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Book Review

THE HUMAN RIGHTS OF PERSONS WITH INTELLECTUAL DISABILITIES: DIFFERENT BUT EQUAL

Edited by Stanley S. Herr, Lawrence O. Gostin,
and Harold Hongju Koh
(Oxford University Press, 2003)

REVIEWED BY MICHAEL H. POSNER*

*Different but Equal*¹ evolved out of the *International Symposium on the Rights of People with Mental Retardation: Should Difference Make a Difference?*, which was organized at Yale Law School by Professors Stanley S. Herr and Harold Hongju Koh in 1995. This book is an important contribution to the field of rights for persons with intellectual disabilities, an element of a steadily expanding global human rights agenda.²

Historically, the international human rights movement—led by nongovernmental organizations (NGOs) like Amnesty International—focused principally on core civil rights violations, including issues related to state-sponsored killing, torture, and arbitrary detention.³ While human rights NGOs continue to document violations in these areas, the human rights agenda has expanded significantly.⁴

The human rights movement also has become a primary force in challenging official discrimination, beginning with racial discrimina-

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1. THE HUMAN RIGHTS OF PERSONS WITH INTELLECTUAL DISABILITIES: DIFFERENT BUT EQUAL (Stanley S. Herr et al. eds., 2003) [hereinafter DIFFERENT BUT EQUAL].

2. See Stanley S. Herr, *From Wrongs to Rights: International Human Rights and Legal Protection*, in DIFFERENT BUT EQUAL, *supra* note 1, at 115 (citing the “growing recognition by scholars and advocates of the applicability of human rights law and UN human rights activities to people with intellectual disabilities”).

3. See *id.* at 131 (noting Amnesty International's campaign against the Soviet Union's use of psychiatric hospitals to imprison political dissidents).

4. See *id.* at 118-31 (discussing the development of the international human rights movement during the last fifty years).

tion.⁵ The United Nations International Convention on the Elimination of All Forms of Racial Discrimination, condemned “any distinction, exclusion, restriction or preference based on race, colour, descent, or national or ethnic origin which has the . . . effect of nullifying . . . human rights and fundamental freedoms in the political, economic, social, cultural or any other field of public life.”⁶ Policies of apartheid were singled out in the document as particularly alarming manifestations of racism.⁷ Many of the earliest diplomatic efforts at the U.N. to enforce human rights standards were directed against the apartheid regime in South Africa.⁸ Broad international support for these efforts enabled the U.N. to adopt a separate convention against apartheid, which pressured the South African government to change.⁹

Over time the antidiscrimination agenda has evolved to include discrimination based on gender, age, and sexual orientation. For example, the language of the Convention on the Rights of the Child, adopted by the U.N. General Assembly in 1989, is perhaps the most inclusive, declaring “that everyone is entitled to all the rights and freedoms set forth therein, without distinction of any kind, such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status.”¹⁰

Substantial efforts are now being made by disability rights advocates to ensure that the rights of persons with physical and intellectual disabilities are also included in antidiscrimination campaigns.¹¹ The essays comprising *Different but Equal* are useful and timely in this context, especially when we consider that the steady march toward ex-

5. See, e.g., International Convention on the Elimination of All Forms of Racial Discrimination, *opened for signature* Mar. 7, 1966, S. EXEC. DOC. C, 95-2 (1978), 660 U.N.T.S. 195.

6. *Id.* art. 1(1), S. EXEC. DOC. C, 95-2, 660 U.N.T.S. at 216.

7. See *id.* art. 3, S. EXEC. DOC. C, 95-2, 660 U.N.T.S. at 218 (declaring that the parties to the Convention “particularly condemn racial segregation and *apartheid* and undertake to prevent, prohibit and eradicate all practices of this nature in territories under their jurisdiction”).

8. See, e.g., International Convention on the Suppression and Punishment of the Crime of *Apartheid*, *adopted on* Nov. 30, 1973, 1015 U.N.T.S. 243 [hereinafter *Convention on Apartheid*].

9. See *id.* art. IV, 1015 U.N.T.S. at 246 (stating the Convention parties’ determination “[t]o adopt legislative, judicial and administrative measures to prosecute, bring to trial and punish . . . persons responsible for [the crime of *apartheid*]”).

10. Convention on the Rights of the Child, *adopted on* Nov. 20, 1989, pmbl., 1577 U.N.T.S. 3, 45.

11. See Theresa Degener, *Disability as a Subject of International Human Rights Law and Comparative Discrimination Law*, in *DIFFERENT BUT EQUAL*, *supra* note 1, at 157 (“Increasingly, nongovernmental organizations that focus on disability seem to have an impact on how traditional human rights norms are interpreted and implemented as well as on how modern human rights instruments are designed.”).

panding the rights agenda has its detractors. Some critics are philosophically opposed to labeling any governmental effort to establish affirmative obligations that provide economic or social supports as “rights.”¹² Others fear that shifting the focus outside the traditional human rights arena will dissipate the struggle against state violations of the integrity of the individual.¹³

Many critics of the broader rights agenda premise their opposition on the lack of clear standards or means of enforcement.¹⁴ Simply stated, calling something a right does not make it so. This argument is legitimate, but critics in this camp generally are not willing to do the hard work of contextualizing basic rights understood in new, more inclusive ways.¹⁵ *Different but Equal* is an important effort toward beginning to fill this void for persons with disabilities. The book is based on two fundamental assumptions: first, that the disabled are equally entitled to basic human rights, such as rights to housing, employment, education, and health; and second, that societies are obligated to make these rights attainable by modifying both the physical and social environments to accommodate difference.¹⁶

In many societies, linking the abstract notion of equality for persons with disabilities with the accommodations necessary to realize their equality is a radical idea.¹⁷ This is in part because the accommodations required are as often a question of attitudes as they are physical or technical assistance.¹⁸ As Mary Robinson writes in the foreword to the book, “[t]rue equality for the disabled means more than access

12. See Harold Hongju Koh & Lawrence O. Gostin, *Introduction: The Human Rights Imperative*, in *DIFFERENT BUT EQUAL*, *supra* note 1, at 1-2 (citing critics’ concerns that government provision of educational, health care, and other services “would place impossible burdens on federal, state, and local governments to provide social services”).

13. See David Kennedy, *The International Human Rights Movement: Part of the Problem?*, 15 *HARV. HUM. RTS. J.* 101, 119 (2002) (stating that “the attention to problems that are peripheral to a broadly conceived program of social justice” may result in the human rights movement “legitimizing more injustice than it eliminates”).

14. See *id.* (discussing the negative effects of “vague and conflicting norms”).

15. Jesse Tampio, Book Note, 16 *HARV. HUM. RTS. J.* 284 (2003) (reviewing MAKAU MATUA, *HUMAN RIGHTS: A POLITICAL AND CULTURAL CRITIQUE* (2002)).

16. See Herr, *supra* note 2, at 115-40 (evaluating international developments in human rights law and encouraging the implementation of policies to ensure the rights of individuals with intellectual disabilities).

17. See *id.* at 137 (noting the “‘special versus general rights’ debate” regarding the appropriate legal protection necessary to ensure reasonable accommodations).

18. See David L. Braddock & Susan L. Parish, *Social Policy Toward Intellectual Disabilities in the Nineteenth and Twentieth Centuries*, in *DIFFERENT BUT EQUAL*, *supra* note 1, at 85-97 (discussing the evolution in social policy regarding care for individuals with intellectual disabilities from the asylum model to contemporary family, community, and rights-based models of support).

to buildings and methods of transportation. It mandates a change in attitude in the larger social fabric—of which we are all a part.”¹⁹

Reviewing Professor Herr’s earlier book *Aging, Rights, and Quality of Life* in 2000, Mark Weber noted aptly that the times are ripe for such a change.²⁰ He dubbed the work timely because “[t]here is a growing realization, both in the United States and abroad, that society frequently violates the basic human rights of people with disabilities.”²¹ One of the most important signs of this progress is the Americans with Disabilities Act (ADA), a comprehensive law passed in 1990.²² In the introduction to *Different but Equal*, Koh and Gostin single out the ADA as “a watershed event for disability rights globally.”²³ On the international stage, they identify more than 180 U.N. documents relating to the rights of the disabled.²⁴ This book seeks opportunities in international human rights law to address the lack of regular and effective enforcement of disability rights, as suggested by the sheer volume of declarations, documents, and, in some cases, legislation.²⁵

One egregious aspect of the problem relates to conditions and practices in institutions that have been created to confine and treat people with physical and intellectual disabilities.²⁶ Dr. Gunnar Dybwad, a leading disability rights activist in the United States and Europe, once reflected on his decades-long work to improve the lives of children with disabilities: “There is no such thing as a good institution.”²⁷ Reports from institutions for the disabled in poor and developing countries substantiate Dr. Dybwad’s conclusion. Many of the worst abuses of both children and adults with mental disabilities have been uncovered in state facilities and “orphanages” in countries like

19. Mary Robinson, *Foreword* to *DIFFERENT BUT EQUAL*, *supra* note 1, at vi.

20. Mark C. Weber, *Aging, Rights, and Quality of Life: Prospects for Older People with Developmental Disabilities*, 31 *LOY. U. CHI. L.J.* 485, 486-89 (2000) (book review) (noting recent legal developments that acknowledge and attempt to remedy discrimination against people with disabilities).

21. *Id.* at 486.

22. Americans with Disabilities Act of 1990, 42 U.S.C. §§ 12101-12213 (2000).

23. Koh & Gostin, *supra* note 12, at 8.

24. *Id.*

25. See Herr, *supra* note 2, at 130-37 (discussing the implementation of international human rights standards).

26. See Braddock & Parrish, *supra* note 18, at 83-93 (discussing the asylum model of care for individuals with disabilities).

27. See Holly Burkhalter & Eric Rosenthal, *The Way to Save Russia’s Orphans*, *WASH. POST*, Aug. 4, 1999, at A21 (“Gunnar Dybwad [] has concluded that four decades of work to improve the living conditions of children with disabilities has taught us one major lesson: There is no such thing as a good institution.”).

China, Romania, and Russia.²⁸ In a hospital in Kosovo in 2000, Eric Rosenthal, executive director of Mental Disability Rights International, recorded a filthy environment in which mentally disabled patients received neither treatment nor stimulation of any kind.²⁹ Women were raped by male patients, while under staff supervision.³⁰ In Russia, many of the children in so-called orphanages have at least one living parent; a parent who was likely pressured to give up his or her disabled child.³¹ In these institutions it is common for children to be put in straitjackets or in wooden pens without regard for hygiene or safety.³² In one orphanage in Moscow, sixteen mentally disabled children died in a span of nine months in 1998.³³ Their cause of death was listed invariably as “deficiencies incompatible with life.”³⁴

Wealthier nations have sought to address these types of abuses by developing more regulations governing such facilities and by moving toward more extensive home care and greater integration of individuals with disabilities into communities.³⁵ Over the past thirty years, the disability rights movement in the United States and elsewhere has made significant strides in compelling the development of enhanced social services and education.³⁶ State systems that once encouraged

28. See Editorial, *Forgotten by the U.N.*, WASH. POST, Aug. 18, 2002, at B6 (discussing patient abuse in institutions in Kosovo, Russia, Romania, and Latin America).

29. See Eric Rosenthal et al., *Not on the Agenda: Human Rights of People with Mental Disabilities in Kosovo*, at 6 (2002), available at <http://www.mdri.org/pdf/KosovoReport.pdf> (last visited Oct. 19, 2003) (describing conditions in Shtime, a Kosovo institution for individuals with psychiatric disabilities). The report describes the conditions in Shtime as follows:

[D]etention in Shtime usually means segregation from society and detention in the institution for life. Living in Shtime is an enormous form of deprivation for a person who must suffer through these experiences for many years. People spend their days in inactivity, without any semblance of privacy, living in filth. . . . There is no decoration or access to reading material, radio, or television in most living areas. There are no clocks to orient people as to time of day. Many people spend their days sitting on benches, wandering the grounds, or sleeping on bare concrete floors.

Id.

30. See *id.* at 8 (discussing allegations of sexual abuse in Shtime).

31. See Sharon LaFraniere, *The Gulags*, TORONTO STAR, Oct. 2, 1999, § L (noting that Russia promotes the institutionalization of children with intellectual disabilities “begin[ning] in the maternity ward” by denying benefits to parents who wish to keep their children while paying parents who turn their children over to the state “the equivalent of about \$13 (U.S.) a month to provincial families . . . and \$21 a month to Moscow families”).

32. *Id.*

33. *Id.*

34. *Id.*

35. See Braddock & Parish, *supra* note 18, at 94-97 (detailing the declining use of institutions and the rise of family, community, and consumer models of care for individuals with disabilities).

36. See *id.* at 96-97 (noting the establishment in the United States of a federally enforced right to education for children with disabilities and the increased prevalence of

families to hospitalize their children with physical and intellectual disabilities have evolved into systems that give greater support to community integration and, in some cases, have ended institutional placements altogether.³⁷

Yet even in the relatively affluent societies that have made important progress in the area of disability rights, the struggle to overcome widespread discrimination against the disabled continues.³⁸ Experts in the field of disability rights have increasingly sought to develop an international context for these issues by placing them in an international human rights framework.³⁹

The editors of *Different but Equal* have produced a readable, comprehensive volume that covers topics ranging from the ethics of disability prevention⁴⁰ to the integration of the intellectually disabled in the workforce,⁴¹ and the history of the self-advocacy movement.⁴² The book is well organized and easy to navigate. In each section the book aims to familiarize the reader with the main themes of the movement, including: historical and contemporary conceptions of disability; international human rights norms generally; international norms as they apply to disability rights; the effect of disability models on social policies, including lifestyle choices by persons with intellectual disabilities; and finally, recommendations for attaining future goals.⁴³

Different but Equal is as much an accomplished contribution to the field of rights for persons with intellectual disabilities as it is a tribute to Stanley Herr, who nurtured the project through his battle with cancer, but tragically did not survive to see its publication. His co-editors

supported community living for individuals with disabilities, and, in Europe, a similar reduction in residential institutions).

37. See *id.* at 96 (describing the decline in states' use of institutions). In 1991, New Hampshire closed the Laconia Developmental Center and became the first state "to provide all of its services to people with intellectual disabilities in the community." *Id.* Subsequently, Alaska, the District of Columbia, Hawaii, Minnesota, New Mexico, Rhode Island, Vermont, and West Virginia have closed all of their public institutions for individuals with intellectual disabilities. *Id.*

38. See Koh & Gostin, *supra* note 12, at 2 (noting that discrimination against persons with physical and mental disabilities "has become a serious and neglected problem that affects large numbers in every society").

39. See *id.* at 4 (discussing the development of a "transnational human rights network" comprised of nongovernmental human rights organizations from around the world).

40. Adrienne Asch et al., *Respecting Persons with Disabilities and Preventing Disability: Is There a Conflict?*, in DIFFERENT BUT EQUAL, *supra* note 1, at 319.

41. Peter Blanck & Helen A. Scharztz, *Studying the Emerging Workforce*, in DIFFERENT BUT EQUAL, *supra* note 1, at 347.

42. Stanley S. Herr, *Self-Determination, Autonomy, and Alternatives for Guardianship*, in DIFFERENT BUT EQUAL, *supra* note 1, at 429.

43. See Koh & Gostin, *supra* note 12, at 6-19 (providing an overview of the book's organization, content, and objectives).

and the contributors clearly have profound affection and admiration for both the man and his lifetime commitment to the rights of a particularly vulnerable segment of the world's population. As both a litigator and a law professor at the University of Maryland, Herr dedicated his professional life to representing disabled children. One of his most notable accomplishments was his work in 1972 on the *Mills* case, which ensured the right to a free and appropriately tailored education for children with all types of disabilities.⁴⁴ The decision in *Mills* led to the passage of the National Education for All Handicapped Children Act of 1975 (now known as the Individuals with Disabilities Education Act).⁴⁵ In 1989, Herr led the legal battle in Maryland against the execution of mentally disabled prisoners, and “[w]hen the Supreme Court abolished the death penalty for mentally disabled criminals, it cited a brief submitted by Herr.”⁴⁶

Lawrence Gostin and Harold Hongju Koh also bring very important perspectives and expertise that enrich the final product.⁴⁷ Professor Gostin is a public health expert.⁴⁸ Linking his two professorships in public health and law, Gostin directs the Center for Law and the Public's Health at Georgetown and Johns Hopkins Universities.⁴⁹ He consults for the World Health Organization and is the Health Law and Ethics Editor of the *Journal of the American Medical Association*.⁵⁰ His publications explore a nexus between international law, medical ethics, and civil liberties, ranging from the ethics of surrogacy to genetic discrimination and the rights of the mentally ill.⁵¹ Gostin also previously edited a volume concerning the implementation of the ADA and the responsibilities the act implies for all Americans—not only those with disabilities and their families.⁵²

44. *Mills v. Bd. of Educ.*, 348 F. Supp. 866 (D.D.C. 1972).

45. Individuals with Disabilities Education Act of 1975 (IDEA), 20 U.S.C. §§ 1400-1461 (2000).

46. *Maryland Leadership in Law*, THE DAILY RECORD, at <http://www.mddailyrecord.com/leadership.2001herr.html> (last visited Oct. 6, 2003).

47. Gostin and Koh, along with Herr, are the book's editors. The pair also wrote the book's introduction. See Koh & Gostin, *supra* note 12, at 1. Gostin also co-authored one of the articles in the book. See Asch et al., *supra* note 40, at 319.

48. See Georgetown Law, *Faculty*, Lawrence O. Gostin, at http://www.law.georgetown.edu/curriculum/tab_faculty.cfm?Status=Faculty&Detail=258 (last visited Oct. 6, 2003) (providing a profile of Professor Gostin).

49. *Id.*

50. *Id.*

51. See *id.* (detailing the published works of Professor Gostin).

52. IMPLEMENTING THE AMERICANS WITH DISABILITIES ACT: RIGHTS AND RESPONSIBILITIES OF ALL AMERICANS (Lawrence O. Gostin & Henry A. Beyer eds., 1993).

Harold Hongju Koh is an internationally prominent legal scholar, policymaker, and human rights advocate.⁵³ Since 1993 he has been the Gerard C. and Bernice Latrobe Smith Professor of International Law at Yale Law School, and until 1998 he directed the university's Orville H. Schell, Jr., Center for International Human Rights.⁵⁴ As of July 2004, Professor Koh will continue his service to the university as Dean of the Yale Law School, an appointment he accepted in November 2003. Between 1998 and 2001 he served as Assistant Secretary of State for Democracy, Human Rights and Labor in the Clinton Administration.⁵⁵ As the State Department's senior human rights policymaker, he traveled extensively and helped shape the most progressive human rights policy agenda in U.S. history.⁵⁶ Professor Koh is also a prolific author on a wide range of human rights and other international law topics.⁵⁷

Different but Equal is divided into five parts. Part One highlights the significance of differing perceptions of disability among cultures. Perception matters because, as Alison Renteln notes in her essay *Cross-Cultural Perceptions of Disability: Policy Implications of Divergent Views*, the ADA protects both persons with actual limitations due to disability and those merely perceived as disabled.⁵⁸ Using anthropological data and arguments from recent American cases, Renteln makes the point that, while disability is universal, the ways in which disabilities are defined or stigmatized are culturally specific.⁵⁹ This contribution to the book is important because cross-cultural knowledge reminds us to be sensitive to varying social and religious beliefs in developing international standards for disability rights.⁶⁰

53. See Yale Law School Faculty, *Curriculum Vitae*, available at <http://www.law.yale.edu/outside/html/faculty/hkoh/CU-koh.pdf> (last visited Oct. 6, 2003) (providing an overview of Professor Koh's career).

54. *Id.*

55. *Id.*

56. As an acknowledgement of Professor Koh's achievements, the *Columbia Journal of Transnational Law* recently named him the recipient of the 2003 Annual Wolfgang Friedmann Memorial Award for outstanding achievements in the field of international law. Columbia Law School, *2003 Annual Wolfgang Friedmann Memorial Award*, at http://www.law.columbia.edu/media_inquiries/news/april_2003/friedmann_award (last visited Sept. 18, 2003).

57. See Yale Law School Faculty, *Curriculum Vitae*, *supra* note 53 (listing Professor Koh's published works).

58. Alison Dundes Renteln, *Cross-Cultural Perceptions of Disability: Policy Implications of Divergent Views*, in *DIFFERENT BUT EQUAL*, *supra* note 1, at 61.

59. See *id.* at 62-71 (discussing conceptions of disabilities in various cultures).

60. See *id.* (noting that "[c]ross-cultural research will also help demonstrate 'best practices,' or exemplary policies that guide the UN in its efforts to promote human rights for persons with disabilities").

Part Two examines enforcement models. To address this question, the authors assess the efficacy of international treaties and non-binding U.N. documents (or “soft law”).⁶¹ Generally, the authors find that, while such instruments have played a significant role in shifting attitudes from the medical model to the human rights model of disability, enactment and enforcement of antidiscrimination legislation at the national level is still lacking.⁶²

Both Stanley Herr (*From Wrongs to Rights: International Human Rights and Legal Protection*) and Theresia Degener (*Disability as a Subject of International Human Rights Law and Comparative Discrimination Law*) criticize the enforcement efforts of the UN Commission on Human Rights as gravely inadequate.⁶³ Although the Commission has issued reports acknowledging persons with disabilities as express subjects of universal human rights, these reports have not led to more formal commitments, such as a binding treaty protecting their rights.⁶⁴ Since the late 1990s, some of these gaps have been addressed indirectly, most recently by a proposal to strengthen implementation of disability rights and to develop a convention devoted to making persons with disabilities “visible” human rights subjects.⁶⁵

Degener identifies other obstacles to the enforcement of disability law, including different approaches to antidiscrimination across national legal systems.⁶⁶ She surveys forty-two countries and identifies four categories for prosecuting disability discrimination law: criminal law, constitutional law, civil law, and social welfare law.⁶⁷ Criminal law proves to be the weakest vehicle because it requires proof that the defendant’s actions were malicious rather than simply neglectful or

61. See, e.g., Herr, *supra* note 2, at 118-23 (reviewing international treaties and UN resolutions regarding human rights standards).

62. See, e.g., *id.* at 136 (arguing that “[t]he international community needs coherent policy making by national and local governments to ensure that human rights standards result in changes to existing norms, programs, and practices”).

63. See *id.* at 125 (declaring that the Commission “remains woefully inattentive to the relevant issues of persons with intellectual disabilities”); Degener, *supra* note 11, at 161 (noting that “[t]oo often, persons with disabilities are still invisible citizens in the mainstream human rights machinery of the United Nations”).

64. See Degener, *supra* note 11, at 160 (urging the development of an international disability convention).

65. See, e.g., Michelle Morgan, *Women with Disabilities: From Invisible to Visible Citizens*, at <http://www.worldenable.net/rights/adhoc2meetbulletin09a.htm> (June 26, 2003) (noting a panel discussion focusing on “the need for a paradigm shift: women with disabilities must be viewed as visible citizens, not, as they often have been in the past, invisible entities”).

66. Degener, *supra* note 11, at 162-74.

67. *Id.*

the result of ignorance of existing regulations.⁶⁸ The most common and useful protection vehicle is civil law—a fact linked to the profound global influence of the ADA.⁶⁹

The ADA puts the United States in a paradoxical position regarding the internationalization of disability legislation. Degener goes so far as to characterize the impact of the ADA on foreign laws as “enormous” and theorizes that “the international impact of this law was larger than its domestic effect.”⁷⁰ Yet Herr describes the unwillingness of U.S. courts to consider international human rights law in domestic cases as a serious inhibition.⁷¹

Currently, the strongest forces for favorable interpretations of international human rights law are nongovernmental organizations (NGOs) focused on disability rights.⁷² Herr exhorts mainstream NGOs to assist by devoting staff and resources to this specialized area, as they have for women’s and children’s rights.⁷³ Degener concludes that, in addition to the work of NGOs with both broad and specialized mandates, more universities should research and teach disability law.⁷⁴

Part Three discusses the disability rights movement’s current and future approaches to legislative change. Like Degener, Dan Shnit also highlights the importance of NGOs and private organizations in representing the rights and interests of persons with disabilities in his essay, *When Legislation Should Take Intellectual Disabilities into Account*.⁷⁵ This is particularly important when it comes to implementing and enforcing antidiscrimination legislation because, as Shnit notes, “[p]ersons with disabilities and their families do not have significant clout as a political group.”⁷⁶ In addition to the lobbying force of NGOs and other groups, Shnit also argues for the creation of agencies with the legal “clout” to educate the public about new disability laws,

68. Degener notes that criminal law often is an ineffective enforcement mechanism because it fails to prevent disability-based discrimination “carried out with the best intentions of the perpetrator.” *Id.* at 164.

69. *See id.* at 167-69 (discussing the adoption of civil anti-discrimination laws in a number of countries).

70. *Id.* at 162.

71. Herr, *supra* note 2, at 133-34.

72. *Id.* at 131-32.

73. *Id.* at 131.

74. Degener, *supra* note 11, at 176.

75. Dan Shnit, *When Legislation Should Take Intellectual Disabilities into Account*, in *DIFFERENT BUT EQUAL*, *supra* note 1, at 258.

76. *Id.* at 256.

enforce those laws, and apply credible punishments for violations of the law.⁷⁷

Shnit's justifiable call for powerful advocacy groups that can act on behalf of persons with disabilities underscores a tension in his essay, and to an extent in the volume as a whole, between a disabled person's right to realize autonomy⁷⁸ and the interventions necessary to help him or her achieve and maintain independence.⁷⁹ His discussion of the value of comprehensive versus specific legislation in guaranteeing the rights of persons with disabilities is a good example of this tension.⁸⁰ Shnit's use of comprehensive legislation most often refers to laws that protect persons with disabilities of any kind (e.g., ADA),⁸¹ although in other instances it refers to guidelines applying to the population at large (e.g., determination of criminal liability).⁸² Specific legislation refers to laws designed for a particular segment of a group, i.e., persons with intellectual disabilities.⁸³

In the first half of his essay, Shnit seems to be arguing that much of the existing legislation is not specific enough to be effective.⁸⁴ In particular, Shnit argues that the "reasonable accommodation" requirement of the ADA is too vague to be enforceable.⁸⁵ "[I]t is not enough to simply mention that . . . employers or service providers must make reasonable accommodations for disabled persons," Shnit states.⁸⁶ "The law must also include standards that specify which accommodations are reasonable."⁸⁷

Examining Israeli disability law, Shnit also expresses concern that laws intended to protect persons with any kind of disability may, in practice, exclude persons with intellectual disabilities.⁸⁸ An unintentional bias toward accommodating physical disability is apparent as well in the popular understanding of the ADA in the United States—many people believe the act is exclusively about wheelchair ramps and other physical modifications to buildings.⁸⁹ Shnit contrasts these leg-

77. *Id.* at 258.

78. *Id.* at 240.

79. *Id.* at 243, 256-58.

80. *Id.* at 250-51.

81. *Id.* at 251-52.

82. *Id.* at 253.

83. *Id.* at 251, 255.

84. *Id.* at 238-39.

85. *Id.* at 242.

86. *Id.* at 243.

87. *Id.*

88. *Id.* at 241-42.

89. See National Council on Disability, *Introductory Paper: The Americans with Disabilities Act 5-6* (2002), available at <http://www.ncd.gov/newsroom/publications/pdf/rightingthe>

islative gaps with a law passed in Sweden in 1993, designed especially for those with intellectual disabilities and autism.⁹⁰ The law clearly specifies the services included in the “individually tailored program” to which every affected individual is entitled.⁹¹ Shnit writes that the Swedish law’s clarity concerning the legal right to specially tailored care makes it “a model for comprehensive assistance and service in the community.”⁹²

Later in the essay, Shnit counters this implicit support of specific legislation with the thesis that “whenever possible, it is preferable to enact general legislation with a broad application rather than narrow, specific legislation.”⁹³ For instance, Shnit maintains that, in the case of laws protecting mentally disabled persons from abuse and exploitation, specific legislation may too readily transfer decision-making power to a guardian or institution.⁹⁴ He resolves the apparent contradiction in his arguments by proposing a two-tiered system of legislation: basic principles protecting persons with disabilities from discrimination should be expressed in general legislation, while the details of implementation—which may vary depending on the nature of a disability—should be expressed in specific legislation.⁹⁵

Part Four of *Different but Equal* examines both the social policies regarding people with disabilities and the conflicts these policies can generate for the movement to realize equality amidst diversity. The section makes explicit the interdependence of civil, political, social, economic, and cultural rights. The selections include a study of discrimination in the workplace,⁹⁶ a survey of material commitment to services for the disabled in various countries,⁹⁷ and ethical perspectives on medical interventions.⁹⁸

The latter essay, entitled *Respecting Persons with Disabilities and Preventing Disability: Is there a Conflict?*, is likely to be of interest to a wider audience because it engages one aspect of the controversial debates surrounding genetic research, testing, and therapies.⁹⁹ In this

ada.pdf (Oct. 16, 2002) (noting the public’s misunderstanding of the scope and degree of the ADA’s influence).

90. Shnit, *supra* note 75, at 246.

91. *Id.*

92. *Id.*

93. *Id.* at 251.

94. *Id.* at 249-50.

95. *Id.* at 252.

96. Blanck & Schartz, *supra* note 41, at 347.

97. John H. Noble, Jr., *The Economics of Equality: An Exploration of Country Differences*, in DIFFERENT BUT EQUAL, *supra* note 1, at 387.

98. Asch et al., *supra* note 40, at 319.

99. *Id.*

essay, authors Adrienne Asch, Lawrence Gostin, and Diann Johnson make explicit the disability movement's rejection of the medical model in favor of the social model of disability.¹⁰⁰ The medical model regards a disability as a condition to be prevented, cured, or otherwise treated, and it places the emphasis on limitation rather than potential.¹⁰¹ Consequently, disabled persons often suffer social and economic marginalization.¹⁰²

The social model of disability shifts responsibility away from the disabled person's "biological, psychic, or cognitive equipment" and toward "the social, institutional, and physical world . . . designed with the characteristics and needs of the nondisabled in mind."¹⁰³ The social model has yet to gain wide currency in many societies, including the United States.¹⁰⁴ The authors note that the Human Genome Initiative, launched by Congress just two years before the passage of the ADA, exemplifies our public understanding of disabilities, namely as "illnesses" or "deformities" to be eradicated.¹⁰⁵ It is difficult if not impossible to maintain respect for the lives and dignity of people with disabilities in a time when eradication of difference through genetic manipulation is within reach.

The authors also stress that the disability rights movement is not opposed to all measures aimed at diminishing or eliminating disease and disability.¹⁰⁶ Improvements in diet, environment, and public safety do not necessarily contradict the worth of persons living with disabilities.¹⁰⁷ Prenatal tests, however, especially those that can determine "abnormalities" only at later stages of pregnancy, present complex moral dilemmas.¹⁰⁸ The majority of fetal conditions that can be detected in the second or third trimesters, for example, cannot be treated, leaving parents with unpleasant information and few options.¹⁰⁹

One option that is routinely pursued in conjunction with prenatal testing is selective abortion.¹¹⁰ This practice presents a clear conflict with the value and dignity accorded to every human life.¹¹¹ Asch,

100. *Id.* at 323.

101. *Id.* at 322-23.

102. *Id.* at 323.

103. *Id.*

104. *Id.* at 320-21.

105. *Id.* at 321-22.

106. *Id.* at 325.

107. *Id.*

108. *Id.* at 326-28.

109. *Id.* at 326-27.

110. *Id.* at 326.

111. *Id.* at 327.

Gostin, and Johnson identify two categories of pressure applied to parents facing the option of selective abortion.¹¹² First, parents are often pressured by medical professionals, most of whom are committed to the medical model of disability and are, therefore, invested in preventing “unhealthy” children.¹¹³ Second, parents who resist or do not confront pressure from their doctor must then consider the wide-ranging social pressures against disability.¹¹⁴ Depending on their economic and social status, they may not be able to access needed services, even where those services are available.¹¹⁵

The many considerations, as well as the social or professional groups involved in these issues, make the medical prevention debate perhaps the toughest testing ground of our commitment to equality for people with disabilities.¹¹⁶ It is also a powerful reminder of our shared humanity.

Part Five of *Different but Equal* reinforces this lesson with the welcome and important inclusion of an essay by the accomplished self-advocate Mitchell Levitz.¹¹⁷ This personal account provides a real life counterpoint to the models, reforms, and other proposals discussed in the previous chapters. Levitz, who has Down’s syndrome, describes his lifelong dream of an independent life and the support and determination that made this possible.¹¹⁸ Acknowledging that services like public transportation and job training have been key to his independence, Levitz is also careful to distinguish support from control.¹¹⁹ Well-meaning family members and advocates, he writes, “should recognize our need for privacy and . . . encourag[e] [us] to take risks and try new things on our own.”¹²⁰ The balance he describes between personal freedom and guidance, which must be calibrated to the individual’s needs,¹²¹ is at the core of all of the arguments in this volume. The future progress of the human rights movement for persons with disabilities in large part will hinge on our willingness to respect and take the necessary steps to work out this balance.

112. *Id.* at 328.

113. *Id.*

114. *Id.* at 328-29.

115. *Id.* at 333.

116. *See id.* at 340-41.

117. Mitchell Levitz, *Voices of Self-Advocates*, in *DIFFERENT BUT EQUAL*, *supra* note 1, at 453.

118. *See id.* at 453-64.

119. *Id.* at 454-56.

120. *Id.* at 454-55.

121. *Id.* at 455.