

DISABILITY AND COMMUNITY LIVING POLICIES

This book provides a comprehensive analysis of the roots of institutionalization, deinstitutionalization legislation and policies of the twentieth century, and twenty-first-century efforts to promote community living policies domestically and internationally, particularly through the role of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), a landmark treaty adopted on December 13, 2006. Rimmerman shows that deinstitutionalization and community living cannot be examined only in terms of the number of institutions closed, but through substantial change in values, legislation and policies supporting personalization, and social participation of people with disabilities. The book includes a significant exploration of US legislation and important Supreme Court decisions compared with European policies toward community living. Finally, it discusses the importance of Articles 12 and 19 of the convention and demonstrates the case of Israel, which has used the convention as a road map for proposing a new policy on community living.

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For my grandchildren, Yarden and Barak

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Preface

Institutionalization of people with intellectual and psychiatric disabilities is one of the most extreme forms of exclusion; deinstitutionalization is considered to be the first taste of emancipation that came amidst massive civil rights movements in the United States and across the Atlantic. *Disability and Community Living Policies* is based on my earlier book *Social inclusion of people with disabilities: National and international perspectives*.¹ In the book, I offered a broad conceptual analysis of social inclusion and provided a comprehensive review of social and legal strategies to promote social inclusion and participation at the national and international levels.

The new book reflects my analysis of the roots of institutionalization, the deinstitutionalization legislation and policies of the twentieth century in the United States and Europe, and the twenty-first-century efforts to promote community living policies domestically and internationally, particularly through the impact of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), a landmark treaty adopted on December 13, 2006, at the United Nations in New York.² The convention establishes international standards regarding the rights and freedoms of people with disabilities and a common basis for greater civic and political participation and self-sufficiency. It reflects core values and principles, such as dignity of the individual, access to justice, the importance of family decision-making, and access to education, independent living, and employment.

One of my early impressions of life in mental institutions was from reading Erving Goffman's book *Asylums*.³ In it, he described the asylums as "total institutions" and as creating "... [a] basic split between a large managed group, conveniently called inmates, and a small supervisory staff. Inmates typically live in the institution and have restricted contact with the world outside the walls. The staff often operates on

¹ Arie Rimmerman, *Social inclusion of people with disabilities: National and international perspectives* (New York: Cambridge University Press, 2013).

² The UNCRPD can be retrieved from www.un.org/disabilities/convention/conventionfull.shtml.

³ See Erving Goffman, *Asylums: Essays on the social situation of mental patients and other inmates* (New York: Anchor Books-Doubleday, 1961), p. 18.

an eight-hour day and is socially integrated into the outside world. Each grouping tends to conceive of the other in terms of narrow hostile stereotypes.”

Another powerful book, published at the same time, was *Christmas in purgatory: A photographic essay on mental retardation*, by Prof. Burton Blatt and Fred Kaplan in August 1966. I still remember the first shocking sentence that opens the introduction: “There is a hell on earth, and in America there is a special inferno,” which reflects the shocking evidence of abuse and neglect in large state institution.⁴

One of the first academics to predict the closure of institutions was Wolf Wolfensberger, a world-renowned advocate and expert on the care of people with intellectual disabilities.⁵ He impressed me with his prediction of five positive trends: development of nonresidential community services; new conceptualizations of and attitudes toward residential services; increased usage of individual rather than group residential placements; provision of small, specialized group residences; and a decline in the incidence and prevalence of severe and profound retardation due to reduction in the birthrate of high-risk groups, improvement of health services for the population generally and for high-risk groups specifically, increased practice of abortion, general environmental betterment, and early childhood education.

My first involvement with deinstitutionalization was through my participation in the “Brick Government Committee” of 1987, which examined the feasibility of transitioning 100 individuals with intellectual disabilities from institutions to community-based programs.⁶ The committee raised concerns about the lack of infrastructure and readiness in the community and recommended gradual transition over time.

In 2007, I was asked by Bizchut, The Israel Human Rights Center for People with Disabilities, to submit my professional testimony to Israel’s Supreme Court regarding the right of persons with disabilities to live in the community. The testimony provided a scientific international base for the right of all people with disabilities, regardless of their functional level, to live in the community.⁷ However, the catalyst for writing the book was my recent involvement in assisting in the formation of the new Israeli community living policy. In 2011, I was asked by the former minister of

⁴ Burton Blatt and Fred Kaplan, *Christmas in purgatory: A photographic essay on mental retardation* (Boston: Allyn and Bacon, 1966), p. v. The first part of the book depicted horribly overcrowded wards, naked and half-clothed residents, and barren rooms. The second part of the book showed the relatively positive scenes from Seaside. The book’s back cover included testimonials as to its importance from Senator Edward Kennedy, Governor George Romney of Michigan, and Governor Karl Rolvaag of Minnesota.

⁵ Wolf Wolfensberger, “Will there always be an institution? Part 1: The impact of epidemiological trends,” *Mental Retardation* 15 (1971), 14–20.

⁶ Ministry of Welfare and Labor, *Report on the feasibility of transitioning people with Intellectual Disabilities from institutions to community-based programs (“the Brick Committee”)* (Jerusalem: Ministry of Welfare and Labor, 1987).

⁷ Arie Rimmerman, *The right of persons with disabilities to live in the community: National and international evidence* (Testimony to Supreme Court case 3304/2007).

Labor and Social Affairs Isaac Herzog to convene an international committee of experts in order to obtain evidence-based data and various opinions concerning Israel's services as compared to other Western countries.⁸ The committee's report, discussed extensively in Chapter 7, is in my opinion one of the early efforts to implement Article 19 of the UNCRPD. It recommended that Israel should ultimately and gradually close all the institutions for persons with intellectual disability and focus on creating community-based services and housing for this population. The report was adopted by the Israeli government and became the new community living policy. In fact, Israel has begun transitioning 900 people with intellectual disabilities from institutions to community-based programs over a period of three years.

A significant conceptual contribution to the book was a seminar organized by Prof. Gerard Quinn at Haifa on May 4, 2015: *Just being me: My right to be in the world (community living) and my right to make my own decisions in the world (legal capacity)* addressed the important link between Article 12 (legal capacity) and Article 19 (community living). The seminar assisted in the writing of my closing remarks and particularly in addressing the importance of person-centered planning and personal budget and core instruments in community-living policies.

The book's underlying message is that deinstitutionalization and community living cannot be examined only in terms of number of institutions or hospitals that have been closed or number of people who live in supported housing. The challenge is substantial change in values, legislation, and policies supporting personal choices and social participation. One of the most important challenges of the book is in clarifying concurrent theological, traditional, and utilitarian values, such as new eugenics ideas that raise doubts as to whether persons with severe disabilities are persons. The belief is that such values encourage the worst practices, such as infanticide, sterilization, denial of human rights, and segregation.

A significant contribution of the book is in comparing US nondiscrimination legislation with European social welfare policies toward deinstitutionalization and community living. It demonstrates that although the two have different paths to community living, both recognize the importance of personal services and budget. Finally, the book provides the reader with information regarding the importance of implementing Articles 12 and 19 of the UNCRPD in promoting community-living policies and the challenges and resistance of implementing them in the United States and Europe. It recognizes the prevailing rationale that the Americans with Disabilities Act (ADA) of 1990 and the US Supreme Court's *Olmstead* decision are sufficient in guaranteeing nondiscrimination in existing US law. It provides insight

⁸ The panel which was held in June 2011 consisted of Prof. Arie Rimmerman, University of Haifa, Israel; Prof. Gerard Quinn, University of Ireland (Galway School of Law); Dr. Joel Levy, former CEO of YAI Network, New York; Prof. Peter Blanck, Syracuse University, New York; and Prof. Meindert Haveman, TU Dortmund University, Germany. The committee's coordinator was Dr. Michal Soffer, University of Haifa.

into the skepticism in Europe regarding the failure of the Structural Funds strategy in changing community-living policies in Central and Eastern Europe. Finally, it recognizes that real challenge is the implementation of personal assistance schemes (Article 19(b)) requiring states to ensure that people with disabilities have access to community support services.

Acknowledgments

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I would like to thank my colleagues with whom I informally discussed some of the ideas examined in the book. Finally, I am grateful to my family for facilitating this important project; they have been a tremendous support for me.