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Stephen J. Meyers
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Spending Down a Grant

GRANT GUIDELINES AND GUARDRAILS

It was November and the rain was pouring. The leaders of the seven grassroots disability organizations that made up the *Comisión Departmental de incidencia y sensibilizacion de personas con discapacidad* (CDIS) – the Departmental Commission for Advocacy and Awareness of Persons with Disabilities in Segovia[1], Nicaragua – were sitting in a small meeting room. I was sitting with them, in the corner, ready to listen. The rain bouncing off the zinc roof above was so loud that we could not hear one another talk, so we sat together patiently, waiting for it to subside. I was glad everyone had made it; a few weeks earlier the river running through the center of town had flooded, filling the streets and cutting one half of the city off from the other. Hundreds were stranded in their homes for several days. Now a cleanup was taking place and dozens of neighborhood groups were sweeping streets and repairing damaged homes. Other organizations were collecting and loading up pickup trucks sent around by the Mayor's Office with clothes, furniture, and other donations to replace what the households closest to the river had lost when the water had come pouring down over its banks. These sorts of voluntary collective actions to help one another were referred to as *solidaridad* ("solidarity"), the centerpiece of Nicaraguan civic culture and a celebrated practice of public participation. To work together to solve concrete problems was both a point of pride and a duty of citizenship. Several of the disability groups I was sitting with in that room had reached out to their members in the flood zone, making sure their families had everything they needed.

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[1] "Segovia" is a pseudonym. Nueva Segovia refers to a collection of several departments (or prefectures) in the northern, mountainous region of Nicaragua, which has several mid-sized cities, all with disability coalitions. This region of Nicaragua is politically important for having been a major battleground throughout the civil war (1979–1990) and for remaining a Sandinista Party stronghold through to the present day.

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Finally, that morning the skies cleared and the monthly meeting of CDIS began. There was only one major item on the agenda: the end of a multiyear grant the coalition had received from the US-based Disability Rights Fund (DRF) to underwrite the coalition's advocacy activities in and around Segovia. CDIS was now five years old. It had been formed in 2008 through the initiative of Handicap International (HI), an international disability-rights NGO headquartered in France, just months after Nicaragua signed and ratified the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). The technical support that helped form CDIS was part of Handicap International's global *Making It Work* campaign to make the UNCRPD "work" by mobilizing local Disabled Persons Organizations (DPO) to push their governments to implement the convention. The $200 left of DRF's several-thousand-dollar grant shared the same goal as HI, of mobilizing DPOs for rights advocacy. DRF's grant had covered a range of activities, including marches down the city's streets, public-awareness radio ads on the disability-rights convention, banners making demands for greater inclusion hung in the central plaza, and workshops and training on political advocacy and the importance of civic engagement. However, the grant would not cover *solidaridad* activities, including those activities directly supporting persons with disabilities who had been hurt by the flood. Those sorts of collective actions, which were essential for ensuring that everyone in the community was able to survive, if not thrive, had to come from local people themselves.

Luis, the president of the Association of the Blind and cochair of CDIS with Alfonso, the president of the Association of the Physically and Motorly Disabled (ADIFIM), explained that they needed to spend the $200 before the end of the year so they could give DRF a final report before reapplying for a new grant. Fatima, the president of the Organization of Women with Disabilities, spoke up, asking if they could just divide the money between the associations. She explained: "We have nothing. No paper, no cell phone, no money for taxis so we can meet." I would soon find out how true this crisis was for the Organization of Women with Disabilities. When I attended their monthly meeting two days later, Fatima read aloud the group's budget, which was in deficit a few dollars because there was nothing left, forcing her, a very poor woman, to pay for cell-phone minutes out of her own pocket just to call the other members to confirm the meeting's time and place. The association supported itself through monthly membership dues of twenty *cordoba*, a little less than a dollar, yet still more than many members could pay. Fatima had to borrow money for the taxi ride to the community center where they met because, as a wheelchair-user, she could not otherwise get there on her own.

Back at the CDIS meeting, a board member of the local *Los Pipitos*, officially the Association of Parents of Children with Disabilities, chimed in with her suggestion of what they could do with the DRF money. She wanted to use it to purchase leg braces for a girl in a poor family whom she had recently visited, but the DRF's grants agreement did not permit this use. Finally, Vicente, president of the Organization of

Disabled Revolutionaries, who had been sitting silently with his jungle hat pulled down low, made the point that they should have used the money earlier to build another ramp for one of the voting stations for the upcoming elections. His association of war-wounded Sandinista ex-combatants had spent the last year on a voting campaign that included building three ramps in three different voting precincts to ensure it was accessible for the presidential elections that they were sure would reelect Daniel Ortego, hero of the Sandinista Revolution and now, decades later, the current president. But Humberto, president of the Nicaraguan Association of the Disabled Resistance (a rival organization of ex-Contra soldiers who had launched a counterrevolution in the 1980s) – himself disabled in combat – explained that the money to pay for these ramps was the government's (not the coalition's) responsibility. It was the same for mobility devices and cell-phone minutes. Indeed, DRF's funding guidelines explicitly stated that their grants were to be used to "strengthen local stakeholders who can hold governments accountable for fulfilling the rights of persons with disabilities." The "stakeholders," of course, were DPOs in local communities around the world, and "hold[ing] governments accountable" meant political advocacy.

The $200 left from the DRF grant could only be used for disability-rights advocacy activities. Basically, the DPOs in the coalition, all membership-based groups of persons with disabilities or the parents of children with disabilities, could lobby the state to assist persons with disabilities, but could not use DRF's support to directly help disabled people (or themselves as organizations), as three of the DPOs seemed to be suggesting. The needs and desires articulated by the representatives from the Organization of Women with Disabilities, *Los Pipitos*, and even the Organization of Disabled Revolutionaries, demonstrate the priorities of many grassroots associations in developing countries. They focus on directly addressing the concrete, immediate needs of their members and others, whether that is ensuring people can meet, receive rehabilitation, or access a building. Of course, from the point of view of international disability-rights organizations like DRF, advocacy is direct action. Indeed, the funding guidelines are justified according to the logic that "by supporting civil-society efforts at country level to ratify, implement, and monitor the UNCRPD, DRF seeks to make a more direct impact on improving the conditions of PWDs [persons with disabilities]" (DRF 2011).

Pouring cement and giving out mobility aids, however, are just the sort of civic participation Nicaragua celebrates as *solidaridad*. Groups collecting and distributing their own resources to help their members, or sponsoring activities that benefit the wider community, are all seen as ways of building a better society and moving Nicaragua forward. This civic culture was established decades earlier during the Sandinista "Revolutionary Period" (1979–1990) of social democracy when young revolutionaries, churches, and hundreds of grassroots citizen groups mobilized for common cause to improve their society by pursuing various social goals. During that period, health and literacy "brigades" of university students, neighborhood associations, and even Catholic study groups led by liberation theologians, came together in “solidarity” to provide thousands of vaccinations and significantly reduce the illiteracy rate, garnering Nicaragua the prestigious UNESCO Literacy Prize in 1980. In this way, Nicaragua achieved high and globally celebrated rates of social progress during a period when it was embroiled in a civil war, suffering under US-imposed economic sanctions, virtually cut off from foreign aid, and struggling with the aftermath of the generations-long Somoza dictatorship, which enriched one family and impoverished an entire country.

The spirit of *solidaridad* that developed during the Revolutionary Period formed the template of a unique civic identity in Nicaragua, which still motivates the actions of both individuals and organizations. To scholars of citizenship, *solidaridad* would be recognized as containing elements of civic-republican citizenship. Republican citizenship, which was first articulated in Ancient Greece, is based on the notion that citizenship is based upon a willingness not only to contribute, but often sacrifice for the public good. The bonds of “reciprocity, trust and readiness to assume duties for the community” instilled by civic-republicanism in Ancient Greece was understood as a necessity of survival for both individuals and the state (Preuss 2003: 4; see also Pocock 1998). Similarly, it is hard to imagine that Nicaragua could have survived, much less progressed, during the Revolutionary Period if its citizens were not organized around the ideals of *solidaridad*.

Several of the DPOs in the room that day had grown out of the Revolutionary Period, and would even refer to themselves as *solidaridad* organizations. Sandinista soldiers returning from the front lines, determined to make the promise of the Revolution a reality in their local community, founded *Los Pipitos*, the Association of the Blind, and the Organization of Disabled Revolutionaries. This sort of civic participation, which harkens back almost forty years, yet still active today, continues to receive international accolades. A recent World Bank report highlighting the fact that Nicaragua’s school enrollment and maternal health-care outcomes are far higher than other countries with similar levels of economic development, credited these outcomes to “pioneering strategies to fight poverty” through projects that “leverage local initiatives that stretch limited resources further and deliver sustainable results” (DEVEX 2016).

Under DRF’s parameters, however, the members of Segovia’s DPOs were forced to brainstorm ideas that were in line with DRF’s emphasis on civic participation through human-rights advocacy rather than *solidaridad*. Martha, vice president of ADIFIM – which had been established long after the Revolution, just a few years earlier as the result of a workshop and seed funding provided by a Danish disability-rights NGO – suggested an “accessibility fair” similar to one she had attended in a neighboring city. Humberto, the leader of ex-Contras with disabilities and a long-standing critic of the Revolution and the Sandinista government, suggested doing a presentation in Segovia’s central plaza on disability human rights and the law. One of the twin teenage sisters who led the Association of the Deaf, which they had founded with a group of classmates a year earlier, signed her suggestion of a disability *fiesta* where they could build awareness about the right to disability-inclusive education.

The suggestions kept coming. They were based on a different vision of civic participation – liberal-individualist citizenship, namely, that individuals and organizations owe nothing to the state because citizenship is a right open to all and not a reward for carrying out certain duties or living according to specific values. Since the writing of Hobbes, Mill, Rousseau, and others, beginning in the seventeenth century, liberal citizenship has been the basis of theories of rights that have undergirded the protection of citizenship being extended to all, no matter their race, class, gender, religion, or any other distinction, including disability. While Nicaragua prides itself on the idea that everyone is included, liberal citizenship differentiates itself from *solidaridad* by focusing on rights claims upon the state as the primary, if not exclusive, way of promoting equality. As such, liberal-citizenship movements focus on nondiscrimination protection, equal access to public goods, and other state actions, rather than self-help and shared sacrifice (Marshall 1998; Oldfield 1998).

At long last, the coalition reached a decision that met DRF's criteria. The coalition would organize an *Intercambio* (exchange) between the DPOs and the local government where they could promote their rights under the UNCRPD. They would invite international NGOs and national DPO networks, too. The plan was that the coalition's leaders from each of the different DPOs would talk about their members' rights and experiences with accessibility, employment, education, and health. Then they would invite representatives from city planning and the local offices of the ministries of labor, education, and health to defend themselves where they had fallen short and explain what they were currently doing to ensure those rights would be implemented. They chose December 2 as the date because it was the last weekday before the International Day for Disability (December 3) and still a month away, giving the coalition time to plan the event. It was also still early enough that they could close the books on the grant before the end of the year, showing that they had completely spent the money and used it properly. Someone began taking down the names of government employees whom they should invite as guests, all people with whom they were on a first-name, friendly basis.

While the immediate conversation during that meeting had been about the seemingly mundane subject of how to spend grant money in a way that complied with stipulations set by a funder, the discussion was actually much more fundamental. It was a discussion about how grassroots associations of PWDs participate in their communities. *Solidaridad* represents an expansive role for civil society, where organizations do everything from responding to floods to educating the broad populace by mobilizing volunteers, pooling their resources, and implementing projects that often both address their members' individual needs and advance the broader social and economic goals of the state. Human-rights advocacy, however, represents a very narrow role for civil society as essentially legal advocates focused on

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holding the state accountable for implementing certain rights and protections. Both are forms of civic participation that bring citizens together to identify and address problems and otherwise help shape their community's future (Adler and Goggin 2005: 236; Lichterman 2011: 227), but they do it on the basis of very different notions of how societies work and the role individuals and groups should play within them if they want to improve their lives and the lives of others.

The passage of the UNCRPD and the international disability movement of global DPO networks and international rights-based NGOs, such as Handicap International and DRF, support rights advocacy as the *sine qua non* of civic participation. DPOs engaging in human-rights monitoring, whether by issuing reports of rights violations or hosting *intercambios*, is broadly believed by all of the main players in the international disability movement to be the key toward ensuring PWDs become fully included and valued within their communities. This emphasis on DPOs doing advocacy has not only become an article of faith within the international disability movement, but has also been inscribed into international human-rights law. As will be discussed below, the UNCPRD ascribes DPOs a specific role within society and in relation to the state. In Segovia, however, fate and faith often motivate organizations to go beyond simply advocating for change, but being implementers of change through *solidaridad*. *Solidaridad* groups not only present their members as contributors who are helping to build a better community, but enmesh them in relationships that may be vital for getting through a time of need, especially when the state is unable to fully respond. To hundreds of disabled persons in Nicaragua who are members of DPOs like those in Segovia, the risks and rewards of embracing one style of civic participation over the other could not be higher. The form of civic participation these associations embrace helps determine who their members are in the community and how they take part in the local and global worlds surrounding them. The fundamental question this book explores is: "How do PWDs and grassroots DPO understand themselves as members of civil society in the era of disability human rights?"

I will argue throughout this book that this question exposes a paradox in the UNCRPD, which I believe is a harbinger for international human-rights law to come. The purpose of the UNCRPD was to empower people with disabilities within their communities, yet, through this new international law, disabled people at the local level potentially lose control over the form, function, and content of their civic participation. While the convention defines a broad array of rights for disabled persons, it also lays out a very specific normative blueprint (or institutional model) of how their organizations should behave. In this way, human rights not only reach down to, but potentially uproot, the grassroots associations of PWDs that the CPRD is meant to protect. Understanding how local groups respond and do (or do not) manage the changes of norms of civic participation and organizational models for DPOs is essential for understanding international human-rights instruments and human-rights movements in the past, present, and future.

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THE ENDS, MEANS, AND ORGANIZATION OF PARTICIPATION

The Preamble of the UN Disability Convention includes the term "participation" four times, and the remainder of the convention uses it an additional twenty-five. The most important use of the term participation in the convention is in its definition of disability itself. The UNCRPD defines disability as "resulting from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective *participation* in society on an equal basis with others" (my emphasis, Preamble e). This is the social model of disability, which conceptualizes disability as the product of societal discrimination and marginalization directed against individuals who have physical, mental, intellectual, or sensory differences. As Vic Finkelstein, father of the social model and founding member of the Union of the Physically Impaired Against Segregation, formed in the United Kingdom in 1972, put it: "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" (my emphasis; UPIAS 1975: 3–4).

The slogan of the international disability movement is "Nothing About Us, Without Us." Its meaning is explicitly about civic participation in the public-policy process. Union of the Physically Impaired Against Segregation (UPIAS) and its counterpart organizations in the American disability movement used the social model to mobilize PWDs in an effort to identify and replace laws and policies that marginalized them from the larger society. A social-model analysis of the discriminatory laws that were on the books highlighted the fact that not only have PWDs been excluded *by* law, but they have also been excluded *from* the lawmaking process. Heretofore, laws and policies regarding PWDs had been advocated for, written, and sponsored by nondisabled people, namely charities seeking to "care" for PWDs or associations of medical specialists advising how to "cure" or "fix" them. As a result, disabled persons had been the object of these charitable and professional organizations providing advice on their behalf, but they had never been members of these organizations nor otherwise enabled to advocate for the very laws and policies that directly affected them. In order to foster change, disability advocates saw the need for their own organizations – organizations of, for, and by PWDs – to gain a seat at the table and establish a more inclusive political, social, and legal order. Thus, legal advocacy through DPO became another dimension of participation and the preeminent understanding of civic participation. Not only was a participatory (i.e. accessible and inclusive) society the end the disability movement sought, but organized political participation through DPOs became the means of choice for achieving it.

Judy Heumann, a contemporary of Finkelstein and today recognized as a co-founder of the American disability movement, established Disabled in Action

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in New York in 1970 as one of the first membership-based DPOs in the United States. Disabled in Action was founded for the purpose of mobilizing PWDs to participate in advocacy. The mission of Disabled in Action (DIA) is: "To raise consciousness among people with or without disabilities concerning ableism, paternalism and derogatory attitudes, as well as laws and customs that oppress disabled individuals in American society; To enact and enforce effective legislation and budget initiatives promoting our ability to live independently by mandating equal access. . .To provide the organizational basis for disabled activists to join in effective unified political action" (Disabled in Action 2014).

DIA's mission statement is exemplary for what Western DPOs have sought to do from 1970 forward. The mission of DIA also demonstrates the multidimensionality of participation from a social-model perspective. PWDs need to develop a political consciousness that will drive them to come together collectively to advocate for a more participatory society. The mission statement is also self-reflective, not only in terms of what individuals with disabilities need to be (i.e. politically conscious) to create change, but also on their need for organizations to effect that change. The last line of DIA's mission statement explicitly states that DIA's purpose is "to provide the *organizational basis* for disabled activists to join in effective unified *political action*" (my emphasis). In short, civic participation for PWDs is only possible through advocacy organizations.

On the other side of the Atlantic, the founding documents of the UPIAS also specified the importance of PWDs participating in advocacy organizations as the primary means for ensuring the state provide "arrangements for us [disabled persons] to participate fully in society." UPIAS' charter states that the Union "aims to ensure that all the *organizations* concerned with disability become fully democratic and responsive to the real needs and wishes of disabled people. We [disabled persons] therefore seek a much greater say in all the *organizations* which affect our lives, both by Union members as individuals and by other disabled people" (my emphasis; UPIAS 1975). What this effectively means is that any organization advising the state on disability law or policy needs to represent the voice of PWDs rather than of the doctors or donors who might have first established those organizations. It is through this lens of the Western disability movement's emphasis on organizations that, in addition to the UNCRPD's definition of disability according to the social model, the term "participation" is used in the convention to mean civic participation as political advocacy through DPOs.

A direct line can be drawn between the Western disability movement's emphasis on DPOs being platforms for political advocacy through to specific articles in the UNCRPD today. The convention reflects the Western movement's emphasis on PWDs participating in defining their rights and holding governments accountable by mandating that DPOs be included in the implementation and monitoring of UNCRPD itself through a number of "groundbreaking provisions" (Sabatello and Schulze 2014: 24). First, the UNCRPD states that States Parties are required, "in the development and implementation of legislation and policies to implement the present convention, and in other decision-making processes concerning issues relating to PWDs, States Parties shall closely consult and actively involve persons with disabilities. . .through their representative organizations" (General Obligations, Article 4). Second, it reiterates the basic human right to freedom of association as PWDs having a right of "forming and joining organizations of PWDs to represent PWDs at international, national, regional and local levels" (Article 29). Finally, and most importantly, Article 33 of UNCRPD goes even further, causing the convention to stand out in comparison to all prior international human rights instruments in terms of the participation of organizations. This article on "National Implementation and Monitoring" specifies that: "Civil society, in particular PWDs and their *representative organizations*, shall be involved and *participate* fully in the monitoring process" of the UNCRPD (my emphasis). Through these provisions in the convention, the norm of PWDs joining their own organizations (i.e. DPOs) for the purposes of advocacy (i.e. advising, representing, monitoring) has been defined within the framework of international law itself.

Maya Sabatello, international disability-rights lawyer and permanent civil-society representative to the UN on disability rights, has made clear how unique and important these provisions are:

> Although *participation* of NGOs and *civil society organizations* in human rights debates and enforcement has been on the rise, particularly in the past couple of decades, there is no doubt that the disability rights movement has taken it to a new level. For the first time in an international human rights treaty, the expertise of those to be protected under the Convention, including their *representative organizations*, is fully recognized. Importantly, the Convention established an explicit positive legal obligation on states to seek their input in all levels of development, monitoring, and implementation of disability rights.
>
> (my emphasis; 2014: 23)

In this way, the UNCRPD continues the tradition of the Western disability movement establishing DPOs for the purposes of legal advocacy. The UNCRPD, in fact, is the culmination of organizing work by the very people who established the first DPOs in the West. For example, the connection between groups like DIA, established in 1970, and the UNCRPD, passed in 2006, could not be more direct. Judy Heumann, DIA's founder, went on from her work in New York to found DPOs in Berkeley, California, which became instrumental in advocating for and advising on the language of the civil-rights provisions in the 1973 Rehabilitation Act and, more importantly, the 1999 Americans with Disabilities Act. Following that work, Heumann became the World Bank's first Adviser on Disability and Development in 2002, a position she used to organize the Global Partnership for Disability and Development (GPDD), drawing together networks of DPOs and progressive, rights-based, international NGOs from around the world. GPDD then became the primary advocate for and principle adviser on the UNCRPD, which was adopted four years later and, as I argue, institutionalized political advocacy as the singular understanding of civic participation for DPOs. As a result, the Western organizational model of DPOs as advocacy organizations was not only globalized, but written into international law.

GRASSROOTS DPOS AS THEIR OWN BARRIERS TO THEIR RIGHTS IN THE GLOBAL SOUTH

Given the West's successful history of establishing DPOs for legislative advocacy and government accountability, international disability advocates today see Articles 4, 29, and 33 as the keystone holding the UNCRPD together and local DPOs, like those in Segovia, as the linchpin for making it work on the ground. Michael Ashley Stein, Rehabilitation International's delegate to the convention drafting process, points out that "the *participation* of persons with disabilities and *DPOs* in Convention related monitoring and implementation at all levels is both implicitly and explicitly woven throughout the entire fabric of the text" (my emphasis: Stein and Lord 2010: 697). In a later article, Stein goes on to explain that, as a result of the way the UNCRPD was written, it was now imperative that grassroots DPOs around the world fulfill their advocacy role because "coordinated actions among disabled peoples' organizations are prerequisites for transforming the UNCRPD's promises into reality" (Stein and Lord 2010: 27).

There is, however, a major barrier to this prerequisite: many of the grassroots disability associations around the world are not anything like the political-advocacy DPOs that Stein would have had in mind. While PWDs have organized themselves into grassroots groups in hundreds of local communities around the world, many of these DPOs have historically been self-help and social-support organizations focused on rehabilitation, employment, and education rather than human rights. They are groups where people with disabilities help one another meet their immediate needs, such as fix a wheelchair or put a roof over their heads, or promote their individual development, such as learn a skill or benefit from a microloan. These types of activities are very different from "consciousness raising" and mobilizing people for political campaigns.

Research conducted prior to the writing and passage of the UNCRPD has observed this difference. For example, Ingstad and Whyte point out that while DPOs in the North were concerned with rights, "in Southern countries, the groups [local DPOs] themselves often feel that the most immediate needs are for practical programs of rehabilitation" (1995: 24). Turmasani similarly describes DPOs in developing countries as too focused on "meeting their [members'] survival needs" (2003: 3) to bother with legal advocacy. These authors attribute these differences to the differing levels of economic development and relative impoverishment of PWDs