008), for example, recently argued that “democratic associations of rights-claiming citizens” were the only positive forms of civil society and guarantor of the social and political inclusion of marginalized groups (p. 253).

In terms of international development policy, what is increasingly defined as “civil society” encompasses only a very small subset of voluntary associations. The example of the narrow definition of civil society given in the UN’s *Handbook for Civil Society* demonstrates an understanding of civil society as groups limited to “scrutinize[ing] the implementation of human rights” or being obligated to “campaign

for the development of new human rights standards” (UN-OHCHR, 2007, p. iii). This definition is the embodiment of rights-based development, wherein economic and social development is promoted by “empowering” (Chapman, 2009) marginalized groups to form grassroots associations that demand recognition of their rights. At the global level, traditional international development NGOs (i.e. Save the Children or Oxfam) increasingly “embrace a human rights approach” to development, moving significant resources out of project implementation (i.e. build orphanages or assist farmers in increasing their yields) and into human rights consciousness raising and advocacy activities (Nelson and Dorsey, 2007, p. 145). On the ground, this means that “where once NGOs concentrated their work on establishing projects to do things like build water supplies or encourage income generation, the same NGOs have increasingly devoted resources to advocacy campaigns directed at global actors” (Rugendycke, 2007, p. 2). Simply put, civil society as advocacy has pushed out civil society as service provision, transferring the onus for addressing poverty from humanitarian or self-help organizations to government. As such, other non-rights-based forms of civil society are deemed illegitimate, unaccountable, or potentially useless, including humanitarian relief NGOs and religious organizations. Increasingly, only social movements and membership-based organizations (unions, indigenous groups, etc.) are recognized as worthy of support because they focus on lobbying and protest activities, thus giving “voice” (Kaldor, 2003). From a rights-based perspective, if development NGOs want to remain relevant, they “must shift, in their primary role, from being implementers and drivers of development to being allies with people’s organizations and social movements in a collective struggle for change” (Chapman,



2009, p.167) because the problem in poor countries “is not lack of resources, but lack of political will” (Normand, 2001 quoted in Molyneux and Lazar, 2003, p. 29). From this perspective, when governments fail to deliver the benefits and services people have a right to, the reason is never understood as the result of a lack of technical or budgetary capacity (i.e. the very poverty that defines a country as developing), but a lack of governmental responsiveness and, in turn, a failure of civil society to have held that government responsible and to have effectively demanded recognition of their rights. Importantly, development NGOs no longer measure the success in terms of concrete outcomes, such as survival needs being met, disease or malnutrition being prevented, or economic development taking place, but in terms of whether or not their beneficiaries (i.e. poor people) have increased “political knowledge” (Williams, 2007).

The result of this new human rights perspective on civil society has been that many foreign aid agencies and international NGOs have begun to purge grassroots service organizations from their support in lieu of advocacy groups in developing countries or to transform existing organizations from service providers into advocates. Equally disconcerting, within the social sciences, civil society has been transformed from a “fuzzy” analytic concept into a precise prescription. The net result has been that civil society is so narrowly defined that its non-conventional forms are dismissed (Lichterman, 2011; Lewis, 2001) and the basic, organizational characteristics of those that do make the cut are ignored (Watkins, Swidler, and Hannan, 2012). If social scientists are going to be able to affirmatively answer the question “Can we still study

the civic?” (Lichterman and Eliasoph, 2011, p. 11), a giant step back needs to be taken. An organizational approach offers that opportunity.

### **Inhabiting grassroots civil society**

In recent years, assumptions that the members of global civil society—international NGOs and grassroots associations—are “doing good” (Fisher, 1997) have been critiqued from a number of perspectives. Neo-colonial theorists have sought to expose “development hegemony” and “NGO-ization” (Kamat, 2002) processes that “discipline” (Ebrahim, 2003) local populations and force them to conform to a global order. Others have sought to demonstrate the link between civil society and neo-liberalism by showing that good governance (Roy, 2008; Manji and O’Coill, 2002) and human rights (Moyn, 2012) campaigns promote policies and processes that impoverish already poor countries and justify growing economic inequality. The most devastating critique of civil society, however, may be found within organizational sociology. Organizational sociologists have pointed out that many of the global organizational models promoted are neither effective (Meyer, Boli, Thomas, and Ramirez, 1997) nor democratically representative (Ghimire, 2011). Instead, the growing “world polity” (Boli and Thomas, 1997) of international and grassroots civil society organizations is simply a response to a sort of organizational “peer pressure,” in which groups, whether at the local, national, or international level, seek legitimacy in the eyes of other organizational actors. This organizational approach to civil society is grounded in sociological institutionalism (Meyers and Rowan, 1977; DiMaggio and

Powell, 1991), which focuses on the informal and formal rules and belief systems (Scott, 1992) that organizations respond to. The power of this neo-institutionalist approach is precisely in its ability to explain organizational conformity across broad fields or environments without assuming that those organizational models are necessarily functional or easily explainable responses to resources. Its deficit, however, is that it often remains superficial and grounded in a macro (or field-level) perspective (Hallett, 2010, p. 55). That said, sociological institutionalism provides a much more objective approach to civil society than what is offered from the perspectives of political theory, political sociology, and development studies.

The “new” sociological institutionalist approach began, broadly, in 1977, with Meyer and Rowan’s article “Institutionalized Organizations: Formal Structure as Myth and Ceremony.” In this article, the authors promoted a new approach to universalizing organizational structures that countered assumptions in organizational sociology about their technical functionality. Instead, they argued that organizational isomorphism was driven by a quest for legitimacy, but that the rules and models that the organizations were responding to were often “myth and ceremony,” meaning that formal practices and procedures were often “decoupled” from actual day-to-day activities. This analytic perspective quickly gave way to organizational studies that emphasized homogenization within organizational environments wherein all the organizations providing a “given product or service” (Scott and Meyer, 1992, p. 129) and other “relevant actors” (DiMaggio and Powell, 1991, p. 65) respond to one another and the organizational models of leading organizational actors. These models, or organizational “scripts” (Jepperson, 2002), are adopted independently from local

context, yet have the power to shape organizational actors' "view of the world and the very categories of structure, action, and thought" (DiMaggio and Powell, 1991, p. 13).

Neo-institutionalism's relevance to global organizational models is evident. In 1997, world society theory was introduced by Meyer, who asserted that "global cultural and associational processes" are primary to local processes because "the worldwide actor is a worldwide cultural construction whose identity and interpretations derive directly from exogenous meanings, which makes the local arena less determinative of actor structuration" (Meyer, Boli, Thomas, and Ramirez, 1997, pp. 163-164). Since then, world society theorists have shown that everything from voluntary associations (Hwang, 2006) through to governmental agencies (Kernaghan, 2000) throughout the world are responses to organizational models that disseminate from the top down rather than local needs or concrete experience. International Relations scholars have also adopted Meyer's approach within IR constructivism because of its ability to explain "unexpected global similarities" in cases where realist and liberal IR theory "would expect difference in behavior by differently situated actors with different interests" (1996, p. 334). Even, or perhaps especially, human rights have been demonstrated to be defined exogenously (Meyer, 2009, p. 284). In relation to social rights, the "structure" of the welfare state (creation of national public health and education ministries and provision of formal rights and entitlements) has been shown to be the response of nation-states to organizational models (Ibid, p. 282), which helps explain why governments adopt treaties despite having any intention of protecting the human rights granted (Hafner-Burton and Tsutsui, 2005) or the functional or financial capacity to provide the promised benefits.

As powerful as the neo-institutionalist and world society approaches are, they do little to tell us anything about actual, day-to-day organizational life or to explain diversity. While world society theory accommodates, if not expects, cross-national hybridity (Drori and Krücken, 2009, p. 20), it does not explain it beyond it being another case of “decoupling.” In recent years, critics of neo-institutionalism have revitalized older theories of organizational sociology that demonstrate the way organizations “selectively and strategically adapt” (Maines, 1977, p. 250) to new environmental pressures and should therefore be understood as “negotiated orders” (Fine, 1984; Gerson, 1976). This is an attempt to move beyond the macro-gaze of neo-institutionalism and to go beyond simply identifying “surface similarities” between organizations (Hallett, 2010, p. 55). Instead, a new, microsociological approach to institutionalism, called “inhabited institutionalism,” has been developed in order to try to understand the ways new meanings and practices are generated internally, within institutions (Hallett & Ventresca, 2006), by organizational actors, the “inhabitants” of institutions. From this perspective, organizations are often shown to become even more diverse when the old clashes with the new (Lounsbury, 2007), although in some cases, complete conformity to new models is compelled from the top down, despite resistance from below (Hallett, 2010). In recent years, the inhabited institutionalist approach has been used to show “bricolage” within organizations (Binder, 2007), wherein different institutional logics are creatively combined, and “translation” processes (Haedicke, 2012), by which local actors use local culture to translate broad, overarching organizational models. Everitt (2012) has recently used inhabited institutions to historicize organizations, showing how they “interpret change in the

institutional environment based on how they have defined their prior experience within that environment” (p. 205). To date, however, an inhabited institutions approach has not been applied to world society theory in order to highlight the power, but also the limits, of global civil society.

Grassroots civil society associations being pressured to adopt the rights-based advocacy model promoted across the international human rights and development field offer an opportunity for an “inhabited” methodological approach. A focus on the day-to-day, face-to-face interactions of small groups in developing countries offers the ability to go beneath the artificial similarities between organizations that are often reflected in mission statements or NGO organized activities that utilize the language of international human rights. Whereas inhabited institutionalism is relatively new, micro-sociologists who focus on small groups have developed many of the methodological and interpretive frameworks that an inhabited approach requires. Eliasoph and Lichterman (2003) have identified “group style” or “recurrent patterns of interaction” (p. 737) as governing the types of collective representations different recreational and voluntary association produce as they interpret facets of public culture. In this vein, Lichterman argues that formal attributes of organizations, including those that fall completely outside of standard definitions of civil society, need to be ignored and the focus should instead be on the “voluntary, collective problem-defining and problem-solving” activities of people, no matter where they are organizationally located (Lichterman, 2011, p. 227). Gary Allen Fine’s “tiny publics” and “sociology of the local” framework (2010) similarly stresses the importance of small groups in interpreting outside events and distinct cultures. Fine’s recent

contribution on group culture and interaction orders has recently offered a way of turning neo-institutionalism on its head, but showing how local, creative action can rise from the bottom up and spread out, becoming transformative within a wider network (2012).

### **Focusing on small grassroots groups in the international disability movement**

In order to understand the creative action and interpretation engendered within the grassroots disabled persons organizations (DPOs) that I studied in Nicaragua, I did two things: I informed myself as deeply as I could on the international disability rights discourse and then I embedded myself within grassroots associations and looked for evidence of its dissemination, incorporation, and/or rejection in their daily activities. Given the expansive nature of the international disability rights movement, as outlined in Chapter 1, these interactions were not hard to identify: international disability NGOs and global disability rights networks and funders were actively engaging the DPOs in my field site and members and leaders of the DPOs in my sample were often explicitly discussing the UN Convention on the Rights of Persons with Disabilities (Chapter 4), the globally promoted norm of self-identifying as a “person with a disability” rather than other forms of identity, such as war wounded (Chapter 3), and disability consciousness-raising (Chapter 5). Each article-chapter outlines the specific methods for data-collection used.

What was revealed throughout was that like Pope John Paul II landing in Nicaragua three decades ago, international NGOs and funders arrive with specific

notions of what civil society should look like and how it should act. They are no longer concerned with a “popular” church that has integrated itself with the government, but with DPOs that continue to see their mission as providing services to their members rather than advocating for human rights. And, like Ernesto Cardenal, they often smile, accept the grant or attend the technical assistance training, and then go on to do their own thing. This is not always the case, however, as some of the DPOs do conform to the international disability rights movement’s model. The power of an inhabited approach, however, is that it offers a way to “get into the heads” of each grassroots association in order to understand how they negotiate change, often reinterpreting or repurposing global models for specific uses and adjust organizational practices accordingly.



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### Chapter 3

#### **The Social Model of Disability under the Shadow of the Revolution: Ex-combatants negotiating disability identity in Nicaragua**

On the morning of July 25, 2012, seven local, grassroots disability associations based in Segovia<sup>1</sup>, Nicaragua, gathered for their fourth annual National Disability Day march down the city's main street. The groups quickly unfurled their banners in front of a little park adorned with a statue of the "unknown soldier," a ubiquitous image throughout Nicaragua of a Sandinista revolutionary launching a Molotov cocktail into the air. The imagined target of the statue's makeshift grenade is either Somoza's National Guard during the 1979 Revolution or a raiding party of Contras during the subsequent, decade-long, civil war. This town in Nicaragua's northern highlands was one of the first places to rebel against Somoza's dictatorial regime, resulting in whole *barrios* being razed by the National Guard, Somoza's personal army. Later, following the Revolution's success, former National Guardsmen and others displaced or disaffected by the new Sandinista government's policies, regrouped in Honduras and initiated a counter, or *contra*, revolution with US support. Segovia, which is near the Honduran border, became a major target for Contra raids, which left hundreds dead or permanently disabled.

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<sup>1</sup> Segovia is a pseudonym to provide anonymity to organizations and their members, who are also referred to through pseudonyms. Nueva Segovia refers to the northern, mountainous region of Nicaragua near the Honduran border, and thus the area where the majority of the fighting took place during the Contra War during the 1980s. It includes several *departmentos* and major cities, each of which has grassroots disability associations and coalitions. I chose to call my field site "Segovia" as the name connotes the general region, but does not give specific information about the city itself, thus akin to calling it "Midwest" or "New England" city.

Segovia's disability rights coalition includes the usual suspects found throughout the international disability movement—associations of the blind, the deaf, and even women with disabilities. It also has two groups unique to Nicaragua: the *Organization of Disabled Revolutionaries* (ORD), ex-Sandinista soldiers with disabilities; and the *National Association of the Disabled Resistance* (ADRN), ex-Contra soldiers with disabilities. On that morning, these two groups were acting in very different ways. Members of the Contra group, just like the members of the mainstream disability associations, were putting on t-shirts emblazoned with “We are disabled, we are equals” across the back. The negligible number of ex-Sandinistas who had shown up as part of the ORD, however, did not bother with the t-shirts. In fact, once the march began, the ORD's president, Denis, who was wearing his jungle hat and combat boots, chose to walk along the sidewalk rather than with the larger group of participants. He spent his time passing out water to marchers from a bag he clutched with his left arm, which had been amputated from the wrist down. Other ORD members also engaged in supporting roles, directing traffic or handing out water, rather than marching themselves. The reason ORD members were so reluctant to join the activities could not be chalked up to a dislike of marching; just a week earlier, during Nicaragua's Revolution Day celebration, they had joined a long parade of other Sandinista veteran groups on the very same street. They simply had little interest in the National Disability Day's activities.

As already mentioned, the ADRN showed up in full force. Their president Humberto, dressed in a white polo shirt and crisp jeans, chose to lumber along with leaders from mainstream disability associations, with his one leg still filled with



shrapnel. These leaders marched behind a banner calling for Nicaragua to fully implement their new disability law, *Ley 763* (2011), which was explicitly modeled after the 2006 UN Convention on the Rights of Persons with Disabilities (UNCRPD). Behind them strode the rest of ADRN's members, mixed in and indistinguishable from the other disabled marchers (Field Notes, July 25, 2012). These ex-Contras, unlike the ex-Sandinistas, did not get to march on other Nicaraguan holidays. Two decades earlier, Contra forces had sought to destroy Segovia. Today, some of those very same Contra fighters, who had been wounded during the conflict, were demanding that the city respect their rights as persons with disabilities.

Segovia, like many far-off corners around the globe, is being incorporated into a growing and powerful international disability rights movement that promotes a new understanding of disability. The associations in Segovia, for instance, are regularly invited to disability rights workshops conducted locally or in Managua by groups such as Handicap International (French), Action for Disability and Development (British), and CBM International (German). At the core of the global movement sits the *social* model of disability, as spelled out in the UNCRPD, which guides the practice of both international and grassroots activists. According to the social model, disability does not result from an individual's physical, cognitive, sensory, or psycho-social difference (or "abnormality"), nor is it best addressed through therapy and rehabilitation. Instead, the social model conceives of disability as the result of societal discrimination (Oliver 1986), best remedied through the promotion and protection of human rights. As such, the logic of the international disability rights movement

portrays persons with disabilities as something of a homogeneous group that shares a singular identity as unjustly discriminated against for their impairment.

The social model is also a tool that raises the consciousness of persons with disabilities, teaching them that “they don’t need to change: society need[s] to change” (Shakespeare 2006, p. 30), which leads to identity politics (Anspach 1979) as a means of addressing disability oppression. By claiming disability (Linton, 1998), disabled persons are not only pressing for a more just social order, but demanding recognition (Fraser, 2003) as full and equal citizens. Powerful international disability rights activists argue that bringing people with disabilities around the world together under a singular identity for advocacy is absolutely necessary for their empowerment (See, for example, Flood 2005). Yet, as my field work shows, the effects of this new identity are not universally positive, nor do all persons with disabilities accept the social model as a true representation of their situation. Instead, different disability groups strategically deploy this logic to either gain advantage or to simply avoid being left behind. They may also counter the disability identity with other identities that they, in fact, believe represents a more authentic self (Taylor, 1989) or use the disability identity in lieu of a more stigmatized and less protected identity, even if that identity is more salient in everyday life. These identity management techniques are not simply about gaining access to material resources, but conduits for participation in the public sphere (Lichterman, 1999). These identity negotiations take place in a local context where the same disability can have very different meanings and ascribe very different statuses for a disabled individual. To demonstrate this, I show the way two veteran

groups use the universal disability identity, with one group embracing it, whereas the other uses it rarely and reluctantly.

In my field site, I found that disability can signify having been wounded in combat, a local and inherently political identity that is more complex than the social model can accommodate. In my site, ex-Contra soldiers who were disabled while fighting in the Nicaraguan Civil War are a politically discredited group who are today presenting themselves as persons with disabilities “through no fault of their own,” thus setting aside their stigmatized identity as “traitors.” By adopting the universal disability identity, these ex-Contras are able to participate in a local coalition as equals and gain resources and recognition on the basis of being part of a protected group. In contrast, ex-Sandinista soldiers disabled in the war are a historically valorized group who are perceived to have protected the community from outside attack. The universal disability identity threatens their status as “war heroes,” their ability to differentiate themselves from other disabled persons, and traditional ties to local elites. Yet, because of the passage of the UNCRPD and a new Nicaraguan disability law, these war heroes must sometimes, in their own view, “lower themselves,” and associate with persons with disabilities in general in order to access benefits that were once theirs by virtue of their extraordinary service, as opposed to being members of a putatively marginalized class.

My research and analysis shows that we cannot assume global identity models will have the same effect as they diffuse across different subgroups. Instead, these new identities, or “scripts” (Goffman 1959), interact with deeply rooted identities and local relations, triggering strategic, and often contradictory, responses by various actors. By

using disabled veterans from opposing sides of a civil war as a case study, I am able to highlight the role local political context plays in shaping the identities of different groups of persons with disabilities and their relationship with the larger community. This “politics of the local” (Fine, 2010) demonstrates the importance of focusing on the complex role small groups play in their members’ identity formation and preservation (Fine, 2012, pp. 162-164). Furthermore, I call into question certain assumptions about the social model of disability and the very conceptualization of persons with disabilities as a singular “group” (Brubaker, 2002). Rather than being universally empowering for all persons with disabilities, the social model creates winners and losers, bringing some persons with disabilities up and others down.

### **The Social Model of Disability and Disability Identity**

Sociologists have addressed disability from both micro and macro perspectives. Today, however, the social model of disability, a macro-structural account of disability (Borsay 1986), is dominant within disability studies and in global disability activism. The social model, however, ignores local realities and the experiences of specific groups. In order to understand divergent reactions to the universal disability identity in my field site, I build upon recent critiques of the social model, social psychological accounts of disability identity, and recent work on the sociology of small groups.

Erving Goffman’s *Stigma* (1963), which identified “abominations of the body” (physical disabilities) as a core category of stigma, inspired many early disability

scholars and activists to investigate the social causes of disability. Goffman's own interest was in the ways individuals "managed their spoiled identities" in everyday interactions; an interest which yielded the concept of passing, defined as the strategic covering up or disclosure of a discredited identity. Within social psychology, passing has become a central concept, utilizing a number of tactics that range from outright lying or fabrication regarding one's personal information (Woods 1994) through to simple discretion regarding personal information (Clair et al 2005; Herek 1996) or to simply avoiding certain conversation topics (Chrobot-Mason, Button, and Declimenti 2001) in a particular setting (DeJordy 2008). Yet, it was Goffman's general observation that persons with impairments are socially stigmatized that became his major contribution to the "social model of disability," the foundation of contemporary disability activism and disability studies in academia. While Goffman's failure to take a structural approach to disability—his "interactionist fallacy" (Gleeson 1999)—has long been a target of criticism for disability studies scholars, his observation that stigma is something imposed upon persons with disabilities is central to understanding that disability is a socially produced identity.

The rise of the Western disability movement was based upon the "conscientization" of persons with disabilities who became aware of disabling social forces and the necessity of political reform (Shakespeare and Watson 2001, p. 562; See also Barnartt 1996; Groch 2001). In 1975, the Union of the Physically Impaired Against Segregation (UPIAS), a progressive, membership group of disabled persons in the United Kingdom, provided the first "social" definition of disability. In their *Fundamental Principles of Disability*, UPIAS highlighted society's discrimination

against persons with disabilities by claiming that: "It is society which disables physically impaired people. Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society" (UPIAS 1976, p. 3-4). A few years later, this conceptualization of disability was dubbed the "social model" (Oliver 1983) to emphasize the point that discriminatory "modes of thought" (Oliver 1990) and inaccessible environments are what disable people, not their impairments. The social model was conceptualized so as to draw a contrast to other understandings of disability, such as the medical and charity models, which emphasize the need to care for, pity, or "fix" (i.e. rehabilitate) individuals with impairments.

The paradigm shift from disability as the result of an individual difference to disability as the "the failure of a structured social environment" (Hahn 1986, p. 128) helped politicize persons with disabilities; cross-disability advocacy organizations soon sprang up, demanding reform (Barnartt and Scotch 2001; Fleischer and Zames 2011). Under the social model, distinctions between individuals with physical, sensory, communicative, intellectual and learning, and/or psycho-social impairments collapse, opening the door toward the development of a common, cross-cutting disability political identity (Putnam 2005; Anspach 1979). Irving Zola (1982) spelled this identity-based mobilization process out in his call for collective action:

We with handicaps and chronic disabilities must see to our own interests. We must free ourselves from the 'physicality' of our conditions and the dominance of our life by the medical world. In particular, I refer to the number of times we think of ourselves and are thought of by others in terms of our specific chronic conditions. We are

polios, cancers, paras, deaf, blind, lame, amputees, and strokes. Whatever else this does, it blinds us to our common social disenfranchisement. Our forms of loss may be different, but the resulting invalidity is the same. . . Not only has this led to an overspecialization of services but to an underdevelopment of our consciousness (p. 243).

According to the social model, persons with disabilities are empowered when they recognize that they are oppressed by an “ableist” social world view (Campbell 2009), a realization that does not promote a feeling of victimization, but instead acts as a “clarion call” for “social change agents” (Charlton 1998, p. 192). Asserting a positive disability identity is considered central to fighting stigma, addressing discrimination, and effecting change (See Darling 2013, pp. 71-74 for overview and critiques of disability identity politics).

Following initial success in North America and Europe, Western activists soon moved towards incorporating all persons with disabilities into a singular, global movement. Few disability studies scholars and activists have questioned the social model’s relevance in non-Western contexts, advocating that it is still the best “explanation of our experience as disabled people whether we live in the developed or majority [developing] world” (Flood 2005, p. 191) and asserting that all persons with disabilities are “united by their shared oppression within the world system” (Sheldon 2005, p. 126). This advocacy, spearheaded by disability organizations in the Global North, led to the 2006 passage of the UNCRPD, which is based upon the social model (Sabatello and Schultz 2014, p. 2). As such, the universal disability identity has been effectively written into international law by categorizing all persons with disabilities as a singular group regardless of local context or disability type.

Even though the social model is now internationally dominant and often used by disability activists and scholars as an “ideological litmus test” (Shakespeare 2006), its limitations have been recognized. Many activists have argued that attention to specific individual or group histories has no place within the disability movement because “the social model must exclude the consideration of personal experience” (Galvin 2003, p. 149) in order to highlight the socially imposed nature of disability. This exclusive focus on social structures, however, falsely presents persons with disabilities as a homogeneous group. As such, it is a case-in-point of what Brubaker (2002) calls “groupism,” the assumption that certain identities and categories actually exist as “things-in-the-world” and as “internally homogeneous, externally bounded groups” (p. 164).

Critiques of the social model contend that disabled persons are diverse and may experience disability very differently in relation to the way their impairment is embodied (Hughes and Paterson 1997; Thomas 2004; Shakespeare 2006), their age or point in their life cycle (Priestley 2003), and the other identities (i.e. race, class, gender, etc.) that persons with disabilities have that may be more important to them individually or within specific contexts (Darling 2013, p. 44). Putnam (2005), incorporating many of these same critiques, argues that the salience of disability as a political identity may also depend on personal experiences with discrimination and individual involvement in the disability movement (p. 194). From a more global perspective, Meekosha (2011) has argued that the social model is rife with cultural assumptions that ignore local realities in the Global South. In a similar vein, but from the perspective of social psychology, Safilios-Rothschild (1970) suggests that the



stigmatization of persons with disabilities is relative to many factors, one of which is the relative importance of activities that carry a high risk of disability, such as war. Building upon Safilios-Rothschild's point, Darling (2013, p. 13-14) argues that social conditions affect societal views of disability, including the way disabled veterans are viewed and, in turn, view themselves.

Disabled veterans are a particularly interesting subgroup for examining identity. Disabled veterans may, in fact, face less stigma and access more benefits than other persons with disabilities. This may explain why veterans often have an ambiguous relationship to other subgroups of persons with disabilities and the disability rights movement. In the United States, for instance, disabled veterans organizations' have both participated in campaigns led by the larger disability movement, such as advocating for accessible transportation (Fine and Asch 1988, p. 3) and nondiscrimination legislation (Barnartt and Scotch 2001, p. 169), and opposed objectives of the larger movement, such as blocking the universalization of disability benefits in order to preserve special privileges and separate treatment (Fliescher and Zames 2011, p. 171). While these latter activities may seem cynical attempts to corner a larger share of public resources, they also have symbolic value in terms of disabled soldiers preserving validation for their service and maintaining a positive sense of self. Messinger (2012), for example, has shown that the rehabilitation regimes for veterans at Walter Reed Army Medical Center in Washington D.C. are as much about soldiers developing socially valued identities as they are about regaining physical functions, an objective further evidenced by official hospital policies that refer to patients as "Wounded Warriors" and "Heroes" (Wool and Messinger, 2012).

Given the topical specificity of disabled ex-combatants in Nicaragua, literature is limited. There is, however, one extremely helpful prior study. Bruun (1995), who conducted fieldwork in Nicaragua during the 1980s, describes a Sandinista soldier, who lost both legs in combat, being publicly honored. This treatment led Bruun to conclude that disabled Sandinista fighters in Nicaragua were achieving a new identity as a war hero. Bruun argued that “What really made this change of identity possible was the political context of [the disabled soldier’s] trauma, which made him more special than he would have been if he had been born disabled” (p. 201).

Neither Bruun nor studies of disabled veterans in the US or Nicaragua, however, consider how different groups of veterans react to the social model or utilize the universal disability identity. Nor do they have the advantage of comparing two groups of veterans from opposing sides of a conflict. My analysis focuses on identity management techniques, utilizing Goffman’s classic account (1963) and recent analyses of stigma management that highlight the fact that individuals are members of multiple identity groups (Brewer 2000; Rockquemore and Brunisma 2002) and “proactively” negotiate their identity (Renflow 2004). I also recognize that not all discredited identities are the same, building upon Falk’s (2000) differentiation of stigma on the basis of “achieved” (based on behavior, such as criminality) and “existential” (through no fault of one’s own, such as ethnicity). In these ways, I am able to show that disabled veterans in Segovia are strategic actors, aware of how they are perceived by others and active in either reshaping or attempting to preserve their place within the social order through their identity work. Persons with disabilities as a “group” (Brubaker, 2002) are not a given. Instead, they are a collection of diverse

individuals with equally diverse life experience. Their social identities as persons with disabilities, war veterans, and political actors, however, are developed, preserved, or transformed within the specific civil society associations that they belong to (i.e. the ORD or the ADRN) (Fine, 2012).

### **Data, methodology and field site**

The international disability rights movement, with the backing of the UN Convention on the Rights of Persons with Disabilities (UNCPRD), has achieved a great deal of success in a very short period of time. As of February, 2014, the UNCPRD, which was passed just seven years ago, had garnered more than a 158 signatories and 141 ratifications, making it one of the most widespread international human rights instruments. In tandem with this large number of States-Parties, UN agencies, international NGOs, and networks of Disabled Persons Organizations (DPOs) have spread throughout the world to promote the UNCPRD and its implementation at the local level. From this global, or macro, perspective, the expansion and influence of the international disability rights movement is beyond question. The ratification of a treaty or the presence of a disability rights coalition, however, do not provide insight into the way the universal disability identity is utilized by local actors in relation to a specific culture. A micro-approach is much more appropriate for understanding how these global changes affect everyday life of particular groups of persons with disabilities.

This article focuses on one aspect of a much larger project focused on the way in which persons with disabilities at the grassroots level interpret and utilize the UNCRPD. As such, I am drawing from ethnographic data and interviews I collected during the summers of 2009 and 2010 and then an 11 month period spanning 2011-2012 in Segovia, where I spent time with members of the seven local disability associations that belong to Segovia's disability rights coalition—the *Departmental Commission for Advocacy and Awareness* (CDIS), various national and international networks and NGOs; local government officials involved in disability, and others.

My decision to focus on persons with disabilities in a developing country was based upon prior professional experience working with landmine survivors and other disabled persons in Central America and Sub-Saharan Africa. Over the years of my tenure as an NGO administrator, I became increasingly concerned with the absence of persons with disabilities from developing countries at the very conferences where global disability priorities and policies were formulated. This pushed me to pursue a research, rather than project management career, so that I could focus on how international agendas matched the local needs and objectives of disabled persons. My specific focus on disabled veterans was motivated by two seemingly contradictory discussions I was involved in during 2011. The first was during an informal meeting organized by the UN Mine Action Service while I was living in Geneva, to discuss the “problem” of landmine survivors and ex-combatants believing they “were more deserving,” and thus resisting integration into national (i.e. universal) disability policies in various countries. The second was just two months later when chatting with a fellow researcher at the UN in New York during the Conference of the States-Parties

to the UNCRPD. While asking her about her work in Tanzania, she had quipped that the “best thing that could happen” for a disability rights movement was a war because disabled veterans made such effective leaders. On the basis of those two discussions, I knew I would have to pay particular attention to disabled veterans when I returned to my field site in Nicaragua.

My primary method throughout my fieldwork was participatory observation, wherein I attended formal meetings and workshops, joined leaders or staff of organizations on their daily activities, spent time in their offices, and visited homes of persons with disabilities. Segovia, while a significant city in Nicaragua, is very much a small town; I ran into members of the organizations on a daily basis, often picking up useful snippets of news or gossip in our quick conversations. I supplemented these observations with semi-structured interviews with group leaders and active members. I also collected numerous documents from organizations and the government. Over the course of the two summers and one year, I recorded 69 formal interviews, attended dozens of associations’ monthly meetings, CDIS’ planning meetings, and weekly planned activities, such as workshops, awareness events, or meetings with local government officials. Through all of this, I learned that the past in Segovia is ever present, especially for the two associations in the local disability rights coalition that represent ex-combatants.

Segovia is a rapidly growing transport hub in the mountainous North as tons of tobacco and coffee stream out of its cement warehouses bound for the ports along the coast. The city draws its identity, however, from its past more so than its present. It was a major battleground during the 1979 Sandinista Revolution and Contra War in

the 1980s. Many of the buildings still bear the scars from when Somoza ordered the city air bombed in 1978 and 1979 in his attempts to quell the rebellion. Many of my informants told me stories of fleeing into the surrounding forest during those attacks. Others spoke of hiding under beds and, according to one, in a baker's oven for days on end as the dictatorship's National Guard conducted door-to-door sweeps looking for Sandinista sympathizers.

Despite the eventual success of the Revolution with the expulsion of Somoza and the establishment of the Sandinista government, peace in Segovia was short lived. Within months, Segovia found itself on the frontline of the Contra War as disaffected National Guardsmen reorganized in CIA-funded camps along the Honduran border and, joined by others disaffected by the Sandinista regime, returned, attacking the new government's outposts and civilian centers (Kinzer 2007).

Finally, in 1989, the Sandinista government, which was tired of a war that had left 40,000 dead in a country of only 4 million, and the Contras, having gone broke after the Iran-Contra Affair ended their covert funding once and for all, signed the Peace Accords. As part of the deal, the Sandinista government offered a blanket amnesty to Contra soldiers.

Two decades later, the memory of the Revolution and Contra War lives on in Segovia, where every barrio's entrance is adorned with a concrete memorial listing the names of Sandinista soldiers who fell and abundant murals commemorate the bravery of the Sandinista soldiers who defended the city from Contra attack. Equally, the Sandinista legacy lives on in politics: 64% of Segovians voted for the Sandinista Front in the 2011 election and nearly every local office is filled by a Sandinista.

It is in this environment that persons with disabilities must negotiate not only their rights, but also their identities. And, as a former battleground populated by the war wounded, politics and disability are intertwined in Segovia. The Organization of Disabled Revolutionaries (Sandinista) and National Association of Disabled Resistance (Contra), each hailing from different sides of the civil war, are two of the most prominent organizations within CDIS. CDIS is a coalition originally organized by Handicap International in 2008 as part of its global *Making It Work* campaign to involve grassroots disability associations in advocating for the local implementation of the UNCRPD. CDIS, which has seven members ranging from the association of the deaf to parents of children with disabilities, is the recipient of both money and immense amounts of technical assistance in the form of workshops on the social model and “disability identity development.” They have also been funded by the US-based Disability Rights Fund to pressure Segovia’s city hall to implement the UNCRPD, which Nicaragua signed and ratified in 2007. This incorporation into the international disability rights field, however, has very different meanings for the two different associations of ex-combatants.

### **Performing Disability in Segovia**

Disability for the ex-combatant members of the Organization for Disabled Revolutionaries (ORD) and National Association of the Disabled Resistance (ADRN) in Segovia has social meaning rooted in a history of war. The ORD are Sandinistas who overthrew a deeply unpopular dictator and then defended the nation from outside

attack. Their disabilities, acquired in battle, are a symbol of valor—a sort of “red badge of courage.” The ADRN are Contras, or the “Nicaraguan Resistance,” a diverse group that included National Guardsmen and other loyalists to Somoza who were displaced when his regime fell Somoza fell, peasant farmers who opposed Sandinista policies, such as price controls on various agricultural goods (Brown, 2001), and other groups disaffected with the new government. As such, many headed to Honduras, only to return to Nicaragua as guerilla fighters, attacking the citizenry. For them, their war wounds remind the larger community of their treasonous past, acting as a sort of “scarlet letter.” The universal disability identity has the potential to wipe away both of these local, political meanings by presenting disability as a universal and ahistorical identity. Each group engages in identity management practices.

### Identifying as disabled

The ADRN is a civil society organization founded in 1990 to represent the interests of disabled Contra fighters. During the 1980s, the Reagan Administration had provided clandestine support to the Contras, causing many to believe they would either be able to retake Nicaragua or eventually be granted US citizenship. In 1987, however, that support was withdrawn as a result of the Iran-Contra scandal, which revealed that US intelligence services had been secretly supporting the Contras against an explicit prohibition passed by the US Congress. Without outside support and nowhere else to go, the Contras eventually agreed to lay down their weapons and return home under a general amnesty.



Segovia's ADRN chapter is one of Nicaragua's largest with seventy members, virtually all of whom are middle-aged men who fought in the 1980s. The vast majority of members have mobility disabilities due to either amputations or loss of functioning in one or more limbs. A few have other types of combat-related disability, such as visual or hearing impairments.

While more than twenty years have elapsed since the end of the Contra War, ADRN members' political identities are as strong as ever. During the ADRN's 2011 end-of-the-year celebration, an annual meeting followed by a barbecue, I was schooled on Nicaraguan politics by half a dozen members determined to tell me how terrible the Sandinistas really were. Less than a month before, Daniel Ortega, had been reelected President of Nicaragua as the Sandinista Front's candidate. Ortega's unique history as an early opponent of Somoza in the 1970s, leader of the Sandinista ruling *junta* and then President during the 1980s, and political come-back with his return to the presidency in 2007, assured him a landside nationally and almost two-thirds of Segovia's vote. To the ADRN members that I spoke to that day, however, Ortega was a potent reminder of their failure two decades earlier, when they had sought to topple the Sandinista regime.

The end-of-the-year celebration in December was held in the ADRN's new hall, which was a large, single room with brick walls, a zinc roof, and a dirt floor. I sat down in one of the rows of plastic chairs and struck up a conversation with another member who was waiting for the meeting to begin. Upon learning that I was an American, he asked me what I thought of Nicaragua's presidential elections. Trying to preserve my neutrality, I told him that I did not know anything about Nicaraguan

politics. “The only thing you need to know is that Ortega is *garbage*,” he said with finality. Another member from across the aisle turned around and joined in. The first thing he did was point to the ceiling and say “*Techo democracia*” (roof democracy). I had heard this term before, but asked him to explain it. To him, it meant that Ortega was buying off the populace by giving them *regalos* (gifts). As we spoke, more members decided they wanted in on the conversation and moved their seats closer. As a group, they reached a consensus that the main problem in Nicaragua was that the people, especially the poor, were stupid and would always vote Sandinista (Field Notes, Dec. 4, 2011).

The conversation we were having was a rare one for me. Since I had lived in Segovia, Ortega and the Sandinista Front were often talked about in balanced, if not glowing terms. The one exception had been during a disability advocacy training for all of the members of Segovia’s disability rights coalition, which was conducted by an NGO from Managua. During a presentation on political advocacy, the trainer tried to make a point by saying that during the Somoza dictatorship, civil society advocacy was impossible, but today advocacy worked because Nicaragua was a democracy. At that point, Humberto, the ADRN’s president, leaned over to another ADRN leader sitting with him in the back and quipped “*Democracia? Techo democracia!*” under his breath (Field Notes, Oct. 3, 2011). It was then that I learned that *techo democracia* was a criticism of the Ortega’s “*Plan techo*,” a set of social programs distributing assistance to vulnerable populations and civil society organizations, including persons with disabilities, who were a priority group. Roofing materials were one of the benefits.

There was no question that members of the ADRN maintained their political identities as being in strict opposition to the Sandinista government. But, they were also doing so with discretion, a basic identity management tactic (Clair et al 2005; Herek 1996). The ADRN were keeping their vocal opposition to the Sandinistas within a “backstage” environment (Goffman 1959), whether by keeping their quips down to a whisper in public (the advocacy training) or reserving their most vociferous attacks for private places (the ADRN hall).

ADRN opposition to the Sandinista Party, however, was not only political, but personal. Throughout my field work in Segovia, ADRN members would tell me about the difficulties they had finding work, alluding to discrimination. In an interview with Humberto, the ADRN’s president, I asked about how ADRN members encountered discrimination in everyday life. Humberto presented a novel view that brought together both sides of the ADRN members’ identities and indicated that he was aware of his members membership with multiple identity groups (Brewer 2000; Rockquemore and Brunsma 2002): “We have here *double* discrimination, for being disabled and the other for not agreeing or matching with the politics of the current government” (my emphasis, Interview: June 7, 2012).

In the disability rights world, “double discrimination” is normally reserved for discussing intersectionalities between gender and disability that make women with disabilities particularly vulnerable (for example, see UN-ENABLE 2013). Humberto, however, was highlighting the fact that his members were a political minority and disabled. As I pressed for more information, however, I learned that not all forms of discrimination are equal.

A(uthor): When your members encounter discrimination, is it mostly for their participation in the war? Or because they are disabled?

H(umberto): Well, with this organization [ADRN], if there is discrimination, it is discrimination because of political creed. Because, for example, right now, with the current government, it is not so much because of disability. For example, Segovia is quite aware [sensitized] and has been regarding disabilities. We talked to the Ministry of Labor and they have already included forty people with visual disabilities. (Interview: June 7, 2012)

Humberto was referring to a meeting earlier that week that I had observed between CDIS, Segovia's disability rights coalition, and the Ministry of Labor's local office. During the meeting, the Ministry and CDIS discussed ways to enforce the new National Disability Law (Law 763), which imposed a hiring quota requiring that persons with disabilities make up at least 2% of the workforce of companies over a certain size. One of the strategies they discussed was to continue a partnership between the Ministry of Labor and the Association of the Blind to place and train persons with disabilities as cigar rollers (Field Notes: June 4, 2012).

A: I know about that—hiring people with visual disabilities. Do you know Nadid, from the Association of the Blind? We visited some of those factories together.

H: Yes, however, there are a lot of employers with a political character and there has been a big impact made by the current [Sandinista] government, which has created a problem with the institutions [government offices]. We have some members of the association in various State institutions, but sometimes you have to hide your political beliefs...

I was working at the INSS [National Institute for Social Security], and Pablo [another ADRN member] too. We worked as security guards and one time we arrived and an official told us that we could no longer work there... We had been given the assignment and objectives—we were fulfilling them—but this government lady told us

“No, I’m sorry, you can’t be here.” We had knowledge of the entire internal process of the institution. But, when we left, it was because of discrimination at the political level.

The association [ADRN] has this friction with the current government that is not so much about your disability, but is a political friction. Yes, there is discrimination, I’m telling you that there are some in the association who have to deny that they were part of the Resistance. In that case, they [the institutions] were violating my rights according to the Constitution, which says I have the right to participate politically. But when they say you have to be affiliated with the [Sandinista] Front to work, then they are discriminating against you and you have a violation of a person’s rights. (Interview: June 7, 2012)

Despite Constitutional protections, ADRN members knew that they were at a disadvantage in a patronage system that reserved government jobs for Sandinista party members. Having to “deny that they were part of the Resistance” was an allusion to concealing discrediting information (Clair et al 2005; Woods 1994) and the fact that it had to be done in government offices, indicative of exercising discretion in particular settings (DeJordy 2008). ADRN members, however, were learning much more subtle techniques. As both Contra and disabled, they were learning that they could pick and choose amongst multiple identities (Brewer 2000; Rockquemore and Brunσμα 2002) according to the situation at hand. While the Contra identity, especially after the reemergence of the Sandinista Party, carried risks, the disability identity could lead to new rights and resources.

During the ADRN’s 2011 end-of-the-year celebration, using disability as a primary identity was openly discussed. The main meeting that afternoon was eventually called to order, bringing an end to my *techo democracia* discussion. The board began by presenting their annual report to the sixty members in the hall. That year’s accomplishments were listed out: seven sets of crutches had been given to

members, the rotating loan fund had provided credit to a dozen others, and so on. The most important accomplishment of the year was the building of the new hall that we were presently sitting in. Without irony, given the members' feelings about Ortega's social programs, the board acknowledged that the land, which had been a vacant lot owned by the city, and the roofing materials, were donated to the ADRN by the local Sandinista government as part of their "*Plan techo*" to assist civil society associations representing marginalized groups.

The board also highlighted ADRN's work regarding the passage of Law 763, Nicaragua's new National Disability Law. One member asked a question regarding disability pensions for ex-combatants. The question was in reference to the 1989 peace negotiations, when Contra leaders held out for both a blanket amnesty and reinsertion benefits for their troops before agreeing to demobilize. The rehabilitation benefits for returning Contras never came to fruition. For years, the ADRN had advocated for their reinstatement. As of December, 2011, however, Segovia's members were informed that the ADRN was only interested in advocating for the implementation of Law 763, "The Rights of Persons with Disabilities." The board vice president, who was speaking, emphasized the point that their advocacy would not be for "combatants," but "universal"—for all persons with disabilities (Field Notes, Dec. 4, 2011).

This message of advocacy on the basis of disability, rather than combatant status, had already sunken in when I interviewed ADRN members a few months later. Longtime member, Francisco Javier, was confident in the antidiscrimination protections offered by Law 763.

A: Do you encounter any barriers in your normal life? For example, discrimination?

F(rancisco): Currently, I no longer do because I am really defending my rights—which say that I should not be discriminated against for having a disability. It's better now because I am defending my rights like any other, I cannot be discriminated against because a person with a disability and a normal person, who does not have anything [any disability], is under the same law. The law is not lost. (Interview: July 13, 2012)

A: Okay. Well, this association has two sides to its identity: persons from the war and persons with disabilities. Is that right, you have those both? Do you experience discrimination for your participation in the war?

F: Before, you could be discriminated against for that reason. There was some [discrimination], but now, at this stage, it is better primarily because the statutes of the association are open and anyone can participate—people with disabilities that were caused by the war as well as disabilities caused by accidents in the street, disease, in general ...

Francisco's second answer refers to recent changes in the ADRN's membership policy. In 2011, the ADRN officially opened their membership up to all persons with disabilities. It was seemingly a way for members to take advantage of the lessening of (or protections from) disability discrimination, while putting aside persistent discrimination towards ex-Contra. While this did not result in an increase in members (they remained an organization made up almost solely of ex-Contra soldiers), it allowed the ADRN to distance themselves from their Contra past and present themselves as non-political. A 2012 recruitment pamphlet echoed language from the UN Convention on the Rights of Persons with Disabilities by stating the association's general objective as: "Contributing to the process for the integration of persons with disabilities in social life and the nation's productivity, in a framework of

respect for their human dignity.” Under the question: “Who can be a member of the ADRN?” the pamphlet stated: “All persons with disabilities can be members of the ADRN...” going on to specify that members can “be a person possessing a disability, *the cause of [which] is not important*” [my emphasis]. Any indication that the ADRN had been and continued to be an organization made up of ex-Contras had been wiped away. These policy changes along with the discussions that took place at the annual meeting exemplify the importance of small, face-to-face groups in formulating and disseminating social identities that members can then take out and use in public (Fine, 2012).

By presenting themselves as persons with disabilities in general, the ADRN is prioritizing a protected identity over a discredited one. In critiques of the social model, Darling, for instance, suggests that other potentially primary identities, such as race or gender, may be more salient to a disabled individual than their disability identity (2013, p. 44). In this case, however, the political identity as Contra is the most salient, as well as the most problematic. By strategically choosing to present themselves as “disabled first,” however, ADRN members had learned that they could advocate more effectively than their Contra identity allowed. Furthermore, they were utilizing the social model of disability by claiming that individual experience and the specific cause of the disability should play no role in disability advocacy (Galvin 2003).

What is so interesting about this dynamic is that many members of the ADRN did not believe that disability discrimination was a major problem, yet were embracing a movement, law, and identity premised on the idea that persons with disabilities are a socially oppressed group (UPIAS 1976; Oliver 1983). In short, their shift to disability



as a primary identity in their public advocacy does not seem to have come from being “conscientized” (Shakespeare 2006), but instead in recognition of the disability movement’s presence (Putnam 2005, p. 194) and the opportunities it had wrought. In this way, claiming disability (Linton, 1998) was not a claim for recognition (Fraser, 2003) as an authentic self (Taylor, 1989).

Jose Santos, another longtime ADRN member, explained the lessening of disability discrimination over the years.

In the year 1990 or 92 until about 94/95 there was a lot of discrimination from disability because it was strange for everyone to see a person using a wheelchair or perhaps really limping—back then there was discrimination. But now, we have sensitized the people and, at least here in Segovia, they are a little more aware and don’t scoff at persons with disabilities. (Interview: July 13, 2012)

The importation of the social model of disability and creation of CDIS, Segovia’s disability rights coalition, also provided the ADRN the language and the opportunity to publicly present themselves through the universal disability identity. These two factors often came together.

The National Disability Day march described in the introduction was only one of many opportunities. Through the coalition, ADRN was able to participate in a series of events and projects sponsored by the Agency for the Promotion of Local Economic Development (APROE), a local government office commissioned to improve Segovia’s economy. CDIS, as one of APROE’s first partners, played a major role in the development of the initiative’s mission and values statement, including the specification that APROE would utilize an “inclusive development approach.” The phrase “inclusive development” is a reference to Article 32 of the UNCRPD.

One of APROE's kick-off events was a meeting, co-hosted with CDIS, for business leaders. Humberto joined the president of the Association of the Physically and Motorly Disabled and a representative from Handicap International, to present the social model of disability and the UNCRPD (Field Notes: October 4, 2011) to attendees in the City Hall. During the presentation, Humberto described the high unemployment amongst his members as the result of discriminatory social attitudes towards persons with disabilities—a problem he explained was best remedied through increased awareness and respect for human rights.

As Humberto spoke, he was, in a sense, imputing disability prejudice upon employers who did not hire ADRN members even though he knew it was their political identities that were the problem. He could do this because the Powerpoint behind him, which was provided by Handicap International and had just been translated into Spanish from its original French, presented disability as a universal identity. The photos included in the presentation were drawn from Asia, Africa, and Europe. Yet, on the other side of the screen stood a ten foot high mural on the auditorium's wall commemorating the Sandinista Revolution, displaying Segovian citizens dead in the street and Sandinista soldiers fending off a Contra attack. By putting the disability identity first, ADRN members were able to proactively present themselves with an identity that made them acceptable claimants for local benefits (Renfrow 2004) as well as legitimate voices in the public sphere (Lichterman, 1999). The greater acceptability of the disability identity is that it presents the stigmatization of persons with disabilities as “existential”—based upon a prejudice that has nothing to do with the actual, individual person (Falk 2000). Discriminating against someone

who has done nothing wrong is socially unacceptable. By framing job discrimination in those terms, Humberto had sidestepped the issue that the far more powerful form of discrimination that he and his members had encountered was based upon an “achieved” stigma (Ibid.) related to their political identities as Contra.

War Heroes or disabled?

While the rise of the universal disability identity was embraced by members of the ADRN, the Organization of Disabled Revolutionaries (ORD) greeted it with suspicion. Instead, members of the ORD—disabled veterans who fought for the Sandinista People’s Army in the 1970s and 80s—preferred to publically act through their identity as “war heroes,” an identity they had been promoting since their founding in 1982 (Bruun 1995). This identity allowed them to take advantage of the local political context when making claims on the basis of individual merit (military service and sacrifice) rather than universal marginalization (i.e. social model of disability). It also allowed them to act through an identity as war veterans that continued to be more important to their sense of self than their disability was. In this sense, ORD members, who in many ways resembled their ADRN counterparts in terms of being middle-aged men who had been disabled in combat, were acting in a very different way. Rather than embrace the disability identity, ORD members were promoting the socially valorized identity of war hero over and above their disability, akin to commonly cited instances of Paralympians (Rembis 2013) or prominent elected officials (Wilson 2013) wanting to be seen as athletes or politicians “first.”

ORD members, who had long experienced a place of social prominence in Segovia, perceived the rise of a disability rights movement as a threat precisely because it collapsed distinctions amongst persons with disabilities. The universalization of benefits through new laws and outreach to disability associations by international organizations, however, often forced ex-Sandinista soldiers to utilize the universal disability identity. In such cases, ORD members were reluctantly claiming their disability identity, despite the fact that it entitled them to certain rights.

One thing ORD and ADRN members seemingly agreed on was that discrimination on the basis of disability was not a major problem. For ADRN members, however, the lack of concern regarding disability discrimination was due to a greater concern with political discrimination and a belief disability “awareness” was on the rise amongst Segovians. For ORD members, however, their lack of concern regarding disability discrimination was based on a belief that if there was disability discrimination, it was less so for those wounded in war, a phenomenon discussed by Darling (2013, p 13-14) and Bruun (1995). For some, their status as disabled veterans had even led to benefits, such as government employment. Several members worked as night watchmen and security guards for local government institutions, the very job Humberto of the ADRN had been fired from.

Fernando, a member of the ORD since 1987, demonstrated his belief that disability discrimination was low, especially for ex-combatants, during an interview with me.

A: How has your disability affected your life? Your work?

F(ernando): This? [pointing to his upper arm] Well, I've never had work other than for the State. So, whatever work I have had has been on their account—they've given me a life.

A: Did you acquire your disability in the War, in the 80s?

F: Yes, in the War.

A: Okay... Do you encounter other barriers in your life? Obstacles? Discrimination?

F: No, I do not think so, especially because I feel that it [his disability] is not visible. [Showing his forearm, which was out of the sleeve] this doesn't look like my arm above because the fracture was up here, although the arm is useless from here down [demonstrating that it is paralyzed].

A: I understand, but what about for others, where the disability is more noticeable?

F: If there is [discrimination], it is very mild. And for a war wound, it is much less.

From one perspective, Fernando could be seen as successful at passing. He is able to pass because his disfigurement is easily concealed (Clair et al 2005; Herek 1996) as a result of its location on his upper arm. But when asked about disability discrimination in general he does not seem worried, especially because he is war wounded and has a government job. In short, Fernando does not seem to be motivated to pass out of a strong desire to avoid disability discrimination.

To Denis, the president of the ORD, the idea of disability discrimination was literally a laughing matter. One afternoon, getting some air from a long city council meeting, I ran into Denis on the steps of the City Hall where he was trying to bum a cigarette off of a local TV journalist who was setting up. Once a smoke had been secured, Denis started pointing to the camera and asking, "Why don't you interview me?" The journalist, who was clearly a friend, answered: "Because you are too ugly." Laughing, Denis turned to me and said, "He doesn't respect my rights. This is

discrimination because I only have one arm!” I agreed, to which the two of them, giggling, waved off my pretend seriousness, repeating “*broma, broma, broma*” (joke, joke, joke).

Despite the fact that being discriminated against for being disabled was an idea ORD members were comfortable playing down or even lampooning, they still did not want to be identified as “persons with disabilities.” During monthly ORD meetings, I would keep a running tally of the usage of the term *lisiados de la guerra* (war wounded) in comparison with the term *personas con discapacidades* (persons with disabilities). The ratio for one meeting was ten to one. When “persons with disabilities” was used, it was often qualified as “in general” (as opposed to war wounded) and almost always as a point of contrast with the members of the group. Their distancing from the identity, however, was not based upon a fear of stigma, but instead a desire to maintain their political identities as ex-combatants. In this sense, they were not passing in order to escape a discredited identity and a desire to be seen as “normal” (Goffman 1963; Leary 1999). Instead, the ORD were trying to stand out and maintain their valorized status. Denis, for example, was confident that the community recognized the ORD’s service:

You think about it, we only believed in defending the Revolution so that today we [Nicaraguans] would be better off... If you go by us in the organization [the ORD], we are seen here [in Segovia] as having been born of the Revolution... We are the dead, the wounded, and the wounded ex-soldiers who participated in the war—that is the Revolution. Those of us who are the Revolution: the mothers of heroes and martyrs that, thanks to this [Sandinista] government today, are eating a little better. I am glad that I gave. (Interview: March 14, 2012)

Denis' passion spoke to how strongly he, like many of the ORD's members, truly identified as veterans who had been engaged in a cause larger than their own. The memory of their service and its concomitant identity was most assuredly preserved by their membership in a small group (Fine, 2012). The strength of the political identity as Revolutionaries for ORD members, however, was tied to the political fortunes of the Sandinista Front. It was no surprise, then, that the ORD's main project for 2011 was an inherently political one. Without the help or participation of any other members of CDIS, the disability rights coalition in Segovia, the ORD implemented the "electoral accessibility project" on November 7, 2011 for Nicaragua's presidential elections. The project, which was funded by the European Union and implemented by ORD chapters throughout the country, consisted of placing "guides" at each polling station to assist wheelchair-users through entrance ways or help people with visual impairments fill out ballots. The local ORD chapter was able to gather twenty volunteers to post at Segovia's voting stations.

While the ORD, in order to receive funding from donors such as the EU, declared themselves non-partisan, Denis admitted with a wink and a laugh that "We are all Sandinista" (Interview Nov. 4, 2011). While Denis displayed no intentions of voter fraud or stuffing ballots, he clearly saw increasing access for disabled voters as a boon for the Sandinista party, whom he characterized as having "always spoken for the poor in its campaigns, and for the vulnerable populations, which we [ORD members] are ourselves, because we were injured in the Revolution." As if to confirm Denis' belief that disability access would increase the Sandinista vote, the still-folded blue vests emblazoned with "Guide" and the EU logo to be worn by volunteers at the

polling stations were sitting in a corner of the office, heaped on top of a pile of Sandinista flags.

Whereas ORD members did not show up in significant numbers for the National Disability Day march on July 25<sup>th</sup>, they were on full parade the day following Ortega's landslide victory that November as well as one of many groups to march on Liberation Day (July 19, i.e. Anniversary of the Sandinista Revolution), Central American Independence Day (September 15), and Segovia's fiesta days. During these events, they were the only association of disabled persons as they marched alongside other Sandinista veterans, secondary school drum corps, and the local Catholic Bishop. The purpose of the march was also different. While the Disability Day march was an advocacy event, these other public events were celebrations of Nicaragua's accomplishments and valorizations of soldiers, students, and the clergy.

When ORD members did need something, their preference was to ask for help through personal contacts with local politicians. In the course of the year, I ran into Denis or the ORD vice president, Juan, at least a dozen times on their way to or returning from the Mayor's Office, where they asked officials, almost all of whom had served in the Sandinista People's Army during the Revolutionary period, for various forms of assistance ranging from burial expenses for an ORD member to a bus ticket for a member working in Costa Rica.

Some ORD members, however, felt that these relationships of reciprocity should be formalized through specific benefits for ex-combatants like themselves. One interviewee, Javier, spoke of the government building "special clinics for those persons that were in the [Sandinista] Front during the war..." The desire to see special



benefits institutionalized for disabled ex-Sandinista soldiers was linked to a concern that their valorized status was under threat, a concern also observed in the advocacy of disabled veterans in the US (Fliescher and Zames 2011, p. 171). Javier went on to explain: “It is clear that we need [more] support, especially because a lot of times, we [ORD members] *are forgotten, or not remembered—the sacrifice that a person who fought in the war has made.* (Interview: June 24, 2012).

Fernando, despite having received a job from the government, echoed Javier’s concerns, linking them to a failure of government institutions to distinguish between wounded soldiers and persons with disabilities in general:

I do not think that we [ORD members] are truly being aided by the Government. They give us very little... In the hospitals we are already not being treated as people with disabilities from the war, but *instead we are treated like any other. There is no longer that merit of before, during war, when everything was for combatants. Already the combatants are no longer treated as combatants in the hospital. There is no longer the priority for the person who went to war... The government no longer has a direct line to people wounded in the war.* (Interview: June 26, 2012).

Fernando and Javier were clearly aware that their privileged identity as ex-combatants was under threat. Similar to recent accounts of wounded US veterans (Messinger 2012; Wool and Messinger 2012), ORD members had acquired their disability identity under a separate rehabilitation regime that characterized them as “War Heros.” During the Contra War in the 1980s, whatever rehabilitation resources the Sandinista government had were prioritized first and foremost for Sandinista soldiers (Bruun 1995). But the concerns with being “forgotten” or losing “merit” seem to go deeper than the loss of material benefits; they are concerns about the loss of

recognition (Fraser, 2003). Part of the ORD's fears today have to do with legal reforms that took place in 2011. That year, Nicaragua passed a new disability law (*Ley 763*) as part of their responsibility to norm national legislation with the UN Convention on the Rights of Persons with Disabilities. As such, the law did not make any distinctions amongst persons with disabilities. This caused a great deal of concern amongst both local ORD members in Segovia and their national office in Managua.

In the Spring of 2012, Denis gave me a copy of a proposal that the ORD national office had sent to the national government. The proposed "Petitioned Agreement with the Government of Nicaragua and Institutions of the State" outlined the ORD's concerns regarding Law 763. The ORD was lobbying for a special seat on a newly created National Council for Disability, justifying their claim on the basis that they had a special duty to make sure that there is "the attention and respect that is deserved by persons with disability resulting from the war." As the law stood, civil society representation was limited to a national disability federation called FECONORI, that CDIS was a member of. The petition also called for the reinstatement of Law 119, which granted pensions to disabled combatants. When discussing the petition with local ORD members in Segovia, they called it a "moral obligation" of the society to care for them.

In order to further understand the context and intention behind the petition, I arranged a meeting with a member of the national board of the ORD in Managua. The board member portrayed the rise of the national disability rights federation, which had advocated for the new law, and the decline of the ORD's influence as a zero sum game:

In the last two years, the [national, cross-disability] movement of persons with disabilities has grown. They have strengthened a lot, they are organizing—fighting and defending their rights... The Federation is working, planning, and anticipating the [new] laws that are coming out... In the last few years, they have grown into a strong organization... For the ORD, however, the problem is ugly. It is a horrible future for us. (Interview: August 21, 2012)

The ORD's attempts to stand out as special amongst groups of persons with disabilities did not go unnoticed by the larger disability movement. A representative from the national disability network told me at a meeting he had organized in Segovia that he was disappointed with the ORD, shaking his head and dismissing them as a group of "showmen" (Field Notes, Oct. 10, 2011). The ORD's refusal to identify according to the universal disability identity put them at risk of sanction, something common within disability pride movements (Casey 2013).

In all of these different ways—preferring to be referred to as "war wounded" rather than "persons with disabilities," publicly tying themselves to the Sandinista party, or lobbying for special status within the National Disability Council—ORD members were utilizing their political identities as war heroes and distancing themselves from their identity as disabled persons. The rise of the disability rights movement and its promotion of a universal disability identity, however, occasionally incentivized or forced ORD members to adopt the disability identity in order to access certain rights and benefits. In many ways, though, these compromises seemed to confront, if not weaken, their collective sense of self as war heroes.

ORD members were reluctant to associate with or participate in any event focused on persons with disabilities in general. Denis, however, felt that it was important that the ORD be represented locally, often with the hope of gaining resources from outside funders or ensuring the ORD receive their fair share of resources distributed through Segovia's disability rights coalition. He was already concerned about not having received funds for a new office through Segovia's *Plan Techo*. The ORD office, which had been given to them back in the 1980s, was a single room in a dilapidated brick building that had been repossessed from a Somoza supporter following the Sandinista Revolution. In addition to the metal desk and plastic chairs, the office was filled with donations from various organizations. In one corner was a pile of old computer monitors and keyboards in black garbage bags that the ORD had received from Handicap International.

During one Sunday meeting, Denis read aloud an invitation for an upcoming conference on disability sponsored by a Managua group and to be held in Segovia's Recreation Center. Each organization was allowed to invite five members, but the ORD had difficulty identifying a single one after it was established that the event was not for war victims, but persons with disabilities in general. After much goading, one of the regular members volunteered. His immediate rewards for agreeing to go were laughs and shoulder slaps from the other ORD members—he was clearly taking one for the team (Field Notes, April 29, 2012). It was also clear that associating with persons with disabilities in general was a step down for the ORD, but something members sometimes felt they had to do.

The most painful instance of ORD members having to associate themselves as persons with disabilities in general, however, came as a result of changes in the law. After the National Assembly passed Law 763 in July, 2011, the national government began a disability certification campaign. The campaign was in accordance with the law's Articles 64 through 67, which focused on obtaining a *carnet de discapacidad* (disability card). Among other things, the card granted discounts on public transportation and access to *medios auxiliares* (literally "auxiliary means") such as crutches and wheelchairs. In order to obtain a card, an individual had to be declared disabled by the Ministry of Health.

Although this was a relatively small part of a broad law that outlined protections from discrimination and equal access to education and employment, the disability card was a fixation amongst ORD members. It was also a bone of contention. The monthly meeting in October, 2011 was dedicated to a discussion regarding registration. A few weeks later in November, representatives from the Ministry of Health and a Cuban Medical Brigade were scheduled to visit Segovia in order to do evaluations and certifications. The central point of discussion was why they (members of the ORD) had to get national disability cards when they already had ORD membership cards. One member held up his ORD card, which was in tatters, to explain "I have had this since 1988/89. I used it then to get anything I need." Denis was at pains to explain that all of the members of disability associations had to do the same. A booklet containing Law 763 published by FECONORI (and paid for by the Danish Association of the Disabled) was passed around, open to Article 65, which outlined the certification process (Field Notes: October 22, 2011).

In early November, the same ORD members who had been incensed over the disability card a month earlier were in line in Segovia's Recreation Center. They were mixed in with members of the ADRN, the Association of the Blind, the Association of the Physically and Motorly Disabled, and all other persons with disabilities in Segovia (Field Notes: November 14-18, 2011).

This act of joining other persons with disabilities in order to access benefits on the basis of the universal disability identity was not a liberating act for members of the ORD. They were not answering a "clarion call" to become "social change agents" (Charlton 1998, p. 192) because they now recognized themselves as oppressed. Instead it was in recognition of the fact that they were losing their privileged status and, as a result of the social model, now part of the same identity category as everyone else. In a reversal of Shakespeare's formulation that the social model taught persons with disabilities that "they don't need to change: society need[s] to change" (2006, p. 30), members of the ORD were slowly recognizing that society *had* changed and now they had to. Their war wounds were no longer perceived as symbols of service and sacrifice, but instead as objects of a shared societal oppression that must be addressed.

## **Discussion and Conclusion**

At this point in time, the lives of persons with disabilities in Segovia are being reordered. The UN Convention on the Rights of Persons with Disabilities is attempting to globalize the social model of disability, which presents disabled persons as a universally oppressed group (Oliver 1986) who must be protected through the

creation of new rights and benefits. While the international and local activism for persons with disabilities is focused on equality, the outcomes of the propagation of the universal disability identity are anything but equal. It has afforded ex-Contra soldiers with disabilities new opportunities to integrate into the community and claim resources. For ex-Sandinista soldiers with disabilities, however, the universal disability identity diminishes their ability to stand out and be recognized as extraordinary local citizens deserving special privileges. In short, rather than raise the status of all persons with disabilities, the social model has a levelling effect: raising some up and pulling some down.

What is happening in Segovia is just one example of a larger phenomenon. Transnational social movements that promote specific paradigms for understanding social marginalization and concomitant identities for making rights claims are spreading throughout the world. The UNCRPD is only the latest in a lengthening line of human rights instruments protecting particular groups. The United Nations' General Assembly has been adopting such instruments since 1965, when it passed the UN Convention on the Elimination of All Forms of Racial Discrimination. Since then, the UN has passed international instruments protecting women (1979), children (1989) and now persons with disabilities (2006) and other international organizations, such as the International Labour Organization, have passed international protections for the indigenous, domestic workers, and other vulnerable populations. Recently, the UN established a Working Group to look into the possibility of creating a human rights convention protecting the rights of older persons (or the "aged"). In each instance, the members of these identity categories are imagined to be to some extent a

homogeneous group (Brubaker, 2002) in need of protection. While the social model of disability has its own, unique history, there are certainly similar logics being applied to other groups.

Many of these models, like the social model of disability, are assumed to be global “goods” that empower the marginalized. The lesson to be drawn from the social model is not that it should be abandoned, but that it should be critiqued. Early disability studies scholars and activists, such as Irving Zola, were primarily concerned with unifying diverse subgroups of persons with disabilities (1982, p. 243) for the purposes of political advocacy. The identity politics pioneered by the Western disability movement in the 1970s (Anspach 1979) was powerful indeed and did bring about important changes. But it also meant that the diverse experiences and identities of persons with disabilities were denied (Shakespeare 2006; Darling 2013; Priestley 2003; Thomas 2004; Hughes and Paterson 1997). Today, the international disability movement is having a similar effect upon diverse groups of persons with disabilities in the Global South by imposing (or imputing) a singular identity upon them (Meekosha 2011; Meekosha and Soldatic 2011; Grech 2011).

The full effect of these global models on particular groups and the way in which they are worked out face-to-face in small group settings (Fine, 2012), however, can only be observed through deep ethnographic analysis. Fortunately, a rich tradition of social psychological analysis has provided conceptual tools, such as identity management (Goffman 1963), for doing so. But, old assumptions about stigma must be challenged by the possibility that awareness campaigns do work (Putnam 2005) and can, in fact, “flip” a traditionally discredited identity, such as disability, into a



protected identity that provides some advantages. Furthermore, the holders of these identities, such as the members of the ADRN and ORD, must be recognized as strategic actors who are aware of the context they live in, the multiple identities that they hold (Brewer 2000; Rockquemore and Brunnsma 2002), and proactive (Renflow 2004) in their appropriation or resistance to various global and local identities available within their environment. At this stage, it is hard to predict whether or not the ADRN will be able to fully shed off their discredited identities as Contra or if the ORD will permanently lose their valorized status as Sandinista war heroes. But, if anything, it is certain that they will actively utilize the identities available towards their best advantage as they either forge ahead or fall back in tactical retreat.

Chapter 3, in full, is a reprint of material as it will appear in *Qualitative Sociology* 2014. The dissertation author was the sole author of this paper.

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## Chapter 4

### Global Civil Society as Megaphone or Echo Chamber?: Voice in the international disability rights movement

#### Introduction

Giving persons with disabilities a “voice” is a central concern for international disability activists and policymakers alike. The United Nations inter-agency task force on disability, UN ENABLE, celebrated the 2006 UN Convention on the Rights of Persons with Disabilities (UNCRPD) as “giving voice” to disabled persons around the world (UN-ENABLE, 2012) and “voice” is ubiquitous as a keyword in international disability rights campaigns. *Voices from the Ground* (2009) is the title of one of Handicap International’s most important reports and End Exclusion, a consortium of European disability organizations, chose “Raise your Voice: Say Yes to Inclusion!” (2013) as their slogan. Most importantly, the two largest global Disabled Persons Organization (DPO) networks claim that they, themselves, *are* the voice of persons with disabilities. The International Disability Alliance (IDA) describes itself as “the most authoritative representative voice of persons with disabilities” (IDA, 2010, p. 7) and Disabled Persons International, another global network, uses “A Voice of Our Own” as its motto.

These celebrations of voice, however, mask deep concerns regarding the voice of persons with disabilities internal to the movement. Global leaders fear that persons with disabilities, especially in developing countries, are incapable or unwilling to use their voice. A recent report by a consortium of NGOs argues that despite the UNCRPD, there is an “absence of the ‘voice’ of persons with disabilities” (Cain,

2012, p.7) in poor countries. International disability advocates and NGO professionals routinely diagnose persons with disabilities in the Global South as lacking the culture, consciousness, or capability to raise their voices in advocacy. The traditional focus of grassroots DPOs on service provision and self-help is viewed as a barrier to the advancement of rights by many advocacy-oriented, Western activists (See Phillips, 2009; Turmasani, 2003; Quinn and Degener, 2002; and Ingstadt and Whyte, 1995). In an interview with a longtime professional from an international DPO network, I was bluntly told that persons with disabilities in non-Western countries “have no culture of human rights” (Interview: July 23, 2010) alluding to them as having internalized the values of a discriminatory culture or suffering from a “false consciousness” (See, for example, James Charlton, 2000, p. 70). After citing failures in implementing the UNCRPD in many countries, the inaugural World Disability Report recommended that local DPOs “need capacity building and support to empower people with disabilities and advocate for their needs” (WHO, 2011, p. 18). All of these concerns about the inability of persons with disabilities to use their voice, however, are countered by another fear: if they do use their voices, they might not all say the same thing. Simply put, too many voices risks weakening the international disability rights movement, which can only advance if “the disability community continue to speak with *one voice*” (RI, 2008, p. 4).

The conceptual importance of voice goes far beyond the world of international disability rights. Its promotion and protection is, perhaps, our era’s deepest concern. Habermas argued that true democracy is ensured through an open “discursive public sphere” (Habermas, 1996; See also Ehrenberg, 1999, pp. 219-224), echoing Arendt’s



view that to be heard is the essence of being human (Arendt, 1972). Kaldor argues that rights depend on a strong civil society, which she defines as “those organizations, groups and movements who are engaged in this process of negotiation and debate about the character of rules [i.e. political regime] – it is the process of expressing ‘voice’” (Kaldor, 2003a, p. 11). It is, therefore no surprise that today’s most active social movements and our most cited global discourse—human rights—are based upon the idea of giving people voice.

Over the years, group-specific, human right instruments, such as UN conventions protecting the rights of racial minorities (1965), women (1979), and now persons with disabilities (2006), have been promoted as a means for protecting groups. In the past, these conventions have been characterized as myth and ceremony (Hafner-Burton et al., 2008), yet more recent scholarship has shown that human rights can be effective when coupled with “voice.” Cole (2012), for example, has shown that when countries ratify Optional Protocols to conventions that include the right for citizens to directly “communicate” to the UN, abuses decrease (Cole, 2009, 2012), upholding legal theorists who have argued that “petition systems... are generally considered the most effective means for the protection of human rights” (Craven, 1995, p. 33) and altering state practice (Donnelly, 1986, p. 611).

A deeper look, however, shows that these provisions are insufficient on their own, but require civil society organizations to back them up. For example, the only times the Convention on the Rights of Women has been effectively used have been when NGOs lodge complaints on individuals’ behalf (Hayes, 2010, pp. 33-35) and when an advocacy-oriented civil society is absent, the right to communicate goes

unused (Abraham, 2003). Fortunately, there is a strong association between the signing of human rights instruments and increases in local engagement with NGOs (Hafner-Burton and TsuTsui, 2005) and transnational networks (Smith and Weist, 2005). As such, the UN Human Rights Programme has begun promoting UN partnership with civil society organizations because associations “give voice to the powerless” when they “scrutinize the implementation of human rights, report violations [of human rights abuses]... and campaign for the development of new human rights standards” (UN-OHCHR, 2007, p. iii).

Yet, despite this positive relationship between human rights and civil society, there are tensions inherent in advocacy networks and international movements. Fifteen years ago, when Keck and Sikkink’s seminal *Activists Beyond Borders* (1998) popularized the notion of global advocacy campaigns, they celebrated the notion that “transnational networks *multiply the voices* that are heard in international and domestic politics” (1998, p. x, My emphasis). More recently, however, human rights campaigns have been shown to only be effective when all the participants stick to a core message and, effectively, say the same thing (Brysk, 2013). This fact has led to NGOs, coalitions, and networks to pressure their grassroots partners—the ones they claim to be speaking for—to fit their advocacy into a pre-set, national or global agenda rather than pursue local concerns (See Chishti, 2002 for on the international women’s movement). In short, international human rights campaigns, which are often characterized as “megaphones,” where the voices of grassroots associations are amplified and heard around the world, often act as “echo chambers,” where local actors are pressured to stick to a predetermined script.

In the aftermath of the UNCRPD (2006), there has been a worldwide effort to organize people with disabilities into DPOs and integrate them into national coalitions and global alliances. These networks have now begun monitoring the implementation of the UNCRPD. Yet, as my Nicaraguan case study shows, these advocacy activities, which are meant to be participatory and empowering, do not reflect the priorities of disabled Nicaraguans and act as dead ends when persons with disabilities at the grassroots level try to use them to express concerns that falls outside of a predetermined advocacy agenda.

In Segovia (a pseudonym), Nicaragua, various international and national disability rights actors have exerted large amounts of control over the local organizations that they have sought to include in rights advocacy. These outside advocates did so by 1.) founding DPOs and a local coalition that reflected international priorities rather than local concerns, 2.) using advocacy trainings as a means of establishing a network hierarchy that keeps grassroots actors “in place,” and 3.) formalizing the UNCRPD reporting system in such a way that the local coalition was unable to use it to communicate their concerns. These outcomes indicate that human rights campaigns can silence voices as easily as they can promote them, calling into question assumptions about their value in providing a means for the world’s marginalized to participate in the interpretation and implementation of human rights instruments.

### **Transnational movements and questions of legitimacy**

Global human rights campaigns are often characterized as mutual, participatory, and “informal and horizontal” networks (Khagram et al., 2002, p.11) that use their “communicative power” (Dryzek, 2000) to give “voice to the voiceless” (see, for example, Keck and Sikkink, 1998; Long, 2008; Kaldor, 2003a). Yet, upon closer examination, the leaders of transnational networks and other global actors lack the traditional authority (Long, 2008) of being democratically elected by the people they claim to represent (see Chandler, 2004, pp. 333-334), oftentimes being self-appointed spokespersons (Ghimire, 2011) or simply the most charismatic voices (Brysk, 2013, pp. 55-77; See also Bob, 2005) that the media can find. This gap between the rhetoric and the reality of representation means the marginalized are limited in their ability to use human rights for their own ends.

In response to these concerns regarding representation, many backers of global human rights campaigns argue that even though leaders are based in the Global North, they are dependent upon the South. Simply put, while groups in wealthy countries might have professional and financial resources, grassroots associations in low-income countries have a monopoly over the “symbolic resources” (Stewart, 2006, p. 200) and “moral authority” (Sikkink, 2002) that transnational networks need in order to claim that they represent the “weak and repressed.” This dynamic produces a “two-way street” where southern groups “provide testimony, stories and information about their situation and [in doing so] confer legitimacy on those [northern groups] that campaign on their behalf” (Kaldor, 2003b, p. 95). Tarrow goes so far as to argue that there is an imbalance, where international NGOs must work hard to be “certified” (trusted) by the grassroots or face backlash (2005, p.195).

The idea that the leaders of transnational networks are dependent upon their members in developing countries and thus maintain participatory forms of organizing, has struck some as naïve. Kowalski (2011) points to the obvious obligation of reciprocity implicit in the provision of aid and Ebrahim (2003) and Kamat (2002) demonstrate how technical assistance (workshops, etc.) “discipline” and “NGO-ize” grassroots associations more so than “empower.” Furthermore, when pre-existing local groups prove recalcitrant, international NGOs and national networks can simply “manufacture civil society from the outside” (Howell and Pearce, 2011, p. 89) by entering local communities and establishing entirely new associations that reflect their priorities.

Lastly, centralizing command and control within movements, while certainly a move away from the informal networks celebrated in the literature, may be necessary for effectiveness. In Brysk’s *Speaking Rights to Power* (2013), she recounts “the development of consistent core narratives” amongst the ingredients of human rights campaigns’ success, adding that “it is also helpful if ongoing social movement, scholarly, or journalistic institutions command a ‘brand’ of authenticity that can *cue, commend, or curtail the proliferation of speakers, messages, and formats*” (My Emphasis, p. 211). While staying “on message” by limiting the number of speakers may contribute towards a movement’s success, it is the very opposite of Keck and Sikkink’s characterization of transnational networks as “multiplying the voices” heard around the world (1998, p. x).

Transnational networks and international NGOs are often framed as “doing good” (Fischer, 1997), yet their “good intentions” should not obfuscate the fact that

they are *organizations* negotiating complex and uncertain environments (Watkins, Swidler, and Hannan 2012). Many organizations try to ensure their long-term effectiveness through centralization and formalization processes. This is as true for civil society organizations as it is for private corporations. De la Porta and Diani (2006) describe this stage in a social movement's lifecycle as when it "becomes an organic part of society and crystallizes into a professional structure," which promotes "disciplined participation and coordination of strategies for achieving the movement's aims" (p. 150; See also Blumer, 1951, p. 203). The positive benefits of bureaucratization and the centralization of power (Gamson, 1975, pp. 89-99) are that they allow civil society organizations to routinely accomplish tasks, develop professional expertise, and engage in lobbying and coalition work (Staggenborg, 1988).

The downside of formalization, however, is a decrease in participation. The more organizations and networks formalize, the more influence they can exert over their members and affiliates (Ibid, p. 601). For those that depend on mobilizing members, this can lead to a frustrated membership that no longer believes it has a voice in decision-making processes (Hensby et al., 2011). While many social movement formalization studies focus on national level movements, Ghimire's recent analysis of transnational networks reaffirms that the day-to-day realities of mobilizing disparate actors means that power and information becomes concentrated in the hands of an elite. As such, leaders of global campaigns, despite being rhetorically invested in democratic participation, set agendas, decide who is "in" and "out," and so on (Ghimire, 2011, pp. 129-142).

The international disability rights movement claims to have given voice to an estimated one Billion persons with disabilities around the world (WHO, 2011), yet it has consistently sought to formalize structures and ensure unity in message. In order to assess whether persons with disabilities are given “voice” through the UNCRPD, it is necessary to interrogate individual interactions between global actors and local, grassroots rights-holders.

### **The Transnational Disability Rights Network**

In recent years, promoting the human rights of persons with disabilities has replaced a traditional international focus on medical rehabilitation. Disability rights advocacy networks and organizations, such as the International Disability Alliance, Action for Disability and Development, and the Disability Rights Fund, have replaced long-established rehabilitation NGOs (i.e. International Committee of the Red Cross) as the global spokespersons of persons with disabilities in developing countries. This international shift reflects an earlier change in the West from disability understood as a medical problem to disability as a rights issue.

The US and European disability movements began during the civil rights struggles of the 1960s, when many persons with disabilities drew parallels between their own marginalization and that of African Americans and women (Groch, 1994 p. 377; Barnartt and Scotch, 2001), arguing that “ableism” was akin to sexism and racism (Harpur, 2009).

The Union of the Physically Impaired Against Segregation, a DPO in the United Kingdom, was one of the first to articulate a social model of disability by

stating that: "It is society which disables physically impaired people. Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society" (UPIAS, 1976, p.14). Political advocacy through membership organizations was seen as key to redressing the problem of living in a disabling society. This organizing task also meant pushing aside traditional organizations, such as the March of Dimes, who were monopolizing public debate regarding disability policy. The disability movement's slogan "Nothing about us, without us" specifically meant that no decision should be made regarding disability without persons with disabilities being part of the policymaking process (Fleischer and Zames, 2001). As such, the movement pressured governments to set up disability commissions or committees composed of DPOs to ensure full representation.

Michael Oliver, who popularized the term "social model of disability," identified institutional representation as one of the movement's key goals, explaining "The traditional voice for disabled people had been the big charities that are still largely run and controlled by non-disabled people. Recent [British] Government initiatives like the establishment of the Disability Rights Commission have done little to change this situation although the number of organisations controlled and run by disabled people has grown steadily at both local and national levels. This trend must be sustained as the voice of disabled people is crucial to delivering on the social model" (Oliver, 2004, p. 22-23).

In tandem with the formalization of political advocacy has been the argument that persons with disabilities must speak in one voice. Prior to the 1970s, there were advocacy DPOs in the West, such as associations of the deaf, the blind, or polio



survivors, but these groups were often in competition with one another over public funds. Coalitions became important forums where diverse DPOs could be brought together to hammer out an advocacy agenda that represented all persons with disabilities, no matter the impairment-type. Jim Derksen, one of the early leaders of the Canadian disability movement and founding father of Disabled People International, laid out this strategy early on: "Let us reason together, let us deliberate on our problems and needs, let us consider our abilities, and when we have agreed on the problems and solutions let us articulate our opinions and ideas in a strong and united voice" (Derksen, 1975, p. 1). In many cases, just bringing DPOs together was insufficient because the leaders of certain disability-specific DPOs were beholden to their members' specific interests. As a result, entirely new cross-disability associations were established in order to lead the charge.

The international disability movement imported these strategies for ensuring that persons with disabilities around the world speak with one voice, often by promoting networks or coalitions commissioned with the responsibility to speak on behalf of numerous DPOs rather than allowing those DPOs to speak individually for themselves. At the global level, the International Disability Alliance was created in 1999 by seven transnational DPO networks and several disability NGOs and was subsequently given full consultative status within the UN, giving it an official advisory role on international disability rights (Lord, 2009).

An important aspect of the UNCRPD is that it has institutionalized DPOs as the UNCRPD's interpreters and monitors at the national level (Stein and Lord, 2012). The Convention states that "Persons with disabilities [shall be] actively involved in the

definition and implementation of their rights, through their representative organizations” in the General Obligations and that DPOs “shall be involved and participate fully in the [treaty’s] monitoring process” in Article 33. The UNCRPD’s Optional Protocol additionally establishes the right of persons with disabilities to directly “communicate” with the UN, to investigate rights violations. Something that became glaringly obvious before the UNCRPD was even passed, however, was that in many countries, there were very few DPOs or DPO networks interested in or capable of doing the type of cross-disability rights monitoring the UNCRPD required.

Ubiquitous amongst comparisons between Northern disability movements and those in the South is the idea that “In Southern countries, the [disability] groups themselves often feel that the most immediate needs are for practical programs of rehabilitation” (Ingstadt and Whyte 1995, p. 24; See also Turmasani, 2003) or, in the case of post-Soviet states, have “a narrow focus on shoring up social programs for certain groups of the disabled” (Phillips, 2009, p. 283). The international working group that drafted the UNCRPD shared these observations, arguing in 2002 that “disability NGOs [in developing countries]... fail to engage with the human rights system” and “there is therefore a need for a new kind of disability NGO – or amalgam of NGOs” (Quinn and Degener 2002, p. 179). From this point of view, “disability awareness-raising and coordinated actions among disabled peoples’ organizations are *prerequisites for transforming the [UN]CRPD’s promises into reality*” (My emphasis; Stein and Lord 2012, p. 27).

As a result of these concerns, international disability NGOs, transnational DPO networks, and global funds have implemented programs to increase the number of

DPOs in the Global South focused on rights advocacy and, thus, suitable for carrying out the civil society monitoring processes detailed in the UNCRPD and its Optional Protocol. Handicap International (HI) and the Disability Rights Fund (DRF), for instance, each have their own programs. HI's *Making It Work* program's mission is to "strengthen [people with disabilities'] advocacy to influence social change" (2013) and DRF, which is a pool of funding supported by multiple donors, has a mandate to "strengthen local stakeholders who can hold governments accountable for fulfilling the rights of persons with disabilities" (2013).

The objective of these programs is to ensure that disabled persons have a voice in the implementation of their rights at the local and global levels. But this goal is coupled with a concern with unity and message control. The International Disability Alliance, for example, has issued recommendations on how DPOs can submit reports to the UN, stating that submitting a report "ensures that issues that are important to small organizations are given a voice" but that for reporting to be effective, DPOs must speak with a "unified voice" and only submit "one comprehensive report" (IDA, 2010, p. 28).

### **Data, methodology and field site**

As of March, 2014, 158 countries have signed and 143 countries have ratified the UNCRPD. The Optional Protocol has also been successful, having garnered 92 signatories and 80 ratifications. Concomitant with the expansion of States-Parties to the UNCRPD, transnational DPO networks and international NGOs have established

new DPOs by the dozen and integrated existing grassroots DPOs into their ranks by the hundreds, including in my field site.

In order to understand how these changes give (or take away) voice at the local level, I spent more than 18 months doing field work in Segovia, Nicaragua, observing seven local disability associations that belong to Segovia's disability rights coalition—the *Departmental Commission for Advocacy and Awareness* (CDIS). My primary method was participatory observation, wherein I attended meetings and workshops, joined leaders in their daily activities, spent time in their offices, visited the homes of their members, and made myself generally useful by volunteering to do small tasks around the office or during events. From the beginning of my fieldwork in 2009, I sought to clearly differentiate myself from international NGO staff and others who were funding, evaluating, or providing technical assistance to local initiatives by presenting myself as an academic. Each association was provided with a description of my research project, the intended use of the data collected (i.e. academic publications), and their rights as associations to operate discretion over the activities I observed. In turn, each association provided me with a formal invitation stating that they understood my research objectives and their rights. There were no instances, however, of associations exercising their right to refuse participation in any activity, but instead far more invitations than I could manage. Over the length of my fieldwork, my success in establishing myself as a neutral observer was confirmed many times when leaders of the local, grassroots disability associations would explain to their members that I was a sociologist doing an *investigacion* (research).

Observations were supplemented with semi-structured interviews. All interviewees were provided with a consent form that described my research and their rights as research subjects, which we would discuss in detail prior to the interview. I have used pseudonyms for all of my interviewees and “Segovia” is also a pseudonym for my field site. *Nueva Segovia* is a region with several large cities, each of which has a disability coalition. Calling my field site “Segovia” is akin to calling it “Mountainous North City.” I maintained some level of regional specificity as *Nueva Segovia* is the region that experienced the greatest amount of combat during the Contra War, which had some impact on the formation of disability associations in the specific region given the larger proportion of wounded ex-combatants and landmine survivors present.

I also spent time in Washington D.C., New York, and Geneva, Switzerland, where I interviewed staff and participated in meetings organized by international NGOs, UN agencies, and transnational networks related to the UNCRPD. Over three years, I recorded 69 formal interviews and attended dozens upon dozens of activities.

With over 100,000 residents, Segovia is one of Nicaragua’s larger cities outside of Managua, the capital, which claims a third of the country’s 6 million residents. Segovia’s economy is dominated by tobacco and coffee, the majority of which is exported. Cigar factories are the largest employers, paying approximately \$130 a month, which is close to the country’s average real GDP of about \$1,700 per person. Nicaragua is the second poorest country in the Western Hemisphere next to Haiti, yet has some of the region’s best health and education outcomes, largely due to close cooperation between government and grassroots organizations.

### **The Voice of Nicaraguans with Disabilities**

The international disability rights community has tried a number of strategies to bring “voice” to the disabled persons of Nicaragua. All of these efforts have centered on formalizing representation through the support and development of DPOs, creation of networks and coalitions, and implementing training workshops on human rights advocacy. Nicaragua offers many advantages. Under the leadership of leftist President Daniel Ortega, Nicaragua was an early signatory (2007) and ratifier (2007) of the UNCRPD and its Optional Protocol (2010). In 2011, Nicaragua created a National Disability Council and passed a new National Disability Law (*Ley 763*), which is based upon the UNCRPD.

Nicaragua, however, presents challenges to the international disability rights movement due to the nature of its civil society. Political culture in Nicaragua valorizes organizations that provide services over those that engage in “rights talk.” This predilection dates back to the Revolutionary period (1979-1990) when hundreds of “popular organizations” were initiated (Ruchwarger, 1987) with a focus on “the struggle for economic survival” (Vanden and Prevost 1993, p. 66) during the Contra civil war and US-imposed sanctions. A strong civil society made up for a weak state that was unable to deliver education, health, and other social welfare programs. While the war is long over, civil society organizations continue to mobilize volunteers or organize people into self-help groups. Many DPOs in Nicaragua are based on this model, putting them at odds with the international priority of using DPOs for

adversarial politics. In the following sections, I will explore attempts to reorient DPOs in Segovia towards advocacy.

### *Establishing a Coalition and new Disabled Persons Organizations*

International funders and NGOs have both sought to bring existing grassroots associations in Segovia together into a disability rights coalition and they have started two completely new DPOs. The results have been mixed. While the coalition has garnered achievements, it has frustrated some members for not reflecting their specific priorities.

In 2008, Handicap International (HI), a European-based disability NGO, and the Disability Rights Fund (DRF), a US-based fund governed by a board of prominent disability activists, initiated the *Departmental Commission for Advocacy and Awareness* (CDIS) through a series of workshops, seed funding, and on-the-ground coordination. This coalition drew together seven local chapters of national associations or independent grassroots organizations in Segovia: the Association of the Blind, *Los Pipitos* (parents of children with disabilities), the Association of the Deaf, the Organization of Disabled Revolutionaries (wounded ex-Sandinista soldiers), the Association of the Disabled Resistance (wounded ex-Contra soldiers), the Association of the Physically and Motorly Disabled (ADIFIM), and the Organization for Disabled Women (ODIFIM). The first five associations have long histories in Segovia and provide their members social support and services. In large part, they have sought to be self-sufficient through various income-generating initiatives, such as selling crafts (*Los Pipitos*) or running a bicycle repair shop (Association of the Blind). Two

organizations in CDIS, however, are new: ADIFIM and ODIFOM, which were established in 2008 and 2009, respectively, as advocacy organizations. Both are supported through membership fees.

I met the local Coordinator for Social Participation for HI in 2009, shortly after CDIS was formed. She explained that CDIS was started because the European office determined that “people [with disabilities] by themselves cannot and will not make demands, so they need an organization to make demands for them” (Interview: August 16, 2009). To that end, CDIS was a success. It regularly met with local government officials to discuss the implementation of new laws and organized meetings and public awareness events that highlighted the need for inclusion. They also, at HI’s suggestion, successfully lobbied Segovia’s City Hall to pass an ordinance create a municipal Office of Disability Affairs, an advisory board, replicating the tradition of DPOs institutionalizing their government oversight (See Oliver, 2004). These advocacy activities were carried out with small grants from the DRF according to its funding philosophy to “strengthen local stakeholders who can hold governments accountable for fulfilling the rights of persons with disabilities. By supporting civil society efforts at country level to ratify, implement, and monitor the [UN]CRPD, DRF seeks to make a more direct impact on improving the conditions of PWDs [persons with disabilities].”

After three years of support, however, CDIS’ funding ended when their proposal for 2012 was rejected. While it is not uncommon for DRF to limit their grant-making to just a few years, the coalition in Segovia felt the end of support was abrupt. The coalition’s co-chair and president of the Association of the Blind, Luis, was at a



loss to explain why their funding was not renewed. He explained that in past years, DRF had requested that they expand out and create DPOs in rural villages, which CDIS had done diligently despite the grant money allocated being inadequate. As a result, Luis had used the Association of the Blind's resources to carry out the outreach objectives set by DRF, assigning one of the association's paid coordinators (funded by the repair shop) to work with the disabled farmers (Field Notes: Nov. 3, 2011). Luis explained that DRF's priorities were out of step with real needs, explaining: "Their [DRF's] ideas of what they want us to do are—Sometimes, we find that we are financed for certain objectives in a particular way that is a bad use of the money, you understand? That is to say they want to pour more into promoting awareness, but we want to strengthen the associations internally. Because, look, how are you going to believe in those associations that are advocating if they have no real capacity. There is no logic [to DRF's funding]" (Interview: August 17, 2012).

Even though DRF had stopped answering emails from CDIS by late 2011, CDIS remained litigious when spending out the final grant. For example, towards the end of 2011, there was still money leftover that was earmarked for advocacy, which had to be spent by December 31. During a CDIS meeting in November, the leaders of the seven member DPOs discussed how to use the remaining hundred dollars. Some wanted to divide it between the associations so that they could use it for supplies, such as cell phone minutes to call their members, a major expense for some. In the end, however, they decided to use the money to hold an *Intercambio* (Exchange of ideas) for International Disability Day, so that the local government, DPOs, and others could discuss disability inclusion goals for 2012. The coalition decided to hold the meeting

on Tuesday, December 6, a few days after the official date of International Disability Day, which had fallen on a weekend (Field Notes: Nov. 3, 2011).

In the end, Luis expressed relief with no longer having to deal with DRF once the final grant was over. In short, he felt that they were prejudiced against poor countries: “The major conflicts with the [Western] funding agencies is the same as in international politics, between the first world and third world countries. They [first world] are always accusing us of breaching human rights...that the government is repressive or antidemocratic. Is that it? Am I [as a disabled person] not getting my rights because the [government] does not want to fulfill it? The problem is that when a State is poor, even if it wants to hand me my rights—for example, access to education—but does not have the ability to train their teachers to take care of you in the classroom if you are deaf, blind, a children with intellectual disabilities... Is it logical to call that a human rights violation?” (Interview: August 17, 2012). Luis, in short, believed the advocacy model had limited applicability in Nicaragua. Instead, he believed the best thing they could do would be to help DPOs pursue their own goals. As such, he had developed a proposal, which had been universally rejected by the disability NGOs he had solicited, to expand the association’s repair shop so that they could better finance their Braille school and a job placement initiative.

The Association of the Blind, which had been established in 1988 by Luis, who was blinded in combat during the Contra War as a Sandinista soldier, was thriving with 200 members, was a prime example of a Nicaraguan “popular organization” (Ruchwarger, 1987; Vanden and Prevost, 1993) and a clear contrast to civil society as “voice” (Kaldor 2003a, p. 11; UN-OHCHR 2007, p. iii). The international disability

movement, however, had created a funding model that only supported advocacy, with no room for services that were essential aspects of DPOs like the Association of the Blind. Participation in the coalition itself had, in fact, siphoned off resources. While Luis was clearly frustrated, he posed no serious threat of “decertifying” (Tarrow, 2005), delegitimizing (Kaldor, 2003b), or altering DRF’s agenda.

The Association of the Physically and Motorly Disabled (ADIFIM), whose President co-chairs CDIS with Luis, offers a contrast. ADIFIM was not established by a local Segovian decades ago, but was instead organized by Dansk Handicap Forbund, a Danish NGO, which held a workshop in Segovia in 2008 (Interview: July 17, 2009). Of the DPOs participating in CDIS, ADIFIM was the “purest” in terms of an advocacy focus. It was also a local chapter of a national network, with ADIFIM-Managua also having been organized by international NGOs.

ADIFIM’s mission is “to develop actions geared towards compliance with human rights by implementing technical capacity strengthening processes for local leaders (women and men), raising awareness, disseminating information to the population at large, exchanging experiences and doing advocacy work leading to reforms of laws that affect the rights of persons with a disability.”

ADIFIM had originally attracted lots of international support beyond the Danish NGO. The national office in Managua had received a \$25,500 grant from the DRF in 2008 to expand into the provinces. ADIFIM-Managua used that money to host workshops on the UNCRPD that local chapters, like Segovia’s, were invited to attend, hosting as many as four in the first half of 2011 alone. In addition to its own activities, ADIFIM also participated in workshops on advocacy hosted by FECONORI (National

Disability Federation), Action for Disability and Development (UK-based NGO), and the European Union (ADIFIM, 2011).

During a monthly meeting I observed in 2009, Alfonso encouraged a visitor to join by explaining that as persons with disabilities they had rights to many things, such as a new wheelchair, but if they did not know the law, they would never be able to demand them from the government. Despite initial success from these recruitment techniques, ADIFIM experienced a dramatic slide in membership from a high of close to a hundred members in 2009 to barely a dozen active members a few years later. In early 2012, ADIFIM was in crisis because it could only muster 15 members for its monthly meetings. According to the organization's official by-laws, a quorum of 50% plus one was required to make decisions, such as electing the board. At that time, it had 70 members on the books, yet the vast majority had not attended a meeting for months. The by-laws were meant to ensure that ADIFIM remain membership-driven, yet they proved a barrier towards the association's ability to function. To deal with this problem, Alfonso announced that after having failed to encourage inactive members to start participating, his new plan was to ask them to formally withdraw so that he could reduce ADIFIM's official membership to less than 30 and thus be able to make a quorum.

Alfonso later explained to me that he believed that few people were coming because they had joined for "benefits" and were uninterested in fighting for their rights. At that time, in the Spring of 2012, Alfonso announced ADIFIM's newest fight (*lucha*): getting the City Hall, which had recently passed a statute creating an Office for Disability Affairs, to allocate space and a budget for the Office. Someone joked

that Alfonso just wanted the office so he could have a nice desk and another quipped that his real ambition was to go to Managua. Alfonso admitted that he was currently running to be to be a representative on the National Disability Council (Field Notes: June 3, 2012). Ironically, Alfonso was advancing his career as a social movement professional (Staggenborg, 1988) at the very time the DPO he led was shrinking.

The apathy of members may have been explained by a disconnect between persons with disabilities who joined ADIFIM seeking concrete help and the organization's focus on legal education and advocacy. A typical meeting centered on Alfonso reading passages from the national law or UNCRPD as members listened. During one meeting in 2011, a new member, who had joined after having her leg amputated as a result of untreated diabetes, wanted to know how to use her wheelchair. She interrupted a discussion on the city's obligations to make public places accessible, to ask a question on how to negotiate ramps. Alfonso gave her a 30 second impromptu demonstration on how to turn her front wheels side to side, but then cut her off from further questions by saying the meeting was not for "therapy," but to "study the law." (Field Notes: October 30, 2011). She never returned.

Segovia's Organization of Women with Disabilities (ODIFOM) was established close to the same time as ADIFIM with the help of Handicap International, to engage disabled women in political advocacy. To that end, the majority of ODIFOM's support in the early years was in the form workshops conducted by international NGOs on self-esteem, consciousness, and women's self-advocacy. ODIFOM, however, suspended meetings in 2012 because very few members were attending and many had joined other organizations, such as a women's self-help group

that provided micro-credit (Interview, June 6, 2012). In the end, the President could no longer afford to organize meetings because she could not afford to buy cell phone minutes.

ADIFIM and ODIFOM demonstrate attempts to “manufacture civil society from the outside” (Howell and Pearce, 2011, p. 89). Both are organizations that reflect the international priority of advocacy. As such, they are strikingly unsustainable given the overriding interest potential members have in civil society associations providing material benefits. They also pose an interesting problem in terms of legitimacy. Kaldor (2003a) argues that membership organizations made up of marginalized populations themselves have the most legitimacy. These two groups, however, seemingly speak for very few, despite retaining seats on Segovia’s DPO coalition, CDIS. Furthermore, their mission and objectives reflect the outside organizations that initiated them far more than their members’ priorities.

#### *Training DPOs as advocates*

Training grassroots DPOs is a central strategy used by the international disability movement to promote the UNCRPD and integrate DPOs into networks and coalitions. The intention behind these workshops is to motivate persons with disabilities to use their “voice” through rights advocacy. Over the past several years, members of CDIS have been awash in trainings; many leaders of Segovia’s local DPOs reported that they attend an average of five or six workshops a year in either Managua or locally in Segovia. An example of one such workshop took place over a

week in October, 2011. The trainers were from a national, Managua-based organization that was funded by international donors, shared an office with Nicaragua's national DPO federation, FECONORI, and had been trained by an international NGO.

The course took place at a local motel and included several members from each of CDIS' seven member DPOs for a total of 30 participants. The training was titled "Organizational Development for Directors" and broken into modules on "Introduction to Political Advocacy," "Laws for the Protection and Benefit of People from DPOs," "The Methodology and Process for Political Advocacy," and "Formalizing Internal Control and Registration."

The first day began with an overview of disability identity. After establishing that persons with disabilities are discriminated against, the trainers explained that a person must recognize their own importance and the importance of their group. According to their lecture, group consciousness would then lead to assertive communication which culminates in political advocacy, which was defined by the trainers as "organized by groups and directed at institutions [government/public agencies]." The last slide of their Powerpoint declared that "Everyone needs to be together and united to participate and fight (*luchar*)" (Field Notes: October 3, 2011), reiterating the unity theme from the earlier, Western disability movement (Derksen, 1975).

The next module emphasized the importance of knowing the law. The UNCRPD was introduced and explained as meant to eliminate the barriers persons with disabilities face accessing their human rights. Next, the participants were divided

into small groups and assigned one or two specific articles to read from the UNCRPD or its Optional Protocol. All of the articles assigned were focused civil society monitoring the Convention, such as Articles 33 (national implementation and monitoring), 34 (the establishment of the UN Committee on the Rights of Persons with Disabilities), and 35-39 (procedures for reporting).

As a participant, I joined the discussion group assigned the two articles from the Optional Protocol that dealt with the UN Committee receiving “communications.” Of the six members, two put their heads down on the table and the others sat silently. It became clear that only myself and our group leader, Humberto, President of the Segovia’s Association of Disabled Resistance, could read. Humberto began reading the article aloud, stumbling over the legalistic language. The text read, in part, “A State Party to the present Protocol recognizes the competence of the Committee on the Rights of Persons with Disabilities to receive and consider communications from or on behalf of individuals or groups of individuals subject to its jurisdiction who claim to be victims of a violation by that State Party of the provisions of the Convention.”

Humberto asked if anyone understood. No one did. He began again, puzzling through, substituting different words for the text, such as “letters” for “communications.” Since no one knew who the “committee” was, I explained that it was a group of experts in New York who checked up on the UNCRPD to make sure countries did not violate it. When it came time for our group to present the article to the whole group, Humberto summarized it as the idea that individuals could make complaints to a group in New York. The trainer then interrupted him with a correction, explaining that the Protocol was not about “individuals” but “*organizations* and



*coalitions.*” She went on to explain that the job of communicating with the Committee needed to follow a process. FECONORI, Nicaragua’s DPO federation, would communicate for Nicaragua, not us. (Field Notes: October 4, 2012).

The final module was on Nicaragua’s National Disability Law (Law 763), which was passed July 28, 2011 and established the National Disability Council. The trainers drilled participants on the hierarchical process for reporting on the Law: municipal committees report to regional committees that report to the secretariat of the national committee (head of FECONORI) which then reports to the National Disability Council. In this way, the trainers were clearly establishing that DPOs were only supposed to use their “voice” through formal, centralized, and bureaucratized channels (Staggenbord, 1988; Gamson, 1975; Blumer, 1951) in order to ensure unity within the movement.

### *Reporting on the UNCRPD*

Parallel or “shadow” reports regarding States Parties’ fulfillment of human rights commitments are perhaps the most important means for civil society to hold governments accountable (Cole, 2009, 2012; Craven, 1995; Donnelly, 1986). Indeed, the UN Human Rights Programme indicates as much when it defines civil society as giving “voice to the powerless” by monitoring international instruments (UN-OHCHR, 2007, p. iii). The UNCRPD and its Optional Protocol, described in the previous section, embrace civil society for that purpose (Stein and Lord, 2012). Throughout 2011, I observed CDIS’s contributions to the national report that

FECONORI (Nicaraguan Federation of Associations of Persons with Disabilities) prepared.

During the first half of 2011, FECONORI organized a survey, which was implemented in Nicaragua's sixteen *departmentos* (i.e. provinces) through the help of local coalitions, including CDIS. The survey was paid for by Handicap International (FECONORI, 2011) and modeled on similar surveys used in other countries. It was also based on the International Disability Alliance's guidelines for preparing parallel reports (See for example IDA, 2010). The report was divided into eight sections assessing access to justice, health, education, employment, social protection, political participation, and culture/recreation, and special section on women and girls with disabilities. This last section compared statistics, such as employment rates, between men and women with disabilities. Data in Segovia was gathered by CDIS under FECONORI's supervision through a formal, 100 question survey of persons with disabilities and inspections of public buildings, such as local schools and the baseball stadium. The report consisted of bullet points explaining the data through statements such as: "1 out of every 4 persons interviewed (26.7%) considers health centers to be fully accessible" (FECONORI, 2011, p. 19).

In October, 2011, I joined the co-chairs of CDIS, Luis and Alfonso, another board member from CDIS, Martha, and Juan, who was from FECONORI's Managua office and was writing the report. The objective of our meeting was to do a preliminary review of the draft and then plan for an open meeting in Segovia to go over the report publicly. Juan began reading aloud, asking for comments after each section and putting corrections (mostly of names or acronyms) in the margin of his

copy. At one point, while going through the section on women with disabilities, Alfonso interrupted to say that the sexual abuse of girls was a problem. Martha, who was a member of ADIFIM and volunteer for *Los Pipitos*, joined in, saying that a teenage girl had been raped and impregnated by her uncle. Luis said this needed to be in the report.

Juan listened and then asked “Is this a problem for everyone with disabilities or just the deaf?” Juan’s question was indicative of his interest in ensuring that the report speak to issues that affecting all disability groups and not one group (impairment type) only (See, for example, Derkson, 1975). Alfonso replied no [the girl was not deaf], but instead had Downs Syndrome. Juan said nothing. Martha recommended sexual education for girls with disabilities who did not know about sex or abuse. Juan said nothing, then cleared his throat and asked “Shall we continue?” after having written nothing down. They did. (Field Notes: Oct. 10, 2011).

Two weeks later, FECONORI and CDIS hosted the open meeting on “The Departmental Report over the Implementation of Our Rights” at a local hotel. This meeting drew thirty-five participants made up of Juan, members from CDIS’ DPOs, and representatives from the City Hall. Juan explained that we would be put into groups, each assigned one section of the report, with the task of deciding if its contents were “yes-correct,” “no-incorrect,” or “*falta*” (incomplete). He then addressed the issue of sexual abuse. He said he understood the concerns about “the girl impregnated by her uncle” and stated that FECONORI would do a future study on “intrafamilial sexual abuse.” He went on, however, to explain that the survey conducted before did not include a question on sexual abuse, thus it could not be included in the report. In

the end, everything in the report was accepted intact, with only minor changes (misspellings) made.

The meeting closed with Juan explaining that this departmental report would be used for a national report. He then laid out some specific criteria for the national report: 1.) The final report must speak of conditions present in all the departments and all persons with disabilities, not just one department or one group; and 2.) All of the departmental reports were being aggregated, with no specific mention of Segovia's concerns. This was in accord with the International Disability Alliance's guidance for producing "one comprehensive report" (2010, p. 28). The meeting ended with his thanks for our valuable support. (Field Notes: Oct. 28, 2011).

Three weeks later, I followed up on the national report by visiting the FECONORI office in Managua, where I interviewed a board member. I asked for an updated version of the Segovia report, but it has not been updated since it had been aggregated into the national report.

The board member explained the federation's history and mission, which was to develop a national advocacy strategy that brought all DPOs together because "*La unión hace la fuerza*" (In unity there is strength). She also explained FECONORI's institutional role as the official national representative of persons with disabilities on the National Disability Council.

FECONORI had had continuous support from international NGOs over the years, including Action for Disability and Development, Handicap International, and Dansk Handicap Forbund. I asked about internal relations between FECONORI and with its regional DPO members (local coalitions, such as CDIS). The board member

explained that these relationships were difficult for FECONORI. Despite FECONORI being “a network of DPOs,” they also found it necessary to distance themselves from those DPOs:

The truth is that four years ago, FECONORI, was in the hands of the associations [local DPOs]. It's not that we have anything against them, but the associations have another, say another style of work... They have other goals, objectives, another vision which is difficult because sometimes the associations have a focus that is not on Human Rights but for the poor, the beggars... But the truth is that is not the issue, the struggle we have is to strengthen the capacities [for advocacy] and the dignity of persons with disabilities, which is different than their approach. (Interview : November 14, 2011)

The board member's frustrations with local DPOs echoes the UN Working Group in 2002, which had lamented that “disability NGOs [in developing countries]... fail to engage with the human rights system” and should be replaced with “a new kind of disability NGO” (Quinn and Degener 2002: 179). FECONORI was the group that had commissioned the CONFIN training described in the section above, which had included an emphasis on FECONORI as the proper channel for advocacy. In these ways, FECONORI was not interested in having the local concerns of its grassroots members “bubble up,” but instead imposing their concerns, as an organization, upon local members from the “top down,” effectively using training and reporting processes to control off-message speakers and maintain a core narrative (Brysk 2013, p. 211) in their disability rights campaigning.

## **Discussion and Conclusion**

The UNCRPD, in many ways, is best practice in terms of institutionalizing a relationship between civil society and human rights. Upfront, in its General

Obligations, the convention states that “persons with disabilities [shall be] actively involved in the definition and implementation of their rights, through their representative organizations” and, further down, specifies a role for DPOs in monitoring (Article 33) and reporting or “communicating” (Optional Protocol). Furthermore, the very existence of the UNCRPD is characterized as a triumph for global civil society, which spent years advocating the UN for a disability-focused convention (Sabatello, 2014, pp. 5-10; Lord, 2009). Now that the convention has been adopted, its realization on the ground marks a new role for civil society, but this time the success of the UNCRPD is characterized as dependent on grassroots, rather than global, voices (See, for example, Stein and Lord, 2012).

The ability for international human rights conventions and local, national, and transnational networks to lend “voice” to marginalized groups deserves considerable attention. There is increasing evidence that the presence of civil society (Kaldor, 2003a) and its engagement with international NGOs (TsuTsui and Wotipka, 2004 and TsuTsui and Shin, 2008) and inclusion in transnational networks (Keck and Sikkink 1998) can have substantive effects in reducing human rights violations on the ground. That said, it is unclear whether or not human rights campaigns represent local rights-bearers themselves, providing them with a forum to fully participate in defining and promoting their rights on an equal basis with international actors.

Human rights are *claims* made by individuals upon their society for the protection of various freedoms and the provision of certain benefits (See, for a brief, theoretical overview, Henkin, 1990, pp. 1-5). Civil society is the institutional sphere where those claims are most commonly articulated. Ensuring that grassroots

associations are fully representative of the marginalized individuals and groups they count among their members is therefore essential if human rights instruments are to be meaningful and relevant at the local level.

In the name of advancing rights and empowering vulnerable populations, international NGOs have sought out grassroots associations that they can provide assistance to and incorporate into their networks. This engagement, however, puts grassroots associations at risk of becoming “subcontractors” (Watkins, Swidler, and Hannan 2012, p. 288) of international NGOs, wherein accountability is redirected “toward funders and away from the group’s grass-roots constituencies” (Fisher, 1997, p. 454). As such, transnational campaigns that claim to “multiply the voices” (Keck and Sikkink, 1998, p. x) heard around the world or attempt to speak (and “make claims”) on behalf of others on the global stage must be questioned. It also threatens to undermine the very legitimacy of extending human rights across new frontiers.

While the idea of human rights, including disability rights, has long suffered critique for being a Western concept imposed upon the Global South (See Meekosha and Soldatic, 2011, for an example of disability rights as a form of “colonization”), human rights theorists have convincingly argued that local differences can be accommodated. Proposing three levels from the global to local, Donnelly (1985) argues that at the international level, human rights are basic “concepts” or principles that are shared widely across cultures, thus little variability would be justified. But, as these general formulations work their way down into states and local communities, where culture does play a role, they can be “interpreted” and “implemented” in ways that allow “room for considerable variation” (p. 34). This local accommodation,

however, is only legitimate if local rights-bearers exercise “voice” in the processes of interpretation and implementation.

The events and relations described above in Segovia, Nicaragua, highlight a basic tension between the objective of “empowering” persons with disabilities to exercise voice over their rights and a desire for mobilized DPOs to present a common front, and thus speak in unison. This problem of attempting to empower a diverse population, yet maintain order and message control, has been observed many times before. Michel’s “iron law of oligarchy,” first enunciated in his *Political Parties: A sociological study of the oligarchic tendencies of modern democracy* (1959 [1911]), is a common touchstone used by investigators of social movements (Gamson, 1975; De la Porta and Diani, 2006; Staggenborg, 1988), international NGOs (Fisher, 1997), and transnational networks (Ghirmire, 2011). In each case, anti-democratic tendencies have been uncovered as movements attempt to deal with the “tactical and technical necessities” (Michels 1959, p. 365) of organization by empowering an elite that can set agendas, maintain a core message, and do many of the tasks. Brysk (2013) and others have identified as a necessity for human rights campaigns to be successful. Handicap International, the Disability Rights Fund, FECONORI, the International Disability Alliance, and others constitute that elite—they have created programs, amassed funds, and outlined objectives that they are now using to draw grassroots DPOs together under a single, global umbrella.

Through the work of international NGOs and funders, groups such as ADIFIM have been “manufactured” (Howell and Pearce, 2011) in such a way that they reflect international priorities, but alienate potential members and reports on the UNCRPD



are able to be easily aggregated into “one, comprehensive report” (IDA, 2010, p. 7), yet they are unable to include the most egregious violation of rights experienced in a community. In a call for “a new kind of disability NGO” (Quinn and Degener, 2002, p. 179), local DPOs are now swamped in political advocacy trainings, yet they cannot get the support to provide the basic services their members want and so desperately need. Rather than acting as a megaphone, where voices from Segovia are broadcast out to the world, the international disability rights movement has sought to bend local DPOs into an echo chamber, endlessly repeating the words of the North throughout the South.

This failure to allow local articulations not only violates the ability of local groups to interpret their rights and take full ownership over them, but it also forestalls creative possibilities for the implementation of rights. Rights are *claims* for public *goods*. Nicaragua’s unique history of popular organizations has produced many DPOs in Segovia with real expertise, ranging from teaching Braille to repairing wheelchairs to operating microfinance, all things that persons with disabilities have a right to under the UNCRPD, yet the Nicaraguan government is incapable of providing from Luis’ perspective (and the fact that the entire GDP of Nicaragua is US\$7.8 Billion, just shy of the annual operating budget of UCLA, a single, American university campus serving only 40,000 students). Rather than simply advocate for rights, DPOs could play a significant role in implementing their rights if outside groups were to encourage creative partnerships between civil society and the state that would build upon existing projects and local expertise while working towards equal access and legal guarantees. But that sort of creativity might mean that what is being said and being done in

Segovia looks different from what might be said and done elsewhere in the name of disability rights. Rather than a failure of unity and movement effectiveness, however, that may, in fact, be a sign of democratic health and an embrace of civil society's diversity.

Chapter 4, in full, is a reprint of material as it appears in the *International Journal of Politics, Culture, and Society* 2014. The dissertation author was the sole author of this paper.

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## **Chapter 5**

### **The Problem of ‘Pretty Little Programs’: Disability consciousness and intra-movement conflict**

#### **Introduction**

The United Nation’s adoption of the Convention on the Rights of Persons with Disabilities (UNCRPD) in 2006 helped launch the international disability movement, a collection of civil society organizations and multilateral agencies seeking to redress the marginalization of persons with disabilities around the world. UN agencies, international disability NGOs, and transnational disabled persons organization (DPO) networks have committed significant resources towards outreach to grassroots DPOs in developing countries. Consciousness-raising has become a central pillar within these efforts. While the UNCRPD, as a human rights treaty, obligates the state to promote the dignity of its citizens, international organizations have chosen to focus on a different group for their campaigns. Rather than hold governments accountable to Article 8 or use social marketing to change societal views regarding disability, international disability rights organizations have focused on disabled persons themselves. From the view of many international activists, systemic change will only occur once persons with disabilities themselves have developed a “disability consciousness” (Groch 1994), becoming aware of their own oppression and committed to collective action. Using a rights-based approach to empowerment (Chapman 2009: 180), many international actors believe that human rights instruments, such as the UNCRPD, are only effective when the rights-bearers themselves believe that they are

deserving of their rights and hold their governments accountable through advocacy campaigns and monitoring regimes.

Grassroots disability associations have become the nexus where international actors seek to instill a new disability consciousness amongst persons with disabilities, volunteers, and professionals in developing countries. They are also the sites of conflict. Many disability-focused civil society organizations at the local level have long histories of service delivery, prioritizing the rehabilitation or livelihood needs of persons with disabilities over and above rights advocacy (Phillips 2008; Turmasani 2003; Ingstadt and Whyte 1994). Private, locally-supported physical therapy clinics and vocational training schools are ubiquitous throughout the Global South. These sorts of organizations, however, have long been marked with suspicion in North America and Europe because they are often segregated institutions supported by charity rather than integrated environments paid for by government, thus ensuring equal treatment. Within disability-only institutions, persons with disabilities are characterized as being at risk of becoming socialized into a “sick role” (Albrecht 1976) and internalizing negative beliefs.

The rise of the Western disability movement was based upon a change in consciousness amongst persons with disabilities who went on to reject the traditional medical model of disability, which emphasized “fixing” impaired individuals, in favor of the social model of disability, wherein “disablement” results from “the failure of a structured social environment to adjust to the needs and aspirations of citizens with disabilities” (Hahn 1986: 128). This paradigmatic shift in thinking helped forge a new political identity amongst persons with disabilities and the development of advocacy

DPOs (Anspach 1979; Barnartt and Scotch 2001) that embraced “confrontation” and rejected “charity” (Fleischer & Zames 2011).

The international disability rights movement, which is dominated by Western activists, interprets the persistence of rehabilitation centers run by grassroots disability associations in developing countries as signifying a lack of disability consciousness within grassroots civil society organizations. Furthermore, the professionals and volunteers staffing these services are seen as a major barrier towards progress by teaching persons with disabilities to be dependents and instilling a “false consciousness” (Charlton 1999) within them. Thus, promoting a disability consciousness (Groch 1994; Barnartt 1996) not only involves changing the way persons with disabilities think about themselves, but it also involves getting local organizations to stop providing services. These outside interventions into local organizations have led to enormous rifts within the international disability rights movement, where activists intervene in the daily operations of local organizations, seeking to fundamentally approach their approach to disability.

Given the globalization of identity movements (Castells 2010), the development of transnational advocacy networks (Keck and Sikkink 1999), and the popularization of rights-based approaches to empowerment (Chapman 2009), it is important to know if assumptions about false consciousness and the utilization of consciousness-raising techniques act as an axis of conflict between global, national, and grassroots partners. The international disability movement provides a window into these dynamics because of the role disability consciousness has historically played within the Western movement and the explicit goal of organizational change

articulated by international actors promoting the movement in the Global South. Using ethnographic and interview data collected over 2009-2012 while embedded as a participant observer within a local disability coalition in Segovia (a pseudonym), Nicaragua, member of the disability unit of a UN Agency in Geneva, and as a participant in international conferences regarding the UNCRPD, I will demonstrate the way shared ideas about the “false consciousness” of persons with disabilities in developing countries and the negative effects of rehabilitation provided by grassroots associations has motivated interventions meant to effect fundamental organizational change against the will of local members. This focus on consciousness contributes towards an often neglected aspect of intra-movement conflict that has important implications for understanding identity movements in a globalizing world.

### **Consciousness, social movements, and disability**

The premium that the international disability rights movement places upon changing the way it’s very constituents—persons with disabilities around the globe—think about themselves and the world around them is a strategy in keeping with many contemporary social movements. When consciousness is raised, individuals stop blaming themselves for their marginality and recognize instead that they are part of a discriminated group that society is holding down. This shift in perspective has been important to a variety of movements, ranging from the women’s movement, where feminist consciousness raising was used to enable women to “increase her awareness, of her oppression in a sexist society” (Perl and Abarbanell 1976: 2) to the organizing of Latin American peasants against the State through the “awakening of critical consciousness” as popularized in Paulo Freire’s *Pedagogy of the Oppressed*

(1970). More recently, it has been applied to movements as diverse as HIV/AIDS activism (Stockdill 2001), undocumented youth advocating for the DREAM Act (Negron-Gonzales 2009), and Asian and Pacific Islanders pushing for more education spending in California (Kwon 2008).

The idea of “false consciousness” and the concomitant necessity of consciousness-raising was originally raised by Marx and Engels in their early work on ideology (Jost 1995; Wood 1988). Marx and Engel’s call to “liberate them [the proletariat] from the chimeras, the ideas, the dogmas, the imaginary beings under the yoke of which they are pining away” (1846: 37) became a cornerstone of both Socialist thought and revolutionary practice. In the West, notions of consciousness went beyond the original focus on class-based oppression to encompass more groups and to consider structural conditions other than the mode of production.

Within political science, Verba and Nie included group consciousness amongst the factors determining who votes, lobbies elected officials, or volunteers for political campaigns in their seminal *Participation in America* (1972). A decade later, Miller et al. (1981) picked up on group consciousness, which had played a supporting role for Verba and Nie, to make it central to his studies of electoral participation, forming the basis for a wave of subsequent studies on black (Shingles 1981), Latino (Lien 1994), feminist (Cole et al. 1998), and, more recently, Muslim (Jamal 2005) group consciousness and political participation. Simultaneously, consciousness was similarly revived within the sociology of social movements.

Originally, sociologists dismissed consciousness as an important factor for understanding social movements (See for example McCarthy and Zald 1973).

McAdam, however, reintroduced the concept in his *Political Process and the Black Insurgency* (1982) under the guise of cognitive liberation, opening the door for others interested in social movement mobilization to develop theories of collective (Katzenstein and Mueller 1987, Klein 1987) and oppositional consciousness (Mansbridge and Morris 2001; Stockdill 2001; Negron-Gonzales 2009). “An empowered mental state “ (Mansbridge 2001: 5) quickly rose within the ranks of social movement theory to become considered one of the most basic resources a social movement can have (Mueller 1987). Mueller, who defines consciousness as “a transforming set of ideas that legitimates opposition to traditional norms, roles, institutions and/or the distribution of scarce resources” (1987: 92), notes that fostering a collective consciousness is important in achieving movement goals as broad as general cultural change through to objectives as specific as increasing public spending.

Theories of consciousness, from the perspectives of traditional Marxism, political participation, and social movement theory, have all been applied to disability. The disability movement first started in the 1960s and 70s, where its founders borrowed ideas from other Leftist movements. In North America, the disability movement began in the 1960s when a handful of disabled students began to see their own marginality through the prisms of the racism and sexism exposed by the civil rights and women’s movements. Soon, these emergent leaders reappropriated the idea of Black Pride and the feminist practice of consciousness-raising for their own political organizing purposes (i.e. disability pride and disability consciousness-raising) (Gorch 1994: 375; see also Barnartt 1996: 7). This phenomena soon garnered the attention of political participation and social movements scholars, who began to apply

various conceptions of consciousness to the emergent disability movement, including labeling it an example of minority-group (Fine and Asch 1988), oppositional (Groch 1994), collective (Barnartt 1996; Barnartt and Scotch 2001), and political (Shakespeare 1993) consciousness. Within this literature, disability consciousness is defined as disabled persons 1.) developing a collective identity, 2.) recognizing themselves as an oppressed group, 3.) rejecting the status quo, and 4.) believing that they can change the situation through collective action (Groch 1994: 377).

On the other side of the Atlantic, Western European activists, such as Vic Finkelstein, President of the Union of Physically Impaired Against Segregation in the United Kingdom, began to apply a Marxist-materialist analysis to disability (Finkelstein 2001; Oliver 1994). Through these efforts, Finkelstein was able to revolutionize the nascent movement in 1976, when he introduced a social definition (or model) of disability: “Disability is something imposed on top of our impairments, by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society” (UPIAS 1976: 3-4). The idea of disability oppression was based on the Marxist conceptualization of exploitation (Abberley 1987: 8; Lang 2001) Along with a structural analysis of disability oppression came a complimentary concern with false consciousness. Working directly off of Gramsci, James Charlton argued that “Society’s backward beliefs about and attitudes toward disability not only are society’s beliefs; they are internalized by most people with disabilities as well. This explains why consciousness, the falsification of it, is not only a crucial element in the oppression of people with

disabilities but also the major barrier faced by the disability rights movement” (2000: 70).

The internalization of negative beliefs—Charlton’s “false consciousness”—was a concern held through the disability movement. Sociologists, such as Erving Goffman (1961) and Robert Scott (1969) had recently turned their analytic lens onto mental hospitals and social service agencies, producing work directly relevant to persons with disabilities. These studies of socialization exposed the way basic interactions between professionals and patients imposed a negative self-concept upon disabled persons. In *Asylums*, Goffman forcefully argues that a mental hospital forces its “inmates” to “accept being a particular kind of person who dwells in a particular kind of world” (1961: 149) and Scott, in *The Making of Blind Men*, argues that one of the most important “functions performed by organizations of the blindness system is to teach people who have difficulty seeing how to behave like blind people” (1969: 71). Soon, these sociological texts were accompanied by autobiographical accounts wherein disabled individuals recounted their own experiences in hospitals, schools, or service agencies. In addition to these traditional institutions, activists also started targeting another group: family. For many persons with disabilities, the fact of being born disabled into an “able-bodied” family meant a life of paternalism (See Sutherland 1981: 101), where parents, in concert with specialists, prevented them from becoming independent. These disability autobiographies soon became a genre unto their own in the 1980s and 1990s (Couser 2013), often follow the same narrative arc: an early life of oppression followed by a moment of “awakening” (i.e. consciousness) that leads to



a new, positive identity and life of political engagement (See, for example, Zola 1982; Morris 1991).

In the majority of accounts of consciousness, the empowering potential of a consciousness-raising is celebrated as a universal good. Some scholars, however, have alluded to a darker side of consciousness, but only in the most limited way. For example, out of an entire volume dedicated to oppositional consciousness (Mansbridge and Morris 2001), only a few paragraphs are dedicated to the problems associated with consciousness-raising within movements. In these brief passages, however, Mansbridge importantly points out potential problems. “Sometimes leaders and activists get in the way. Sometimes they promote a way of being that looks good to them, in the enclaves in which they talk mostly with one another, but that does not work in the lives of others” (Mansbridge 2001, 250). As such, oppositional consciousnesses are ideologies themselves—rigid orthodoxies that promote a “deafness to new and contradictory information” (252). Likewise, studies specific to the disability movement have also made cursory allusions to problems with disability consciousness. Namely, that its promotion can drive activists to become essentialist (Barnartt 1996: 10) or militant and heavy-handed (Groch 2001: 92) in their treatment of other persons with disabilities who do not share their view. In each of these cases, however, the potential negatives of consciousness have not served as impetus for further research or substantive analysis.

## **Settings and Methods**

My research has reached across the whole of the international disability rights field in order to understand how priorities set in UN agencies or international NGOs headquartered in D.C., New York, or Geneva affect the daily operations of organizations in Nicaragua's hinterlands. On the international level, I spent two months in Washington D.C. in 2010, where I interviewed over a dozen executive directors and disability focal persons in international NGOs, global DPO networks, and UN agencies in D.C. and New York. I then spent the first six months of 2011 working as part of the disability unit in a UN agency in Switzerland, where I was in contact with disability specialists in other UN agencies and a participant in inter-agency meetings. Lastly, on the international level, I participated in international disability rights conferences that took place in D.C., New York, Jakarta, Indonesia, and Istanbul, Turkey throughout 2010-2012.

At the grassroots level, I chose Segovia (pseudonym), a sizable city in Nicaragua's mountainous north. Nicaragua provides an interesting context for studying the effects of the international disability rights movement. This Central American country is the second poorest in the Western Hemisphere with a national GDP of just US \$7.8 Billion for its 5.7 million citizens. For comparative purposes, the University of California system's annual budget for 2011-2012 was close to three-times the size of Nicaragua's entire economy at \$22.5 Billion, with UCLA, the largest of the ten-campus, spending \$5.3 Billion annually on just 40,000 students. The GDP per capita in Nicaragua is \$1,300 or about 2.7% of the American GDP per capita of \$47,000. Nicaragua is also significant because of the 1979 Sandinista Revolution and the 1980s Contra War, which not only left 40,000 citizens dead and many more

wounded, but also institutionalized a unique culture of solidarity, whereby the government and civil society organizations attempt to solve social problems collectively through “popular” or “mass” organizations (Anderson and Dodd 2005; Babb 2001; Ruchwarger 1987), several of which disability organizations.

Segovia has approximately 130,000 citizens spread over a relatively large geographic area. I chose Segovia because it had one of Nicaragua’s first disability rights coalitions, which provided me an entry point for studying the individual disability associations that make up its membership. The seven members range from associations for the blind, deaf, and mobility disabled through to organizations representing wounded veterans from opposing sides of Nicaragua’s civil war. Most importantly for this paper, the coalition includes a parents of disabled children association. Over three summers (2008, 2009, 2010) and an 11 month period spanning 2011-2012, I was a participant observer embedded within these local associations. I also visited and interviewed staff from international NGOs and national networks, government offices, private businesses, schools, and other institutions, joining leaders or staff of organizations in their daily activities. I supplemented my participant observation with semi-structured interviews, recording 69 with members of Nicaraguan associations and 12 with members of international NGOs and agencies. In all cases, pseudonyms are given for subjects observed and/or interviewed. I also collected documents whenever available.

### **Disability consciousness and the problem of grassroots associations**

In the following analysis, I will draw out the role consciousness plays in international actors' understanding of grassroots disability associations and its usage to justify fundamental change within local organizations.

For a few days each year, the world's most prominent disability activists and policymakers gather for the Conference of States-Parties to the UN Convention on the Rights of Persons with Disabilities (UNCRPD) at the United Nations in New York. The stated goal of States-Parties Conferences is for signatories of the treaty (i.e. states) to report on the progress they have made implementing the international human rights instrument at home through national legislation and public policy. Official ambassadors and governmental emissaries, however, constitute a small fraction of the hundreds of conference participants who include the disability focal persons of UN agencies, heads of international NGOs, directors of global disabled persons organization (DPO) networks, administrators of foreign aid agencies and private foundations, and an assortment of recognized or self-appointed disability rights experts. Equally so, the official reports given by countries in the assembly room seem downright perfunctory in comparison to the animated discussions occurring in hallways, café tables, and seminar rooms of the UN Annex where representatives from civil society and multilateral organizations identify problems encountered with the implementation of the UNCRPD and plot new interventions.

During the 2011 Conference, I attended a workshop concerning the right to inclusive education, which is enumerated in Article 24 of the UNCRPD. What began as straightforward presentations given by speakers from a UN agency and a mainstream human rights organization soon transformed into an open discussion on

the obstacles encountered towards implementing inclusive education policies in developing countries. Within minutes, one particular problem rose to the surface: resistance to change from grassroots disability associations and disabled persons themselves. A general consensus formed as the facilitators, presenters, and audience members argued that DPOs in developing countries need “a clearer understanding” and that, as international advocates, the people in that room had the responsibility to provide local DPOs with “an improved concept” of what their rights mean and how they should be implemented.

One short exchange illustrates the way the problem of grassroots associations is understood by many who participated that day. The top disability person from a UN agency stated that “the problem has been [local] advocates have been too focused on the education of persons with disabilities and not on changing the whole system” and “want to keep their *pretty little programs*” going, referring to schools and facilities specifically for children and youth with disabilities that are operated by grassroots disability groups at the local level. The education specialist for a major international funder responded to this observation with “we need to get DPOs themselves to understand the policy, the meaning of the UNCRPD, its interpretation, and how it can be applied.”

An international consultant on inclusive education, whose clients include the United Kingdom’s largest disability NGO and who has done training work in more than a dozen countries from South Africa to Argentina, minced no words when he forcefully stated that “we must *reeducate* disability advocates [in developing countries]” (Field Notes, September 14, 2011).

Terms such as “improved concept,” “clearer understanding,” and “reeducation” are indicative of the belief held by many international disability activists that persons with disabilities and their advocates at the local level lack a disability consciousness. The continued existence of “pretty little programs” is seen as a tale tell sign that grassroots associations simply “don’t get it” because they continue to view disability in terms of providing rehabilitation services or concrete benefits rather than advocating for rights. Disability consciousness is equated with rejecting the status quo and attempting to change the situation through collective action (Groch 1994), a set of practices very different from operating service programs. In the specific case of education, special schools are seen as equivalent to segregated institutions run by professionals immersed in the medical model, such as the mental health hospitals or disability service agencies studied by Goffman (1961) and Scott (1969).

The right of inclusive education advocated by international organizations means that persons with disabilities have the right to attend the same public schools and learn in the same classroom as all other children. As a right, governments are responsible for the education of children with disabilities, a responsibility many countries have historically neglected, evident in a UNESCO’s estimate that 90% of children with disabilities in developing countries not attending school at all. When education is available, it is often through either chronically underfunded special schools; in state-sponsored institutions, a policy common in Post-Soviet states and the object of deinstitutionalization campaigns (See Ziegler 2010: 147-183); or left as a gap filled by civil society. In many cases, as alluded to in the comment about disability associations wanting to hang on to their “pretty little programs,” DPOs and other

organizations themselves have taken pride in establishing schools for children who are either deaf, blind, physically, or developmentally disabled.

Ensuring inclusive education requires far more than simply allowing children with disabilities to attend regular schools, but also requires the removal of barriers, both physical and instructional, so that teachers are able to accommodate different learning styles and students have equal access to information and instruction (i.e. multiple formats, such as Braille, etc.). It also requires a raised consciousness that extends far beyond educators. In the words of the European Disability Forum, “We must realize that in order to change the system, and ensure the inclusion of pupils with disabilities in mainstream schools, a revolution must occur in peoples’ minds including families and organisations of disabled people” (EDF 2010: 211). Inclusive education is not simply about government policy, but also about the way people with disabilities (and their families) think—change begins with “a revolution in peoples’ minds”. That revolution, however, also means that grassroots associations must stop supporting special schools.

In an essay on false consciousness in *The Disability Studies Reader*, a widely used textbook, Charlton explains the link between false consciousness and schools in this way: “It is possible to identify numerous ways that students with disabilities are controlled and taught their place...” going on to enumerate labeling, symbols, structure, curricula, and other elements of segregated schools or classrooms. He then goes on to show why special education (as opposed to inclusive education) is part of the able-bodied hegemonic force: “Special education, like so many other popular reforms won by popular struggle, has been transformed from a way to increase the

probability that students with disabilities will get some kind of education into a badge of inferiority and a rule-bound bureaucratic system of separating and then warehousing millions of young people the dominant culture has no need for” (2006: 223-224). As a result of education and other manifestations of disability oppression, persons with disabilities, are taught self-pity, self-hate, and shame, and prevented from “knowing their real selves, their real needs, and their real capabilities” (220). From this point of view, the stakes could not be higher. Equally so, those who advocate for special schools and other rehabilitation facilities are purveyors of false consciousness, endangering the minds and agency of the persons with disabilities they educate.

The tension between prominent actors within the international disability rights movement, such as the participants in the UN meeting, coalitions like the European Disability Forum, and individual activists such as Charlton, and grassroots disability associations supporting “pretty little programs” is just one specific example of a larger gap between global (Northern) and local (Southern) goals. The difference in mission and practice between DPOs in Western countries and those in developing countries is well documented. An early comparative study spells the problem out: “In Northern countries, such organizations [DPOs] are mainly concerned with the rights of disabled people; through publicity and lobbying, they attempt to change laws and policies in order to promote integration in all sectors of society. In Southern countries, the groups themselves often feel that the most immediate needs are for practical programs of rehabilitation” (Ingstadt and Whyte 1995: 24; see also Turmasani 2003). The result of this recognized gap has been a policy of programs meant to change grassroots disability associations from a focus on service and self-help into organizations focused



on advocacy through a flood of funding and technical assistance designed in the North and implemented in the Global South, of which consciousness-raising is one of the dominant tools.

The local iteration of the worldwide priority to spread a disability consciousness took face in Segovia in 2008 when Handicap International, the Disabled Rights Fund, and other international NGOs initiated the Departmental Coalition for Advocacy and Awareness (CDIS). This coalition brought together seven grassroots associations, such as the Association of the Blind, the Organization for Disabled Revolutionaries (wounded Sandinista soldiers), and *Los Pipitos* (parents of children with disabilities), which will be the focus of this paper.

On my research visit to Segovia in 2009, I met with the ex-patriot (French) assistant regional director of a European NGO that had backed the formation of the CDIS. He worked out of a Central American regional office, but was in Segovia for Nicaragua's National Disability Day (August 25). He explained that, in the past, his organization had funded rehabilitation programs, including a prosthetic center close to town. A new directive from Europe a year earlier had told the regional office to redirect their programming towards promoting the UNCRPD. As a result, they decided to organize local disability associations for advocacy in various cities throughout Central America. The regional office also stopped funding the prosthetic center, which closed down, leaving many local residents in need of new artificial limbs to go without. This new policy was in keeping with a new best practice guide on service provision in low-income countries that his organization and 34 other international NGOs had recently signed, which states that "As a human right, rehabilitation is a

government obligation. This means the government has the responsibility to ensure the availability of P&O [prosthetic and orthotic] services” (Landmine Survivors Network 2006:17). This new principle also applied to grassroots associations; they should not be funding their own self-help projects, but advocating that the government do so for them, a common end-goal of consciousness movements in general (Mueller 1987) and the Western disability movement specifically (Silvers et al. 1998: 35).

Our interview turned to the possibility of whether or not the government had the capacity to manage something as expensive as the clinic. “They [government] have the money, they just don’t want to spend it. And they don’t have to. No, because the people here, the disabled people won’t ask for it.” I asked for further explanation, which resulted in the declaration that “Nicaraguan people do not have a culture of rights” and a long, illustrative story about how in France, if an electric company overcharged its customers, the French people would be in the streets and refuse to pay. In Nicaragua, however, according to my interviewee, people would pay the bill even if they knew they were being cheated. He ended the example in a mocking voice, saying “Oh, I am so poor, I can’t do anything” (Interview notes: August 25, 2009). His characterization of Nicaraguans was in keeping with concerns about false consciousness, evidenced in self-pity and helplessness. It also showed a level of disdain.

In addition to starting the coalition for all seven local associations, international NGOs also targeted specific grassroots associations in order to change their practices. In Segovia, many set their sights on the local chapter of *Los Pipitos* (officially, the Association of Parents of Children with Disabilities), a prominent

member of CDIS and one of the most respected civil society organizations in town. *Los Pipitos* is a national network made up of dozens of local, self-governed and self-financed chapters throughout Nicaragua's cities and towns. The association dates back to the Revolutionary era and has strong ties to the Sandinista ideologies of "solidarity" and "citizen power." *Los Pipitos* was founded by Olmar Cabeza, a Sandinista guerilla army commander during the 1979 Revolution and current member of the National Assembly. When Cabeza and his wife gave birth to twin girls with Down syndrome in the early 1980s, they began organizing other parents of children with disabilities to support one another in caring for their children. *Los Pipitos* is prototypical of the *organizaciones de masas* or "popular organizations" that were established during the Revolutionary period (1979-1990) when a financially strapped government encouraged the local citizenry to initiate campaigns and organizations directed at resolving social problems in lieu of public services.

The Segovia *Los Pipitos* chapter is exemplary as a solidarity initiative, having garnered the support of the whole town. It consists of a small complex of well-maintained offices, classrooms, a physical therapy building, auditorium, basketball court, and series of workshops. During the day, teenagers and young adults with disabilities rotate between working in sheltered workshops learning piñata, candle, and furniture-making and group activities ranging from dance to discussing feelings or learning social skills. Many parents, who send their children there, describe it as initiating a "powerful transformation" in their children's lives, whereas before attending *Los Pipitos*, they were either isolated at home, bullied in regular public school, or attending the much less well resourced special school. Through the *Los*

*Pipitos* program, however, their children have made friends, learned skills, and developed healthy self-esteem (Field Notes: October 28, 2011). But the Youth Center is out of step with the international disability rights field. As a segregated learning environment, privately run (i.e. charity), and administered by professionals, it combines into a powerful cocktail of rights' violations. The center is the very essence of the "pretty little programs" that the UN disability focal person was concerned about during the UN meeting in September, 2011. Additionally, as a disability initiative primarily led by mothers of children with disabilities, who dominate the board, it is a cause of concern for the dangers of the type of paternalism that prevents children with disabilities from developing into independent adults (Sutherland 1981).

Despite the fact that the Ministry of Education in Nicaragua has begun to actively promote inclusive education and integrate children with disabilities into regular schools and the Ministry of Work (i.e. Labor) has passed legislation promoting equal access to employment and vocational education for persons with disabilities, many parents in Segovia still chose to send their kids to *Los Pipitos* because they feel their children get more attention in comparison to the public schools where teachers often manage classrooms of more than 60 students, often without sufficient desks, textbooks, or basic means of education. Parents also believe that working in the sheltered workshops at the youth center is more beneficial than a regular job despite the fact that it is unpaid. From a disability consciousness perspective, *Los Pipitos* only perpetuates segregation and could potentially cause psychological harm to the youth (See, for example, Charlton 2006: 223-224).

A number of international NGOs had offered outreach to *Los Pipitos* for decades, but as the rights-based approach to disability became dominant within the international disability movement following the passage of the UNCRPD in 2006, supporting *Los Pipitos* became increasingly problematic. Organizations, such as Handicap International, began to focus on teacher-training for inclusive education in public schools as a means of drawing students away from *Los Pipitos* and into an integrated environment in keeping with the new norm of inclusion. During my field research between 2011-2012, however, far more direct methods of addressing *Los Pipitos* were employed.

In September, 2011, I was invited as a participant observer of a workshop being given at *Los Pipitos* Youth Center by a European-based international disability NGO being conducted by Gretchen, a German ex-patriot consultant who covered Latin America for the organization. Her organization had an over hundred year history, originally as a missionary society focused on the blind, but since the passage of the UNCRPD, it had rebranded itself as a cross-disability rights organization and launched its “International Advocacy and Alliances” initiative in 2007 to promote disability rights. When I first met Gretchen in 2009, she was providing human rights workshops to the local disability associations. At that time, she told me she had doubts about their effectiveness specifically because she felt disabled Nicaraguans lacked a “consciousness” (Interview Notes: August 15, 2009). Despite those doubts, she had continued promoting rights and was using that occasion to conduct a workshop on the right to “inclusive employment” (Article 27 of the UNCRPD) for *Los Pipitos* staff members, parents, and youth that day.

The centerpiece of the workshop was a series of pictures. Gretchen showed a picture of a man begging in the street, asked “is this employment?” The participants answered “no.” Through question and answer they defined employment as being paid a salary for work. She then asked, gesturing towards the carpentry shop and piñata workshop down the hall from the auditorium, “Well, they [disabled youth] are working next door—making things—is that employment?” The participants happily answered “yes.” Then she asked if they got paid. “No.” Then she explained that it’s not employment. The participants were quiet.

Her next slide was of a cement wall with a sign “Workshop for the disabled” and a chain-link fence in the foreground, a picture taken of a sheltered workshop in Africa. Gretchen asked “How does this make you feel?” Participants were animated “It looks like a prison!” Next, she asked “Would you want to go in there?” No way... Gretchen continued: “For me, I think: I don’t want to go in there. What kind of people are in there? Would you want to get to know them? No way...” Then she asked “Is this inclusive?” No, it is segregated. The following slide was of a metal workshop with half a dozen people working together at various stations, some were disabled. “How about this?” Looks really nice. “What do we see?” Everyone is working together. They look happy. “Working together” got written on the paper. Then, Gretchen asked: “Are the workshops next door inclusive?” No... Finally, someone protests. “Yes...but this is a really nice place to work. It is clean, friendly, and safe!” Gretchen was silent. Eventually she explained that people with disabilities have a right to inclusive employment and the Youth Center is against their rights.

Later that day, I interviewed Gretchen and we discussed the workshop. She explained “*Los Pipitos* needs to change” and discussed the UNCRPD as the opportunity for that change. She even admitted that not that many years before she had supported the Youth Center, but had woken up to the fact that the model was wrong. The locals would now have to follow suit. The “locals” did not want to follow suit, however, and Gretchen’s workshop had little, immediate effect. Change, however, did come.

Segovia’s Youth Center was not only out of step with Gretchen, an international disability expert from Germany, but also the *Los Pipitos* national office. In recent years, *Los Pipitos* on the national level has transitioned from a self-help network of parents to a disability rights organization. It had also begun receiving funding from some UN agencies and other international disability NGOs. A revamped national website now states that their mission is to bring together civil society and the State “to promote the Human Rights of people with impairments and/or disability, so that together, we can organize, define, legislate, and implement policies, programs, strategies and services.” Their main strategies for doing this are to “raise awareness in families, raise awareness in the community, and advocate for legislation, public policies, and [change] institutions [agencies] of the State.” At one time, the pride of the national network, Segovia’s Youth Center had become a thorn in its side, as the national office sought to bring local chapters around to its new advocacy model.

In early 2012, change came fast. One morning in February, I stopped by to find the Youth Center’s entranceway chained shut. The local board had been dissolved and staff fired by the national office. A couple of days before, the national office in

Managua had announced the changes. Local parents in Segovia had then begun organizing a meeting in order to pass a protest vote, but as soon as the national office got word of this, they sent national staff to Segovia and implemented a lock out, closing the doors to the main gate and posting a security guard.

A month later, a new director, Julia, was appointed by the national office. Julia was unique in that she had no prior experience with either *Los Pipitos* or disability. Her most recent professional experience had been running a women's rights program in Managua. In many ways, she represented the professionalization (Staggenborg 1988) of *Los Pipitos* as a social movement organization rather than either a continuance as a self-help membership organization of parents or a rehabilitation facility. Julia's primary skill was, it turned out, consciousness-raising and advocacy.

Julia went to work quickly, implementing her own program. The workshop doors were closed permanently and day program ended, replaced by a new program whereby the youth would be brought back to the Center once a week to participate in workshops on their rights. She only hired a couple of staff people back, but this time as workshop facilitators. I attended the first workshop on March 16, which had the stated intent of facilitating an exchange of experiences. I later learned from Julia that she believed that exchanging common experiences was the starting point for consciousness-raising. This is no surprise given her experience in promoting women's rights, which has long seen the move from the "personal to the political" (Perl and Abarbanell 1976: 2) beginning with exchanges of personal experience in small groups.



The facilitators encouraged each of the two dozen young persons with disabilities, who had been drawn from *Los Pipitos* and the local associations for the deaf, blind, and motorly disabled, to introduce themselves and talk about their work experience. Several, across groups, were working in tobacco factories. Many of the *Los Pipitos* youth talked about working in the center's piñata making and carpentry workshops, one lamenting that it was now closed, leaving him with nothing to do. Two young men from the Association of the Blind were at a bakery. Lastly, the cadre of young women from the Association of the Deaf described having been trained in hairdressing at Segovia's Special School, but not having found jobs in that field.

At this moment, Julia, who had been listening from the wings, stepped forward to directly address a young woman who had stated that she had been looking for a beauty shop job for four years. Julia launched into a pep talk to the young woman at a speed far faster than the sign language interpreter could interpret: "You need to fight for equality. You need to feel it in your heart and your blood. You need confidence to work! You need the motivation. You need to fight day by day. You need to tell the government of your right!" Now, expanding out to the rest of the group of youth, Julia went on "These are powerful stories you have told. You need to demand from society your insertion into the world of work. You need a clear vision of your life project. This is your right." She went on about how you can like to study, but you must have a vision for a job. She ended by warning that they will all encounter big obstacles, but must fight harder (Field Notes: March 17, 2012).

I interviewed Julia a few days. After only a few weeks on the job, she announced that she was exasperated with the parents and youth with disabilities

themselves. She outlined how the culture within the family and the children and teens with disabilities, who had internalized that culture, now constituted their greatest barrier towards attaining their rights. “The family: the problem is when the families fails to be conscious –Do not have a vision...People with disability are going to have a lot of problems, but the primary constraint is the family.” Julia went on to explain that others in society, such as employers, also lacked consciousness, despite changes in the law, but the “bad thinking” of people with disabilities was their own worst enemy. Despite the negative feedback, Julia, nor the national board whom she was in constant contact with, demonstrated any willingness to change their approach. Without a board, the local parents no longer had an official means by which to make their concerns heard within either the local chapter or national network. Mansbridge discusses one possible problem with consciousness movements as leaders and activists getting in the way, promoting practices that look good to them but do not work for others (2001: 250). In this case, the leaders were not simply in an enclave, but hostile to the input of others. An imputed lack of consciousness upon both parents and the young women and men with disabilities justified cutting off local input.

In subsequent weeks , Julia began a two-pronged program: consciousness-raising directed at society in general and consciousness-raising directed towards the youth. She began sponsoring radio ads declaring that persons with disabilities had equal human rights (Field Notes: April 23, 2012) and organized a conference on disability rights for all the members of CDIS (Field Notes: May 9-11, 2012), many of the DPOS, whom she saw as not doing enough.

For the youth, the consciousness-raising workshops eventually became self-esteem workshops. As the youth were exhorted to identify jobs that they wanted, Julia would complain to me that the only one that they came up with—to work in a tobacco factory—was without “value” (*valor*) (Field Notes: May 16, 2012). It should be noted that the tobacco factories are the main source of formal employment in Segovia, with some employing as many as 3,000 workers, paying wages of about \$130 a month. Several had relationships with the associations for the blind and deaf, hiring dozens of young persons with disabilities from those groups. For Julia, however, the desire to work in a tobacco factory was a sign of low self-esteem.

Members of the Managua office began monitoring activities, something they had not done before. For example, two national board members accompanied the youth on a march Julia had organized, using the *Los Pipitos*’ bus to bring all of the young people with disabilities together and march through a number of side streets to the Mayor’s Office carrying placards announcing “We are equals” and “Respect our rights” that the national office handed out. Marching against city hall is not only meant to create awareness, but an attempt to create a “redistribution of economic and political power” (Michaekilkis 1997:20), an explicit objective of the human rights-approach to disabilities and a way making up for the gap left by the closure of the Youth Center: it is not *Los Pipitos*’ responsibility to care, train, or find jobs for youth with disabilities, but the government’s.

While all of these activities are in keeping with the priorities of developing a disability consciousness and the international disability rights field, they left the parents of *Los Pipitos* dismayed and many of the young people displaced. The number

of disabled youth participants in these activities dwindled, although their presence in town grew, with many wandering the streets during the day. Eventually the national office had to allow the local chapter to elect a new board, which was demanded by their by-laws and necessary for the local chapter to maintain its registration as a civil society organization. The national office supervised the election, with the national Vice President giving a prayer that the Segovian parents put the interests of the youth over their own and that there be no conflict (Field Notes: May 20, 2012). A new board, made up of local mothers, was elected. Their first official act was to fire the Julia, end the weekly consciousness-raising workshops, and began planning to reopen the Youth Center.

On our final meeting, the day before Julia left, she explained to me that she had done an analysis of her labor inclusion program and concluded that the reason why none of the teens had found new jobs was because the youth themselves lacked self-recognition (*auto-reconocer*)—consciousness. They did not have the self-esteem necessary to enter the labor market.

Julia's analysis reflected Western conceptions of false consciousness amongst persons with disabilities. In *Disabled We Stand* (1981), where Sutherland coined the term "disablement," traditional services and charities are depicted as teaching persons with disabilities to become dependents. "Charities, while playing a major part in maintaining our dependent role, propagate the belief that we are helpless and, without their existence, would be even worse off than we already are" (117). The organizations considered most pernicious are those dealing with children and youth. A popular disability narrative is of having been made a "poster child" for a charity, thus being

exploited through fundraising propaganda (Longmore 2013). The family also comes under scrutiny. Sutherland argues that “even the most accepting and supportive of parents are, if they are able bodied, unlikely to be able to avoid contributing to one aspect of our oppression, which is our lack of a cultural identity... This leaves us isolated and less capable of resisting attempts to make us cooperate with things [taking on dependency roles] that we might reject if we felt stronger in our disability” (1981:101). As a parents association serving youth with disabilities, the militancy, which has been observed in the Western disability movement (Groch 2001: 92), by which it was forced from a locally-controlled youth program into a consciousness-raising and advocacy organization is justifiable from an activist point of view. Lives are at stake.

The new board, on the other hand, was not worried about “disabling” their children, and instead planning to strengthen the *Los Pipitos* Youth Center by making it self-sufficient and increasing its vocational rehabilitation activities. One board member had made a deal with a cigar factory to begin manufacturing wooden cigar boxes in the carpentry workshop and another had begun contacting supermarkets and *pulperias* (corner stores) to sell bread that the mothers as volunteers and the youth could bake on premises (*Los Pipitos* had an industrial kitchen). With the profits, they could operate the Center and provide social and educational programming in addition to the vocational training. The Vice President of the Board framed these activities in terms of Nicaraguan solidarity. She explained that despite what society says, “I always say it is a blessing to have a child with a disability, and we have that child but

we do not have the resources, therefore we respond with solidarity” (Interview: August 12, 2012).

Solidarity is a term with a very specific meaning in Nicaragua. During the 1980s, the Sandinista government was embroiled in the Contra War and budget-less in the face of economic sanctions. As a result, it was incapable of addressing the most basic social issues. Under the rubric of “solidarity” there were massive organizing campaigns to mobilize citizens and establish “popular” associations. By 1985, more than half of all Nicaraguans belonged to at least one association and many had multiple memberships (Ruchwarger 1987). Examples range from neighborhood daycares or rural farmers’ cooperatives through to the *Cruzada Nacional de Alfabetizacion* (Literacy Campaign), which mobilized an estimated 90,000 university student and adult volunteers to teach basic reading and writing to residents in urban slums and rural villages who had been denied access to education under the Somoza dictatorship. The campaign resulted in a 37% drop in the illiteracy rate in 1980 (Arnave 1980; Hirshon 1984) and became emblematic of Nicaraguan identity (Hanemann 2005; Brentlinger 1995).

Despite the fall of the Sandinista government in 1990, the mass organizations have continued, representing “the best prospects for confronting the nation's need for economic and social justice” (Babb 2001: 10) after neoliberal structural adjustment policies were implemented, doing away with what was left of public services. They are also the place where “Nicaraguan citizens continue to ‘learn’ a very specific form of democracy” (Anderson and Dodd, 2005). *Los Pipitos* began in the 1980s as a mass organization. The local board wanted to continue that tradition as well as ensure

sustainable and high quality opportunities for their children. In doing so, however, they were offering a model out of step with the disability rights movement and unacceptable to an essentialist (Barnartt 1996) focus on advocacy.

## **Conclusion**

A consciousness perspective on social movements has a great deal to offer in terms of understanding mobilization processes (Katznestein and Mueller 1987; Mansbridge and Morris 2001). It also offers insight into the tensions that develop within movements as a result of the operating assumptions of leaders and activists regarding the very people they seek to mobilize. Ironically, consciousness movements that ostensibly promote empowerment, can undermine participants' ability to control local organizations.

There are very good reasons why the international disability movement and its national partners have targeted service providers. As Goffman (1961), Scott (1969), Sutherland (1981), Charlton (2006), and others have articulated so well, rehabilitation and special education facilities and professionals wield incredible power over the people they serve and have contributed towards circumscribing persons with disabilities to a "sick role" (Albrecht 1976). That said, however, the power to impute an identity upon another is not limited to rehabilitation professionals alone. In this case study, from the international level down to the grassroots, UN officials, international NGO staffers, and an Executive Director appointed as a change agent within an organization, assume that persons with disabilities and the parents of disabled children in Nicaragua operate under a false consciousness. This imputation of

a falsely conscious identity may have similar consequences for personal agency as the identity of “sick.” The assumption contributes towards a heavy-handed and militant approach (Groch 1994) towards individuals and organizations that fail to comply with international standards and a single-minded refusal to recognize differences (Mansbridge 2001; Barnartt 1996) or listen to voices on the ground that may explain deviant behavior. The conscious/falsely conscious divide contributes to an “enemy within” mentality. In *Disability Protest*, a history of the disability rights movement in the United States, Barnartt and Scotch describe a consciousness perspective as helpful in identifying “who is with us and who is against us” (2001: 31). In this situation, anyone who fails to comply with prescribed change is deemed to be “against” the movement.

Many disability rights movement activists and scholars have concluded that disability consciousness will not develop organically among persons with disabilities, especially those embedded in traditional services or networks, and instead must have a disability consciousness purposefully “introduced” to them from the outside (Groch 1994: 386 and 391). Just as international disability NGOs launch technical assistance programs in the Nicaragua to promote advocacy over and above services and *Los Pipitos* appointed Julia to lead Segovia’s chapter, assumptions about what persons with disabilities and their parents think are made by outsiders. Not only were the international NGO employees I profiled from France and Germany respectively and Julia a native of Managua and a veteran of the women’s (not disability) movement, none of these purveyors of disability consciousness were persons with disabilities themselves nor parents of children with disabilities. Legitimacy in the field is



seemingly won by espousing an ideology of disability consciousness rather than living a life with a disability.

With the advent of transnational advocacy networks (Keck and Sikkink 1999) and the incorporation of social movement techniques as part of a rights-based approach to development and empowering marginalized groups in developing countries (Chapman 2009), it is increasingly important that the role and consequences of consciousness are examined. While broadening individuals understanding of their own situation, improving self-esteem, and bringing people to collective action can all be important factors in creating positive social change at the systemic level, certain assumptions and techniques may be responsible for intra-movement conflict and the loss of local control.

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## **Conclusion**

### ***“Obras, No Palabras!” – Works, Not Words!: Rights, Resources, and Relevance: Solidarity in the rain***

Six months out of the year, Segovia is an oven. The dirt roads are seemingly made of dust ready to rise up in a yellow cloud at the slightest provocation. At the end of August, however, the sky darkens and the rainy season begins. First, the sound of rain pings along the tin roofs, slowly increasing in volume and frequency, and then, in a singular clap, begins to pour down in sheets. People outside run for the nearest cover and people inside stay put. Within minutes, the dirt roads turn into mud rivers that then flow into the city streets where the block paving stones begin to burgeon and swell, eventually turning over and opening up potholes the size of basketballs. Everyone is stranded: children in school, workers in factories, old ladies in Church, and pedestrians under an awning or inside a corner store. Everyone has to wait, sometimes for hours, until the rain stops and the streets drain. It is during those months that the seemingly odd (and inherently inaccessible) architectural decision to build the foundation of houses, curbs, and, where they exist, sidewalks two or three feet above the surface of the street suddenly becomes clear. Even at that height, water can still rise high enough to enter homes and storefronts.

At the end of a solid eight days of rain in October, 2011, things dried out enough that the city reopened and I could actually cross the street in front of my home without having to wade in water up to my knees. I had heard that the river had burst its

banks, effectively cutting off the northern half of the city and wiping out a dozen homes built in a low-lying area just three blocks from the central plaza. I walked down there, seeing the water still three feet high, and then headed for the grocery store and then, as a luxury after having been stuck inside for so long, the collection of molding books donated from Spain that was known as the “city library.” The rains, however, opened up again and I found myself now stuck about twenty blocks from home. I spent the time chatting with a school teacher who was likewise stranded. She told me that all of the schools had been closed for a week and a half. She then asked me if I had seen where the river had flooded. I just had. Some of her students had lost their homes. Some were now staying in the city’s recreation center where she had been volunteering—cooking, cleaning, and keeping the children busy. When she found out the library was open, she had come here to pick up picture books to keep the small children entertained. I asked her about their houses. Was the city going to rebuild them? Was there some kind of insurance? “The city?” She asked, “No.” I pressed further, asking about the “government in general.” No, she said, and then she launched into an explanation of how things worked in Nicaragua. It is not the government that responds, but the people. “We respond with *solidarity*,” she explained. Already, there were trucks being filled up with furniture, clothes, toys, and even construction materials. Segovians—regular people—were going to rebuild those houses and replenish all that had been lost in the flood. The Sandinista Mayor, a widely popular figure in Segovia, had been one of the first to offer to donate his time and money. (Field Notes: October 26, 2011).

## **Precariousness**

In the first paragraph of the Introduction, I discussed Bryan Turner's important 1993 article "Outline of a theory of human rights." This was a first attempt to develop a sociology of human rights. In it, Turner argues that sociology can offer an ontological grounding for human rights through a sociology of the body and the universal precariousness of our social institutions, a theme he returned to more than ten years later in *Vulnerability and Human Rights* (2006). I agree with many others (Waters, 1996; Stammers, 1999) that sociology should not play a role in defining what should and should not be a human right, but instead focus on the way rights are constructed. But, the notion of human vulnerability and the precarious nature of our ways of dealing with it are still important insights. Rights are claims on others, and they are claims based on the notion that we are interdependent and often in need of mutual support and protection. The problem with Turner and many others is that the only social institution they can imagine—or they willingly prescribe—is that of a state. That is why human rights advocacy has become conflated with human rights realization. The idea is that states that are held accountable can and will, if pressed hard enough, fulfill rights. In a sober critique of human rights, Shafir (2004), building upon Hannah Arendt's original insight regarding the fact that people who are stateless are therefore rightless (Arendt, 1951), argues that the "sovereign nation-state still remains the sole institution that administers and enforces rights, even those conceived to be universally held [i.e. international human rights]" (Shafir, 2004, p. 11). That insight has made its way into development thinking, where international NGOs and grassroots associations partner together to pressure states to implement human rights



standards locally (see, for example, Chapman, 2009). While Nicaragua is certainly a sovereign state, however, it is arguably unable to fulfill many of the social and economic rights enshrined in the UN Convention on the Rights of Persons with Disabilities. Unable, that is, unless rather than the state, we look to civil society to fulfill rights, which is indeed what seems to be happening in many cases.

Nicaragua is the second poorest country in the Western Hemisphere, just one slot above Haiti, which was recently ranked between the Central African Republic and Afghanistan on a list of “failed states” (Fund for Peace, 2014). Nicaragua is not a failed state, but it is poor. The real GDP per capita is just US \$1,349.00 (World Bank, 2012), making for a national GDP of about \$7.7 Billion. While that may seem to be a lot, to put things in perspective, the University of California at Los Angeles (UCLA) had an annual operating budget in 2012 of \$5.3 Billion, which covered the educational and research expenses of just 40,000 students, faculty, and staff as opposed to Nicaragua’s 6 million citizens. Nicaraguans get by on less than 3% of the American GDP per capita of \$47,000, but, as I would argue, only because they work together and mobilize resources, including volunteer labor, through civil society. If Nicaragua’s government were to levy a 100% tax and redistribute it perfectly, the average Nicaraguan would still not be able to afford to buy their textbooks for a year in relation to the UCLA analogy, much less a meal card for the cafeteria or a new laptop, not to mention tuition. In terms of disability, a high quality wheelchair can cost as much as a new car. Yet, the regional administrator for an international disability NGO blames Nicaraguans with disabilities for lacking a “culture of rights” because he firmly believes that “They [government] have the money, they just don’t want to

spend it. And they don't have to. No, because the people here, the disabled people won't ask for it" (Interview notes: August 25, 2009; Chapter 5). This belief is in keeping with rights-based development, which argues that the problem in developing countries "is not lack of resources, but lack of political will" (Normand, 2001 quoted in Molyneux and Lazar, 2003, p. 29; Chapter 2). In turn, political will is something created through an active, advocacy-oriented civil society which mobilizes the populace and forces the government to create new entitlements as opposed to the organization itself providing its members services.

Luis, the president of the Association of the Blind, however, has a different view:

I believe that the Mayor's Office alone does not have a sufficient budget for all [the needs of persons with disabilities]. They have a list of priorities, for example, people with unemployment, single mothers, children in the street, the people with AIDS, and people with disabilities. But it is a lot, I believe that they do not have sufficient financing for the streets, for the trash, for all... I believe that in the perspective of the international organizations, their professionals and the people and the leaders with disabilities that are in America and Europe—that in the United States when they have a new benefit, they have a Government with the sufficient funds and then the law does not only have the meaning of a desire. I believe that here the law is a desire or an objective for the future because you need to wait for the capacity... they can rapidly carry out the law. But I believe that when an American person is thinking about the meaning of a new law, for example in Nicaragua, they believe that the words are a reality. But that is not here. Right, it is impossible, yes? (Interview: March 21, 2012)

Luis could have also added those made homeless by the flood to the list of the vulnerable and included dredging the river as another item that the City Hall must cover. Importantly, Luis cites the needs of others—"people with unemployment, single mothers, children in the street, the people with AIDS"—which contextualizes

persons with disabilities within a population defined by vulnerability, but also “solidarity,” or a concern with others. This recognition of the needs of others, however, flies in the face of the American disability movement, where advocates argue that persons with disabilities deserve a disproportionately larger share of public spending because justice demands that society make “the commitment of resources [to persons with disabilities] to correct the disadvantaging outcomes of exclusionary past practice. It is appropriate—indeed, it is requisite” (Silvers et al., 1998). Luis seems reluctant to demand more, literally seeing more of scarce resources for persons with disabilities equals less for people with HIV or living in the street.

I believe that the belief that advocacy can lead to access to resources is rooted in a very Western notion of a discursive public sphere, for which human rights has become a universal language. It seems that having a voice in this public sphere is the answer to all problems. In this respect, Habermas is the most influential thinker of the past century in terms of both political thought and political action. I would also argue he is the most mis-read, or, perhaps more precisely, *un*-read. Habermas locates the development of the public sphere within a culturally and economically distinct environment. For Habermas, the public sphere as he conceives it did not exist until there was a healthy, bourgeois society (Habermas, Lennox, and Lennox, 1974, p. 51). It would seem that its application to developing countries then necessitates some revision. But, instead, there is a blind faith that if only people are given “voice,” meaning that they belong to a civil society conceptualized as “those organizations, groups and movements who are engaged in this process of negotiation and debate about the character of rules [i.e. political regime]” (Kaldor, 2003, p. 11; Chapter 4),

they will have whatever they need. In this sense, participation in a Habermasian public sphere in a developing country gets theorized as development through a “speech act” in so much that poverty can be addressed simply by people speaking up. While this characterization of rights-based development and the political sociology of civil society (Chapter 2) may seem unfair, it reveals that the conceptual tools political theorists, social scientists, and policymakers apply to developing countries are often developed within the ivory towers or executive board rooms of the Global North and then dropped on the Global South. When they do not produce the intended outcomes, it is never the theorists, but always the theorized, who get the bulk of the blame for things not going according to plan. Even the very notion of social movements as either oriented towards “recognition” (i.e. identity politics) or “redistribution” (Fraser, 2003) forecloses the possibility that social movements might also be generative, meaning that they create goods rather than demand them from others.

### **Rights and Local Relevance**

*“Obras, no palabras”*—“works, not words” is a very practical Nicaraguan phrase. It connotes a disinterest in discourse and a focus on concrete action. The Solidarity tradition of mass organizations that address the “struggle for economic survival” (Vanden & Prevost, 1993, p. 66; Chapter 1) makes sense in a world defined by its human precariousness and the lack of state resources that could address it. Nicaragua is just one example of one society that has found a way of dealing with its precariousness. Persons with disabilities reflect that in grassroots disabled persons organizations’ (DPOs’) survival depending on helping its members either access

resources through identity work (Chapter 3) or by generating it itself (Chapters 4 and 5) with their own, self-supported programs. There is another chapter, yet unwritten, summarized in Chapter 1, regarding a collaborative effort to realize the “right to work” through cooperation between the local disability rights coalition and a city hall initiative.

The study of the interaction between human rights and civil societies (emphasis on the plural) from an “inhabited institutionalist” perspective (Hallett and Ventresca, 2006; Chapter 2) is a deep well. The UN Convention on the Rights of Persons with Disabilities is just one of many human rights instruments. Over the past decades, the UN General Assembly has adopted a number of conventions focused on specific groups: racial minorities (1965), women (1979), children (1989), and now persons with disabilities (2006). Other international organizations, such as the International Labour Organization, have developed rights instruments for the indigenous, domestic workers, and other vulnerable populations. Currently, there is a push for a UN convention on the rights of older people (or “aged”). Each of these human rights instruments gives impetus to transnational movements to incorporate grassroots associations into their networks. Each of these groups is distinct. While the social model of disability views disability as purely a social construction, there is still an “embodied” element to impairments (Shakespeare, 2006, pp. 7-83) that makes the disability experience distinct and not addressable through rights advocacy alone. In the case of persons with disabilities, however, they have a long history throughout the world of coming together and forming their own associations, even if those associations have been service-oriented rather than advocacy-based (Turmasani,

2003). Among other groups, such as the indigenous or the “aged,” there are certainly different experiences in terms of grassroots associations. For example, how easily do tribal or kinship-based associations (indigenous) integrate into transnational rights networks? And are older people organized in the Global South into distinct groups, or are they more likely to be embedded within multi-generational family networks? What do these factors mean in terms of their ability to participate in human rights campaigns or for those campaigns to reflect the way they interpret their experience and identify needs? Each of these groups can be compared with one another. Equally, Nicaragua’s culture of solidarity, legacy of civil war, and history of mass organizations is certainly unique, but other countries are sure to have equally unique civic traditions and environments. Already, Phillips (2010) has looked at persons with disabilities in post-Soviet Ukraine and I have done some work in Cambodia and Indonesia (Meyers, Karr, and Pineda, 2014). The legacy of totalitarian states as well as NGO intervention (Cambodia was briefly a UN protectorate following the end of the Khmer Rouge regime, meaning that UN agencies and NGOs carried out all functions of government in the 1990s and founded dozens of “local” NGOs), is sure to shape DPOs in distinct ways and determine their internal group styles and external engagement with global actors.

Lastly, this shift towards pushing civil society towards a human rights advocacy model may come at a very real cost. Ironically, it may make grassroots associations both less representative and less effective. From a neo-institutionalist perspective, organizations can be understood as responding to the pressures of their organizational environment, irrespective of whether or not the norms they conform to

accomplish immediate goals. Local civil society associations in developing countries often find themselves in two organizational environments. Grassroots groups that get funding from the international community are often those led by leaders with “marketing” savvy and the willingness to adopt the priorities of outside donors, even when that alienates them from their base. Unfortunately, “what plays best overseas seldom corresponds to what matters most domestically” (Bob, 2005, p. 193). Even transnational networks that espouse horizontal forms of participation have proven to concentrate power in the hands of the few, leaving those working in the field marginalized from the agenda setting process (della Porta et al., 2006, p. 51; Ghimire, 2011). Within grassroots groups themselves, elites can form made up of leaders capable of interacting with international donors, leaving regular participants out of the conversation (Biekart, 1999, pp. 298-299). When local groups refuse to conform to the pressures exerted by the international actors dominating their organizational environment, international NGOs and donors have engaged in “manufacturing civil society from the outside” by establishing entirely new local organizations in lieu of partnerships with existing associations. This can result in a “dislocated new civil society” (Machetti and Tocci, 2011, p. 50) that has little connection to the actual populous, yet claims to speak for “the people” at the grassroots.

The international disability movement, which is dominated by the North, has recently begun to be criticized for ignoring complexities on the ground in the South and attempting to homogenize approaches to disability along the lines of western thinking and models (Grech, 2009). These “globalizing campaigns” have been critiqued for using the UNCRPD as impetus to fund local-level campaigns centered on

legislative reforms that do little to redistribute resources from North to South, address histories of colonialism or contemporary global inequalities, or address the concrete medical or survival needs of persons with disabilities in poor countries (Meekosha & Soldatic, 2011; Meekosha, 2011). They also threaten to destroy the very thing that many persons with disabilities count on to survive: their association and cooperation with one another.



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