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Introduction

The twenty-first century finds a significant decline in the number of people with disabilities living in institutional care on both sides of the Atlantic. The US Supreme Court's *Olmstead* decision of 1999 is considered a milestone in establishing non-discrimination policy on community living of people with intellectual disability/developmental disability (ID/DD).¹ European deinstitutionalization community living policies are more scattered because of core differences in the social welfare approaches of social democratic, liberal, and conservative countries, and particularly between them and the former Communist states of Central and Eastern Europe. The book provides eight chapters of updated comparative analyses of community living between the United States and Europe with respect to changes in values and ideologies, policies, and legislation, and particularly to their response to the UNCRPD.

This Introduction presents the structure and scope of the book, assuming that the nature of change toward people with disabilities is rooted in our personal and societal values. This is the assumption of Chapter 2: that it is impossible to comprehend the legal and civic rights of people with disabilities, whether they have legal capacity or are considered part of society, without studying the way that Judeo-Christian theologies treat people with physical and mental impairments.² Interestingly, current Judeo-Christian scholars have looked for modern interpretations to bridge the dissonance between the biblical texts and progressive ideas of equality and inclusion of people with disabilities. One of the most important milestones of ancient times was the Roman law of guardianship which has had a remarkable impact on Western civilization and Western legal thought. Although

¹ Mary Beth Musumeci and Henry Claypool, *Olmstead's role in community integration for people with disabilities under Medicaid: 15 years after the Supreme Court's Olmstead decision* (The Kaiser Commission on Medicaid and the Uninsured, June 2014).

² See Carmelo Masala and Donatella Rita Petretto, "From disablement to enablement: Conceptual models of disability in the twentieth century," *Disability and Rehabilitation* 30 (2008), 1233–44. The article provides a general view of the conceptual elaborations on disablement in the twentieth century and discusses the role of these different contributions in developing the current concepts of disablement.

it is paternalistic in nature, it recognizes the need of certain people who are unable to take care of themselves to be protected by the law. The principles of the guardianship law exist in current Anglo-American legislation, such as a guardian's responsibilities, a commitment to keep inventory of the property, and liability when inappropriate decisions are made.

Chapter 3 discusses and provides updated analysis of the UNCRPD, and in particular Article 12 (legal capacity) and Article 19 (living in the community). Article 12 expresses the fundamental right of persons with disabilities to exercise their legal capacity on an equal basis with others. Article 19(a) of the UNCRPD, as well as Article 3(a), addressing individual autonomy,³ is closely linked to the right to legal capacity, primarily because the person's needs to be recognized before the law is crucial for making decisions about place of residence and where and with whom he or she will live. Each person has the right to legal capacity on an equal basis with others.⁴ There is no doubt that the state has an important duty in ensuring that persons with disabilities exercise their right to legal capacity by providing support when needed.⁵ It demonstrates the link between with Article 19 regarding the person's choice of where and with whom he or she prefers to live. The chapter suggests that Articles 12 and 19 of the UNCRPD go hand in hand, and progress in one area positively affects the other area. Challenging institutionalization is thus interwoven with challenging the legitimacy of guardianship and developing alternative models for supported decisions.

Chapter 4 provides a comprehensive evidence-based view of the US institutionalization era, the emergence of deinstitutionalization in the second half of the twentieth century, and discusses in depth the impact of the latter on life of people with psychiatric and intellectual disabilities. The focus of the chapter is naturally the ADA (Title II) and the Supreme Court's *Olmstead* decision, including the litigations related to this landmark determination. It presents the debate that is still ongoing in the twenty-first century, that is, whether its nondiscrimination strategy has brought about the desired outcome. Finally, the chapter introduces the distinctive difference between the *Olmstead* Supreme Court decision and the UNCRPD,⁶ regarding deinstitutionalization and community living policy. The conclusion is that while the *Olmstead* nondiscrimination decision allows states the freedom to determine the pace and cost of deinstitutionalization, the UNCRPD refers to the absolute right of persons with disabilities to choose where and with whom they prefer to live in the community. In this regard, the convention's human rights champions the needs and desires of the individual over financial or political concerns.

Chapter 5 presents institutionalization in Europe until World War II. It analyzes the differences and variations among countries, including the eugenics influence

³ Article 3(a) is as follows: "Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons."

⁴ Article 12(2) of the UNCRPD. ⁵ Article 12(3) of the UNCRPD.

⁶ In particular, Articles 12 and 19 of the UNCRPD.

that has been associated with sterilization and segregation policies to the extreme of the killing of the “unfit” in Germany. The chapter focuses in particular on thorough examination of mental health policies in Italy and the United Kingdom, demonstrating the different commitment of transitioning from segregated hospitals to community living programs. Similar analysis, but with different models of welfare states, is presented with respect to intellectual disabilities. The chapter summarizes core longitudinal studies on deinstitutionalization of people with mental illness and intellectual and developmental disabilities (IDD). Furthermore, it discusses in depth the role of the Council of Europe and the EU in promoting community living policies, with their challenge to narrow the disparities between Western and former Communist states of Central and Eastern Europe regarding institutionalization and the lack of community living programs.

There is a very comprehensive review and analysis of the use of the Structural Funds to promote change in the former Communist states of Central and Eastern Europe, including the concern that the changes may fail. In addition, the chapter examines the impact of the UNCRPD on European community living policy. The European Court of Human Rights (ECHR) was influenced in the 2010s by the UNCRPD in ruling against violations and denial of civil rights in institutions in the former Communist states of Central and Eastern Europe. There are examples demonstrating the linkage between the European Court of Human Rights (ECHR) and the UNCRPD. Similarly, the EU 2010–2020 Strategy reflects commitment to the implementation of the UNCRPD.

Chapter 6 includes a comprehensive comparison between US and European policies and discusses their challenges in promoting community living for all people with disabilities. It demonstrates the different paths to implementing the deinstitutionalization policy in mental health and intellectual disabilities on both sides of the Atlantic. The chapter explores the core differences between the two, which reflect the conceptual and political views of human rights and social policy. US nondiscrimination legislation guides deinstitutionalization and community living. Class litigations (such as *Olmstead*) are essential in interpreting the ADA and in guiding policy implementation. The European path reflects welfare policy first and anti-discrimination legislation and litigations second.⁷ The chapter also clarifies the differences in their political systems and in their core policies toward disability. European disability policy is collective and based on the social model and the responsibility of the social and political systems to correct evils and problems. A regulatory policy such as the Structural Funds is dominant, as litigation in the ECHR's is secondary.

Another difference that is introduced broadly is that the fundamental difference between EU and US community living policies is related to their differing

⁷ Gerard Quinn and Eilíonóir Flynn, “Transatlantic borrowings: The past and future of EU non-discrimination law and policy on the ground of disability,” *The American Journal of Comparative Law* 60 (2012), 23–48.

approaches toward the UNCRPD. The EU ratified the UNCRPD in 2011,⁸ and, in fact, used it as a road map for the European Disability Strategy of 2014–2020. The United States has not ratified the UNCRPD and has instead based its community living policy on the *Olmstead* anti-discrimination interpretation of ADA Title II.

Chapter 7 presents the case of Israel in transitioning from a mixed policy of institutional and community care to community living policy. The case of Israel is interesting because it provides an insightful look at the report written by the panel of International Committee of Experts on Community Living of People with Intellectual Disabilities (ID), based on Articles 12 and 19 of the UNCRPD.⁹ The panel demonstrated how the convention could be used as an effective instrument at the national level, examining the current Israeli system and offering progressive changes toward future community living policy.

The book ends with final thoughts (Chapter 8) about deinstitutionalization and community living policies in the United States and Europe. One of the important conclusions is that deinstitutionalization and community living policies cannot be examined only in terms of number of institutions or hospitals that have been closed or number of people who are living in community settings. The significant change has to be in values, legislation, and policies that contribute to personal choices and social participation.

In terms of values, the chapter suggests that it is difficult to believe in substantial change without recognizing past and prevailing theological and eugenics ideas. While earlier conceptualization, such as the medical model, normalization and the social model, and the nondiscrimination approach dealt with deficits and barriers, the convention is actually the first call for a person-centered approach. The major effort of deinstitutionalization in the twentieth century was the transition of people with intellectual and psychiatric disabilities from institutions to community-based programs, current in Europe and the United States. The shift toward human rights and personhood is reflected in a growing recognition that services have to be personalized in terms of planning and budgeting.¹⁰ This means that funding of

⁸ EU ratifies UN Convention on disability rights, January 5, 2011; available at <http://europa.eu/rapid/pressReleasesAction.do?reference=IP/11/4>.

⁹ The panel report is reviewed in a forthcoming publication by Arie Rimmerman and Michal Soffer, “The making of disability policy in Israel: Ad-hoc advisory experts panels.” In *Policy analysis in Israel*. Edited by Gila Menahem and Amos Zehavi (University of Bristol: Policy Press, 2016) pp. 109–120.

¹⁰ See, for example, Simon J. Duffy, “Person centred planning and system change,” *Learning Disability Practice* 7 (2004), 15–19; Simon J. Duffy and Helen Sanderson, “Person-centred planning and care management,” *Learning Disability Practice* 7 (2004), 12–16; David Felce, “Can person-centered planning fulfill a strategic planning role?” Comments on Mansell & Beadle-Brown, *Journal of Applied Research in Intellectual Disabilities* 17 (2004), 27–30; Jim Mansell and Julie Beadle-Brown, “Person-centered planning or person-centered action? Policy and practices in intellectual disability services,” *Journal of Applied Research in Intellectual Disabilities* 17 (2004), 1–9; Jim Mansell and Julie Beadle-Brown, “Person-centered planning or person-centered action? A response to the commentaries,” *Journal of Applied Research in Intellectual Disabilities* 17 (2004), 31–35. In the response, Mansell and Beadle-Brown argue that extending person-centered planning for all people

services follows the person and not the service provider, and that users are free to choose their preferred degree of personal control over service delivery according to their needs, capabilities, current life circumstances, preferences, and aspirations.

In conclusion, the author believes that the UNCRPD is not only the road map for creating progressive community living but a challenge for Western countries in examining their current legislations, policies, and practices. Europe has to deal with significant gaps in deinstitutionalization policies and lack of community-based services in EEL countries. The United States, which has not ratified the UNCRPD, has to examine the benefits of the UNCRPD to its domestic policy. In terms of legal capacity and people's autonomy, it is evident that the guardianship laws are uneven among states. Therefore, if the United States ratifies the UNCRPD, many states will need to amend their guardianship laws to bring them in line with Article 12.

with disabilities in the United Kingdom is too ambitious. They express concerns that the plans are not feasible and are far from being an effective way of changing the lives of people with intellectual disabilities. There are current budgetary control mechanisms that undermine the individualized, tailored nature of planning and, therefore, the introduction of a new model of planning will not in itself be likely to change the experience of service users.