

“THROUGH THE WILD CATHEDRAL EVENING”: BARRIERS, ATTITUDES, PARTICIPATORY DEMOCRACY, PROFESSOR TENBROEK, AND THE RIGHTS OF PERSONS WITH MENTAL DISABILITIES

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Michael Stein and Janet Lord’s excellent paper on the relationship between Jacobus tenBroek’s vision and jurisprudence and the United Nations Convention on the Rights of Persons with Disabilities (UN CRD) stands on its own as an important and powerful piece of scholarship and advocacy, urging a vision of social justice that resonates for me. There is nothing in it for me to critique, and little for me to add. I do, though, want to suggest that their paper and Professor tenBroek’s work should both serve to remind us that there is still so much for all of us to do in this area of law and society.

Professor Stein and his colleague wonderfully contextualize Professor tenBroek’s writings with the UN CRD, and that is a major accomplishment. But it is one that has led me to think a bit about the particular significance of Professor tenBroek’s work for persons with mental disabilities, the core of my professional work.

Writing about tenBroek, Professor Mark Weber has pointed out how tenBroek’s writings reflect a “history of people with disabilities as a gradual progression from compelled separation toward integration,” noting how “fear of and repugnance to disability thrive when people with disabilities are locked away,”¹ and how our social policies led to a “legacy of prejudice and exclusion.”² The UN CRD certainly reinforces and emphasizes an integration model, and that is a very good thing. But I remain more than a bit skeptical as to the ultimate “real life” impact of the UN CRD in many nations, including our own. I will turn to United States-based Americans with Disabilities Act (ADA) as the source of a parallel.

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1. Mark C. Weber, *Home and Community-Based Services, Olmstead, and Positive Rights: A Preliminary Discussion*, 39 WAKE FOREST L. REV. 269, 273–74 (2004).

2. Mark C. Weber, *Disability and the Law of Welfare: A Post-Integrationist Examination*, 200 U. ILL. L. REV. 889, 901 (2000).

In 1999, in *Olmstead v. L.C.*, the U.S. Supreme Court held that the ADA entitled the plaintiffs, residents of Georgia Regional Hospital, to treatment in an integrated community setting as opposed to an unnecessarily segregated state hospital.³ In writing the majority opinion, Justice Ginsburg stressed that “[u]njustified isolation . . . is properly regarded as discrimination based on disability,”⁴ and ordered that states be required to maintain “a comprehensive, effectively working plan for placing qualified persons with mental disabilities in less restrictive settings,”⁵ thus explicitly endorsing the ADA’s “integration mandate.”⁶ At least one commentator has characterized this decision as one that “genuinely awaken[s] the nation’s conscience.”⁷

The significance of the “integration mandate” phrase should be crystal clear. According to Professor John Jacobi, “The opportunity for ‘life, liberty and the pursuit of happiness’ for *Olmstead* plaintiffs depends almost entirely on the integration mandate.”⁸ But in many jurisdictions, this opportunity has not materialized, and there has been a cottage industry of litigation over the waiting lists that have developed in jurisdictions; some states have imposed waits up to seven years.⁹ Professor tenBroek and a colleague wrote about this over 40 years ago, yet, in many ways, little has changed.¹⁰

Professor Stein and Ms. Lord also write eloquently about the connection between Professor tenBroek’s work, the UN Convention, and “participation in cultural life,”¹¹ noting how deprivation of meaningful opportunity in such areas “can be devastating.”¹² This perspective struck a special chord with me, because I believe that this approach has the capacity to resuscitate an important, yet now nearly dormant, aspect of

3. 527 U.S. 581, 582 (1999).

4. *Id.* at 597.

5. *Id.* at 597, 605–06.

6. I discuss this in Michael L. Perlin, “*Their Promises of Paradise*”: Will *Olmstead v. L.C.* Resuscitate the Constitutional “Least Restrictive Alternative” Principle in Mental Disability Law?, 37 HOUS. L. REV. 999, 1003 (2000).

7. Samantha A. DiPolito, *Olmstead v. L.C.—Deinstitutionalization and Community Integration: An Awakening of the Nation’s Conscience?*, 58 MERCER L. REV. 1381, 1382 (2007).

8. John V. Jacobi, *Federal Power, Segregation, and Mental Disability*, 39 HOUS. L. REV. 1231, 1247 (2003).

9. Sandra L. Yue, *A Return of Institutionalization Despite Olmstead v. L.C.? The Inadequacy of Medicaid Provider Reimbursement in Minnesota and the Failure to Deliver Home- and Community-Based Waiver Services*, 19 LAW & INEQ. 307, 310 n.20 (2001) (discussing *Lewis v. New Mexico Department of Health*, 94 F. Supp. 2d 1217 (D.N.M. 2000) (finding a two- to seven-year wait for services clearly unreasonable), and *Boulet v. Cellucci*, 107 F. Supp. 2d 61 (D. Mass. 2000) (holding that a reasonably prompt movement off waiting list for Medicaid waiver services is within ninety days)).

10. See Paul Steven Miller, *Disability, Civil Rights, and a New Paradigm for the Twenty-First Century: The Expansion of Civil Rights Beyond Race, Gender, and Age*, 1 U. PA. J. LAB. & EMP. L. 511, 520 n. 44 (1998) (discussing the older “custodial” attitude towards people with disabilities “typically expressed in policies of segregation and shelter, of special treatment and separate institutions”) (quoting Jacobus tenBroek & Floyd W. Matson, *The Disabled and the Law of Welfare*, 54 CAL. L. REV. 809, 816 (1966)).

11. United Nations Convention on the Rights of Persons with Disabilities, G.A. Res. 61/106, at 27, U.N. Doc. A/Res/61/106 (Dec. 13, 2006), Article 30, available at <http://www.un.org/esa/socdev/enable/rights/convtexte.htm> (UN CONVENTION).

12. Michael Stein & Janet Lord, *Jacobus tenBroek, Participatory Justice, and the UN Convention on the Rights of Persons with Disabilities*, 13 TEX. J. C.L. & C.R. 157, 182 (2008).

the rights of persons in psychiatric institutions. I characterize these rights as “other institutional rights.”¹³ Let me explain.

The history of expansion of the substantive civil rights of persons institutionalized because of mental disability generally follows two paths: the development of the right to treatment¹⁴ and the development of the right to refuse treatment.¹⁵ But this cursory approach obscures the rights of such persons to exercise civil rights while institutionalized, an area of civil rights that is now, less than thirty-five years after its first articulation, nearly forgotten. This category bundles rights that we think about occasionally (e.g., the right to vote;¹⁶ the right to sexual interaction)¹⁷ with those that we rarely consider (e.g., the right to exercise;¹⁸ the right to freely practice religion;¹⁹ the right to be paid for institutional work;²⁰ the right to free speech).²¹ I have written about all of these topics in a mental disability law treatise.²² By way of example, the section of the supplement to that treatise that deals with “other institutional rights” topics takes up only seven pages,²³ the section that deals with the right to refuse treatment encompasses twenty-three pages,²⁴ and the section that deals with sex offender laws spreads out to forty-three pages.²⁵ Clearly, these are areas of the law that appear to have fallen by the advocate’s wayside.

But, as Professor Stein and Ms. Lord underscore, the UN Convention speaks to an important array of participatory civil rights. They do us a favor by highlighting these rights, and by stressing their value and worth. But I want to take this one step further. Perhaps this focus will serve to invigorate this area of patients’ rights in *domestic* law and revive it from its current dormancy. In the parallel area of correctional law, domestic courts have not hesitated to cite to international standards in cases involving, for instance, the “double

13. See generally, MICHAEL L. PERLIN, *Other Institutional Rights in MENTAL DISABILITY LAW: CIVIL AND CRIMINAL*, Ch. 3C (2d ed. 1999); Michael L. Perlin et al., *Therapeutic Jurisprudence and the Civil Rights of Institutionalized Mentally Disabled Persons: Hopeless Oxyoron or Path to Redemption?*, 1 PSYCHOL., PUB. POL’Y & L. 80, 97 (1995).

14. See PERLIN, *supra* note 13, Ch. 3A, §§ 3A-2 to 3A-5.5.

15. See *id.* at Ch. 3B.

16. See, e.g., *Developments in the Law—The Law of Mental Illness VII: Voting Rights and the Mentally Incapacitated*, 121 HARV. L. REV. 1179 (2008).

17. See, e.g., Michael L. Perlin, “*Limited in Sex, They Dare*”: *Attitudes Toward Issues of Patient Sexuality*, 26 AMER. J. FORENS. PSYCHIATRY 25 (2005); Michael L. Perlin, *Hospitalized Patients and the Right to Sexual Interaction: Beyond the Last Frontier?* 20 NYU REV. L. & SOC’L CHANGE 517 (1993–94).

18. See, e.g., PERLIN, *supra* note 13, § 3C-6.5.

19. See *id.* at § 3C-3.1.

20. See *id.* at § 3C-37.1i; see also, e.g., Michael L. Perlin, *The Right to Participate in Voluntary, Therapeutic, Compensated Work Programs as Part of the Right to Treatment: A New Theory in the Aftermath of Souder*, 7 SETON HALL L. REV. 298 (1976).

21. See *id.*, e.g., at § 3C-3.3.

22. See PERLIN, *supra* note 13.

23. See MICHAEL L. PERLIN & HEATHER ELLIS CUCOLO, *MENTAL DISABILITY LAW: CIVIL AND CRIMINAL*, 2006–07 Cumulative Supplement (2007), at 39–46 (all supplemental listings to Chapter 3C).

24. *Id.* at 16–39 (all supplemental listings to Chapter 3B).

25. See PERLIN & CUCOLO, *MENTAL DISABILITY LAW: CIVIL AND CRIMINAL*, *supra* note 23, at 14–57 (all supplemental listings to § 2A-3.3).

bunking” of inmates.²⁶ It is my hope that Professor Stein and Ms. Lord’s paper will lead to a similar focus in domestic mental disability law institutionalization cases.

These comments of mine, however, go simply to “the law.” We must go beyond the law and focus also on the issues of *attitudes*. In another article, Professor Stein cites the political scientist Harlan Hahn who has asserted that able-bodied society feels “existential anxiety” towards persons with disabilities.²⁷ That “anxiety” is at the core of my writing about sanism and pretextuality. I will explain these briefly and then seek to demonstrate how these concepts are so intertwined with Professor tenBroek’s scholarship and advocacy.²⁸

Sanism is an irrational prejudice of the same quality and character of other irrational prejudices that cause (and are reflected in) prevailing social attitudes of racism, sexism, homophobia, and ethnic bigotry. It infects both our jurisprudence and our lawyering practices.²⁹ Sanism is largely invisible and largely socially acceptable. It is based predominantly upon stereotype, myth, superstition, and de-individualization, and is sustained and perpetuated by our use of alleged ordinary common sense (OCS)³⁰ and heuristic reasoning in an unconscious response to events both in everyday life and in the legal process.³¹

Pretextuality can explain the ways in which courts accept (either

26. See generally *Lareau v. Manson*, 507 F. Supp. 1177, 1187–89 n.9 (D. Conn. 1980); see generally, MICHAEL L. PERLIN & HENRY A. DLUGACZ, *MENTAL HEALTH ISSUES IN JAILS AND PRISONS: CASES AND MATERIALS* 1026–49 (2008).

27. Michael Ashley Stein, *Disability, Employment Policy, and the Supreme Court*, 55 STAN. L. REV. 607, 631–32 (2002) (“Harlan Hahn . . . asserts that able-bodied society feels ‘existential anxiety’ towards the disabled.” (quoting political scientist Harlan Hahn, *Toward a Politics of Disability: Definitions, Disciplines, and Policies*, 22 SOC. SCI. J. 87 (1995))); Harlan Hahn, *Civil Rights for Disabled Americans*, in *IMAGES OF THE DISABLED, DISABLING IMAGES* 181, 182 (Alan Gartner & Tom Joe eds. 1987).

28. It is with this in mind that I chose my title. It comes from Bob Dylan’s masterpiece, *Chimes of Freedom* (1964) and is found in this verse, a verse that I believe resonates for the purposes of this symposium:

Through the wild cathedral evening the rain unraveled tales / For the disrobed
faceless forms of no position / Tolling for the tongues with no place to bring their
thoughts / All down in taken-for-granted situations / Tolling for the deaf an’ blind,
tolling for the mute / Tolling for the mistreated, mateless mother, the mistitled
prostitute / For the misdemeanor outlaw, chased an’ cheated by pursuit / An’ we
gazed upon the chimes of freedom flashing.

BOB DYLAN, *CHIMES OF FREEDOM*, on *ANOTHER SIDE OF BOB DYLAN* (Columbia Records 1964).

29. See generally, MICHAEL L. PERLIN, *THE HIDDEN PREJUDICE: MENTAL DISABILITY ON TRIAL* 21–59 (2000); Michael L. Perlin, *On Sanism*, 46 SMU L. REV. 373 (1992).

30. OCS is a “powerful unconscious animator of legal decision making,” Michael L. Perlin, *She Breaks Just Like a Little Girl: Neonaticide, The Insanity Defense, and the Irrelevance of Ordinary Common Sense*, 10 WM. & MARY J. WOMEN & L. 1, 25 (2003) (OCS is a “powerful unconscious animator of legal decision making.”); see Richard K. Sherwin, *Dialects and Dominance: A Study of Rhetorical Fields in the Law of Confessions*, 136 U. PA. L. REV. 729, 737 (1988) (OCS exemplified by the attitude of “What I know is ‘self evident’; it is ‘what everybody knows.’”).

31. Perlin, *She Breaks Just Like a Little Girl*, *supra* note 30, at 24–25, citing Michael L. Perlin, *Half-Wracked Prejudice Leaped Forth: Sanism, Pretextuality, and Why and How Mental Disability Law Developed As It Did*, 10 J. CONTEMP. LEG. ISSUES 3, 4–5 (1999).

implicitly or explicitly) testimonial dishonesty and engage similarly in dishonest and frequently meretricious decisionmaking. Specifically, this is the case where witnesses, especially expert witnesses, show a high propensity to purposely distort their testimony in order to achieve desired outcomes. This pretextuality is poisonous. It infects all participants in the judicial system, breeds cynicism and disrespect for the law, demeans participants, and reinforces shoddy lawyering, blasé judging, and, at times, perjurious and/or corrupt testifying.³²

How are these concepts related to the topic of today’s program? Writing about Professor tenBroek’s scholarship, Andrew Weis has noted, “Although persons with disabilities possess mental and/or physical impairments, society’s physical obstacles and *attitudinal barriers* more often ultimately handicap or impede their pursuit and enjoyment of daily activities.”³³ Recently, I have turned my attention to these concepts in the context of the relationship between international human rights and mental disability law.³⁴ In an article that is currently in press, Professor Eva Szeli and I look at the recent work of Professor Tara Melish on this topic and then consider sanism in the specific context of the Convention about which Professor Stein writes so eloquently:

In arguing why the United States should ratify the new UN Convention, Tara Melish focused on the “deeply entrenched attitudes and stereotypes about disability that have rendered many of the most flagrant abuses of the rights of persons with disabilities ‘invisible’ from the mainstream human rights lens.”³⁵ These stereotypes are the essence of sanism; vigorous, advocacy-focused counsel is needed to answer and rebut them.³⁶

Here, Professor tenBroek’s thoughtful voice demanding participatory justice for persons with disabilities³⁷—an eloquence matched by Professor Stein’s, both in this paper and elsewhere³⁸—resonates for us. One of the hallmarks of the process that led to the publication of the UN Convention was the participation of persons with

32. Perlin, *She Breaks Just Like a Little Girl*, *supra* note 30, at 25.

33. Andrew Weis, *Peremptory Challenges: The Last Barrier to Jury Service for People with Disabilities*, 33 WILLAMETTE L. REV. 1, 29, n.122 (1997) (emphasis added).

34. See, e.g., Michael L. Perlin, *International Human Rights Law and Comparative Mental Disability Law: The Universal Factors*, 34 SYRACUSE J. INT’L L. & COMMERCE 333, 333 (2007); Michael L. Perlin, *International Human Rights and Comparative Mental Disability Law: The Role of Institutional Psychiatry in the Suppression of Political Dissent*, 39 ISRAEL L. REV. 69, 89–92 (2006); MICHAEL L. PERLIN ET AL., INTERNATIONAL HUMAN RIGHTS AND COMPARATIVE MENTAL DISABILITY LAW: CASES AND MATERIALS 283–319 (2006).

35. See generally, Tara Melish, *The UN Disability Convention: Historic Process, Strong Prospects, and Why the U.S. Should Ratify*, 14 HUM. RTS. BRIEF 37, 44 (Winter 2007).

36. Michael L. Perlin & Eva Szeli, *Mental Health Law and Human Rights: Evolution and Contemporary Challenges*, in MENTAL HEALTH AND HUMAN RIGHTS (forthcoming Michael Dudley ed. 2008).

37. See, e.g., Jacobus tenBroek, *The Right to Live in the World: The Disabled in the Law of Torts*, 54 CAL. L. REV. 841, 842 (1966).

38. See, e.g., Michael Ashley Stein, *Disability Human Rights*, 95 CAL. L. REV. 75 (2007).

disabilities and their clarion cry, “[N]othing about us, without us.”³⁹ This has led commentators to conclude that the Convention “is regarded as having finally empowered the ‘world’s largest minority’ to claim their rights, and to participate in international and national affairs on an equal basis with others who have achieved specific treaty recognition and protection.”⁴⁰

But to what extent *can* we count on the UN Convention to change the underlying attitudes about which Professor tenBroek wrote so lucidly decades ago? I wish I were more confident. The new UN convention mandates that “States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.”⁴¹ Elsewhere, the Convention commands:

States Parties shall ensure effective access to justice for persons with disabilities on an equal basis with others, including through the provision of procedural and age-appropriate accommodations, in order to facilitate their effective role as direct and indirect participants, including as witnesses, in all legal proceedings, including at investigative and other preliminary stages.⁴²

The extent to which this Article is honored by signatory nations will have a major impact on the extent to which this entire Convention

39. See, e.g., Rosemary Kayess & Phillip French, *Out of Darkness into Light? Introducing the Convention on the Rights of Persons with Disabilities*, 8 HUM. RTS. L. REV. 1, 4 n.15 (2008):

See, for example, Statement by Hon Ruth Dyson, Minister for Disability Issues, New Zealand Mission to the UN, for Formal Ceremony at the Signing of the Convention on the Rights of Persons with Disabilities, 30 March 2007: ‘Just as the Convention itself is the product of a remarkable partnership between governments and civil society, effective implementation will require a continuation of that partnership.’ The negotiating slogan ‘Nothing about us without us’ was adopted by the International Disability Caucus, available at http://www.un.org/esa/socdev/enable/documents/Stat_Conv/nzam.doc [last accessed 13 November 2007].

For a thoughtful discussion of the “unrelenting advocacy” of disability rights group in the Convention-drafting process, see Amita Dhanda, *Constructing a New Human Rights Lexicon: Convention on the Rights of Persons with Disabilities*, 5 INT’L J. HUM. RTS. 43, 55 (2008).

40. Kayess & French, *supra* note 39, at n.17 (“See, for example, statements made by the High Commissioner for Human Rights, Louise Arbour, and the Permanent Representative of New Zealand and Chair of the Ad-Hoc Committee on a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities, Ambassador Don Mackay, at a Special Event on the Convention on Rights of Persons with Disabilities, convened by the UN Human Rights Council, 26 March 2007, available at [http://www.unog.ch/80256EDD006B9C2E/\(httpNewsByYear_en\)/7444B2E219117CE8C12572AA004C5701?OpenDocument](http://www.unog.ch/80256EDD006B9C2E/(httpNewsByYear_en)/7444B2E219117CE8C12572AA004C5701?OpenDocument) [last accessed 13 November 2007].”).

41. UN CONVENTION, *supra* note 11, at art. 12.3. See generally, Stein, *supra* note 38. For a thoughtful and comprehensive predecessor article, see generally Aaron A. Dhir, *Human Rights Treaty Drafting Through the Lens of Mental Disability: The Proposed International Convention on Protection and Promotion of the Rights and Dignity of Persons with Disabilities*, 41 STAN. J. INT’L L. 181 (2005).

42. UN Convention, *supra* note 11, at art. 13.1.

“matters” to persons with mental disabilities.⁴³ It is still a *very* open question as to whether or not these rights will actually be given life, or whether they will remain little more than “paper victories.”⁴⁴

Writing in 1993, Eric Rosenthal and Leonard Rubenstein first illuminated how the MI Principles “come from an individualistic, libertarian perspective that emphasizes restrictions on what the state can do to a person with mental illness.”⁴⁵ A presenter at a conference held at New York Law School on the treatment of persons with mental disabilities referred to this article and then told the audience, “Without advocates willing to get in the trenches and fight for these ideals, so that they might become a reality for persons with mental disabilities, these treaties and standards remain mere words without action.”⁴⁶ This is a goal to which all of us who take this area of law and society seriously should aspire.⁴⁷

43. See generally, Michael L. Perlin, “*I Might Need a Good Lawyer, Could Be Your Funeral, My Trial*”: *Global Clinical Legal Education and the Right to Counsel in Civil Commitment Cases*, 28 WASH. U. J. L. AND POL’Y, (forthcoming 2008). An important, still-unanswered question is this: to what extent will the Convention be a “human rights convention for the 21st century,” see Lisa Waddington, *A New Era in Human Rights Protection in the European Community: The Implications [of] the United Nations’ Convention on the Rights of Persons with Disabilities for the European Community*, manuscript at 4, available at <http://ssrn.com/abstract=1027872> (accessed January 26, 2008), or a “moral compass for change,” Gerard Quinn, *The UN Convention on the Human Rights of Persons with Disabilities*, at 3, available at <http://www.nhri.net/2007/Berlin-Quinn.2.pdf>, as distinguished commentators have predicted.

44. Michael L. Perlin, “*What’s Good is Bad, What’s Bad is Good, You’ll Find out When You Reach the Top You’re on the Bottom*”: *Are the Americans with Disabilities Act (and Olmstead v. L.C.) Anything More Than “Idiot Wind?”*, 35 U. MICH. J.L. REFORM 235, 246 (2002) (“Mental disability law is strewn with examples of ‘paper victories . . .’”) (quoting Michael Lottman, *Paper Victories and Hard Realities*, in *PAPER VICTORIES AND HARD REALITIES: THE IMPLEMENTATION OF THE LEGAL AND CONSTITUTIONAL RIGHTS OF THE MENTALLY DISABLED* 93 (Valerie J. Bradley & Gary J. Clarke eds., 1976)).

45. Eric Rosenthal & Leonard S. Rubenstein, *International Human Rights Advocacy Under the “Principles for the Protection of Persons with Mental Illness”*, 16 INT’L J.L. & PSYCHIATRY 257, 260 (1993). In 1991, the UN General Assembly adopted the *Principles for the Protection of Persons with Mental Illness and for the Improvement of Mental Health Care* (widely referred to as the ‘MI Principles’). G.A. Res. 119, U.N. GAOR, 46th Sess., Supp. No. 49, Annex at 189, U.N. Doc. A/46/49 (1991). Until the ratification of the UN Convention, they were seen as “the most comprehensive international human rights standards for persons with mental disabilities” that had ever been promulgated. See Perlin & Szeli, *supra* note 36, manuscript at 3.

46. Symposium, *International Human Rights Law and the Institutional Treatment of Persons with Mental Disabilities: The Case of Hungary*, 21 N.Y.L. SCH. J. INT’L & COMP. L. 361, 381 (2002) (remarks of Jean Bliss).

47. See Perlin, *Universal Factors*, *supra* note 34, at 357.