

CIVILIZING DISABILITY SOCIETY

The United Nations Convention on the Rights of Persons with Disabilities (CRPD) is increasingly used to civilize grassroots disabled persons' organizations (DPOs) around the world. The international disability rights movement actively promotes the CRPD's key norm that disabled persons mobilize in support of their rights under the Convention. The unintended consequence of these activities, however, is that local groups focused on social support and service provision, rather than disability-rights advocacy, are targeted for change. While the resources provided by international actors to grassroots organizations provide new opportunities, they also create barriers to local groups' ability to promote full civic participation of their members in the local community. Through a detailed account of grassroots DPOs in Nicaragua, *Civilizing Disability Society* demonstrates how local organizations navigate pressures from abroad as they attempt to concretely address the health, education and economic needs of their members at home.

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Edited by Peter Blanck and Robin Paul Malloy

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Civilizing Disability Society

THE CONVENTION ON THE RIGHTS OF PERSONS
WITH DISABILITIES SOCIALIZING
GRASSROOTS DISABLED PERSONS' ORGANIZATIONS
IN NICARAGUA

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Acknowledgments

This book represents both an individual effort and a community product. I, as the author, am individually responsible for all its flaws. For its positive aspects, however, many others deserve far more credit than me. There is not a single page of this manuscript that does not reflect the lived experiences of persons with disabilities in Nicaragua. I only hope that I was able to represent accurately the stories, insights and needs of persons with disabilities in the same manner in which they so honestly shared them with me. I am also indebted to my colleagues at the University of California, San Diego and University of Washington in Seattle. Their thoughts and encouragement played a large part in both the inception and the completion of this book.

The story behind the research for this book began more than seventeen years ago. I first visited Nicaragua as a young project coordinator for a small international non-governmental organization specializing in prosthetic rehabilitation. During that time, I learned that the lives of persons with disabilities were far more complex than any international organization or donor was willing to admit. My organization's activities were largely driven by international priorities. First, we focused on providing landmine-survivor assistance under the 1997 Convention on the Prohibition of the Use, Stockpiling, Production and Transfer of Anti-Personnel Mines and Their Destruction (aka Ottawa Landmine Treaty), and later we started to promote rights under the 2006 Convention on the Rights of Persons with Disabilities. In both cases, our activities were developed in response to international funders, global best-practice norms and the latest development "fad" (i.e. microcredit) rather than to the persons with disabilities who we publicly held up as the center of our "community based" and "participatory" mission. Luckily, however, I was able to use that job to begin to meet, talk to and spend time with persons with disabilities "on the ground" in Nicaragua. These local interlocutors generously shared their time with me and were often willing to tell me things that I did not want to hear: that their new artificial limb was useless without a job, that they would rather work in a factory than

be given a microloan to start a small business, that their deepest need was for companionship and community, that they could not care less about international laws and treaties, and a myriad other things that departed from those that I and others claimed was what they needed and wanted.

I no longer work for an international non-governmental organization, but I see the story around the world as continuing to be much the same. Today, a full decade after the Disability Convention, international organizations are increasingly pulling local DPOs into their work. But, as much as this may sound like a good thing, it is putting these grassroots groups into the same position in which I found myself so many years ago: leaders of local DPOs are often pressured to respond more to international funders, best-practice norms and new fads than to the persons with disabilities whom they were chosen to lead. In “Segovia”, the pseudonym for my field site in Nicaragua, however, I was invited into the lives of these DPOs, where both their leaders and regular members shared with me their private gripes, life stories and time by inviting me to participate in their meetings, come into their homes and be a part of the larger community. I appreciate this openness and hospitality, not only because it made my field work possible, but because it put these DPOs at great risk. As a white, educated, non-disabled and internationally connected North American, I was extremely grateful that the persons with disabilities I spoke to were willing to critique international ideas and practices that emanated from people very similar to myself. They had every right to be suspicious of me, a so-called international expert getting a fancy degree coming from the Global North. I am grateful and undeserving of their incredible honesty with me.

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