

Book review

International Journal of
Comparative Sociology
1–4

© The Author(s) 2022

Article reuse guidelines:

sagepub.com/journals-permissions

DOI: 10.1177/00207152211069586

journals.sagepub.com/home/cos



Claire Spivakovsky, Linda Steele, Penelope Weller (eds), *The Legacies of Institutionalisation: Disability, Law and Policy in the “Deinstitutionalised” Community*. Hart Publishing, Oñati International Series in Law and Society: Oxford, 2020; 272 pp. ISBN 9781509930746, £58.50 hardback.

Reviewed by: Peter Blanck, *Burton Blatt Institute* (<http://bbi.syr.edu>), *Syracuse University, USA*

At the heart of disability antidiscrimination civil laws such as the Americans with Disabilities Act (“ADA”), the disability human rights paradigm embedded in the United Nations Convention on the Rights of Persons with Disabilities (“CRPD”), and, increasingly, various countries’ domestic laws, lies the requirement that social institutions affirmatively remove attitudinal and structural barriers confronting people with disabilities so they can fully exercise their rights to participate and live inclusively in society. But even before the ADA and the CRPD mandates, in the 1970s, the movement for the right of people with disabilities to live and participate fully in their communities had already taken hold as part of the “deinstitutionalization” of large congregate care facilities such as state hospitals and nursing homes (Blanck, 2020, 2021a).

Legacies of Institutionalisation: Disability, Law and Policy in the “Deinstitutionalised” Community, edited by Claire Spivakovsky, Linda Steele, and Penelope Weller, presents an important and well-timed collection of writings examining the legal, policy, and practice-related dynamics of deinstitutionalization. With an array of contributors from multiple perspectives and countries, the volume examines whether contemporary laws, policies, and practices reflect a *meaningful* advancement of full and equal inclusion, and participation in community, for people with disabilities.

As an American reviewing this volume, it is exceedingly beneficial to view the deinstitutionalization project through a periscope other than the oft-used, sometimes parochial US one. This is particularly true now because, as of yet, the United States has not ratified the CRPD, although I hope it may still do so. I commend the editors for compiling such an enlightening and useful compendium.

Before I proceed, I should acknowledge the most fundamental aspect of the American-centric perspective when looking at deinstitutionalization. Our ADA applies to US state and local governments, as set out in Title II of the Act. The Act requires the inclusion of people with disabilities into their communities in accord with the *Olmstead* “integration mandate” derived from the foundational US Supreme Court ADA Title II case of the same name (*Olmstead v. L.C. ex rel. Zimring*, 1999). *Olmstead’s* recognition of unjustified institutional isolation of persons with disabilities as a form of discrimination was, and remains, significant. The high court reasoned that institutional placement of persons against their preference, even when they can handle and benefit from community settings, perpetuates unwarranted assumptions that persons so isolated are incapable or

unworthy of participating in community life. Furthermore, confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment (Blanck, 2021a).

Looking beyond the United States, Article 19 of the CRPD subsequently mandated (in 2006) that States Parties to the Convention recognize

the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community. (CRPD, Article 19)

Other articles of the CRPD, such as Article 12, presume that all people have legal capacity and that governments must take appropriate action to provide people with access to the supports they need and want to make their own life decisions (CRPD, Article 12; Shogren et al., 2019). CRPD Article 28 likewise recognizes “the right of persons with disabilities to an adequate standard of living for themselves and their families, including adequate food, clothing and housing, and to the continuous improvement of living conditions” (CRPD, Article 28).

Legacies of Institutionalisation, arriving about a half-century into the various societal and legal developments concerning deinstitutionalization, organizes its examination into three parts (seventeen chapters in all): “Power Dynamics that Shape the Conditions and Possibilities of People with Disabilities Within and Beyond Sites of Physical Confinement”; “Complicated Alliances: The Confluence of Ableist, Sanist, Gendered, Classed and Racialised Logics in Law, Policy and Practice”; and “Institutionalisation and Human Rights: The Role of the CRPD in the Emancipation of People with Disabilities.”

Part one examines “the complex legacies of institutionalisation in practice” (Intro., at 11), looking within and beyond concepts of physical segregation to examine the societal power dynamics and relations that have fashioned, and continue to shape, the sorting of individuals based on difference in personhood. This part paints a broad picture of the injustices resulting from segregation on the basis of disability (in both institutionalized and “community” settings), using autoethnographic accounts (Bronson, Ch. 1) and multiple forms of interdisciplinary analysis of mental health, citizenship, employment, education, and carceral laws and policies.

The chapters in part one illustrate the ways in which a medicalized model of disability—focused historically, and still today, on individual deficits, with disability conceived as an infirmity that precludes and disempowers equal participation in society—was rejected by the human rights model in the CRPD. The CRPD (as does the ADA) recognizes disability as a concept that continuously evolves as persons with impairments confront the attitudinal and environmental barriers that hinder full and effective participation and integration in society on an equal basis with others. This is the central insight and mantra of the global disability rights movement—disability is an interaction between a person with an impairment and the physical world and society in which the person lives.

Part two, the heart of the volume, brings to the fore the results of societal oppression on the basis of individual difference, from an intersectional perspective (e.g. in consideration of disability and gender; Kaprin & O’Connell, Ch. 9), as facilitated by social institutions and legitimized in law, and as echoing historical roots. The chapters in part two also examine “resistance, protest, and dissent” (Part two intro., p. 103) to such structural and attitudinal discrimination (Beaupert & Bielfeld, Ch. 11). Ameil Joseph (Ch. 7) connects the current pastiche of anti-immigrant, nativist, and nationalist discourse, expressed in the United Kingdom via Brexit and in the United States via Trump’s call for wall building, to its historical roots in concepts of “disability,” ableism, and eugenics. The “biopolitics” (discussed by Douse, Ch. 10) associated with disability,

as shown in the settler-colonial “population management” regime toward Australia’s indigenous population (Soldatic, Ch. 8) and by the “mixed successes” of that country’s deinstitutionalization movement (Karpin & O’Connell, Ch. 9), illuminate the lasting social and individual wounds of segregation and exclusion from community.

The chapters rounding out the volume in part three “consider[] the role of the CRPC in the emancipation of people with disabilities from the legacies of institutionalisation” (Intro., at 13). These chapters address the work and efficacy of the CRPD as a human rights instrument. Despite advances, the chapters in part three present divergent views about the implementation of the CRPD, as interpreted by the UN Committee on the CRPD (the treaty’s interpretive body) and the States Parties (Bartlett, Ch. 12, for instance, discusses the Committee’s Article 12 General Comment). In Chapter 13, Lucy Series examines *Olmstead*-like litigation as to the nature of “deprivation of liberty” in the UK Supreme Court’s decisions *P v. Cheshire West and Chester Council and Another*, and *P and Q v. Surrey County Council*, UKSC 19 (2014).

Today, in the United States through the *Olmstead*, and across the globe through the CRPD, integration mandates are changing lives for the better, particularly when appropriate community and decision-making supports are made available to individuals with disabilities (Blanck, 2019). Nonetheless, the same problems of unjustified segregation can and do exist today in community settings, even outside of an institution. In the United States, courts find that isolation in the home for a person who might otherwise benefit from experiences in the community may violate the ADA’s integration mandate. Under *Olmstead*’s integration mandate, isolation in one’s community home can be as, or more, harmful than confinement to an institution. *Olmstead*, as one US court found, “bars unjustified segregation of persons with disabilities, wherever it takes place” (*Steimel v. Wernert*, 2016: 911).

Across the globe, a new generation of people with disabilities, building on the efforts of many others, is coming forward. Many in this generation never have known an America without its ADA and they will not know a world without the CRPD (Blanck, 2019). Nonetheless, taken as a whole, the editors and contributors to *The Legacies of Institutionalisation* recognize that there currently remain many questions as to the full and equal participation in society of persons with disabilities.

The Legacies of Institutionalisation derives from a workshop held in 2018, and so the contributors could not appreciate the profound and immediate changes in community life that were about to arise from the COVID-19 pandemic and the resulting global health and economic emergency. Certainly, as the editors acknowledge, the “post-institutionalisation” era (Spivakovsky, Steele, & Weler, intro.) has become even more uniquely complicated. We have to wonder, “What will be the new norm latitudes of the ADA’s and CRPD’s civil and human rights protections?” (Blanck, 2021a, 2021b).

The pandemic is profoundly affecting the lives of persons living with disabilities across the life course, wherever they are living, whether they have multiple, intersectional minority identities associated with race, ethnicity, sexual orientation or gender identity; are addressing the limits of age; or are facing the many and varied challenges of disability otherwise or in conjunction with these other life experiences (Blanck, 2021b).

Even with all the changes from the pandemic, the contributors were remarkably prescient as to how the “failures of deinstitutionalisation,” and the new calls for individual “control, confinement, and segregation,” might play out in dire ways in the post-pandemic world (Spivakovsky, Steele, & Weler, intro.). Widespread poverty and economic insecurity, homelessness, isolation and loneliness, shortages in affordable housing, and dire medical needs as byproducts of the pandemic, if not addressed, may portend a “homecoming” to the asylum for people with disabilities and other marginalized groups in society.

As guiding beacons, the ADA's integration mandate and the CRPD's command in Article 19 to bring an end to institutionalization offer hope of a future in which all people, regardless of individual difference and circumstance, will be welcomed as full and equal members of society. The 20 diverse contributors—from Australia, the United Kingdom, Canada, Spain, and Indonesia—speak to the “possibilities, limits, and contradictions” in the deinstitutionalised society (Spivakovsky, Steele, & Weler, intro.). But the promise of a truly integrated community will be severely tested in law, policy, and practice as society emerges from the shadows of the pandemic.

References

- Blanck P (2019) Why America is better off because of the Americans with Disabilities Act and the Individuals with Disabilities Education Act. *Touro Law Review* 35: 605–618.
- Blanck P (2020) *Disability Law Policy*. Minneapolis, MN: Foundation Press.
- Blanck P (2021a) Americans with Disabilities Act at thirty: Disability law, policy, and practice in 2020. *Journal of Disability Policy Studies*.
- Blanck P (2021b) Thirty years of the Americans with Disabilities Act: Law students and lawyers as plaintiffs and advocates. *New York University Review of Law & Social Change* 45: 8–24.
- Olmstead v. L.C. ex rel. Zimring, 527 U.S. 581 (1999).
- P v. Cheshire West and Chester Council and Another; P and Q v. Surrey County Council, UKSC 19 (2014).
- Shogren K, Wehmeyer M, Martinis J, et al. (2019) *Supported Decision-Making: Theory, Research, and Practice to Enhance Self-Determination and Quality of Life*. New York: Cambridge University Press.
- Steimel v. Wernert, 823 F.3d 902 (2016).
- United Nations Convention on the Rights of Persons with Disabilities (CRPD), Articles 19, 12, 28, et seq. Available at: <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/convention-on-the-rights-of-persons-with-disabilities-2.html>