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Through the Wild Cathedral Evening: Barriers, Attitudes, Participatory Democracy, Professor TenBroek, and the Rights of Persons with Mental Disabilities

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

By: Michael L. Perlin*

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," and how our social policies led to a "legacy of prejudice and exclusion." 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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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

4. Id. at 597.
5. Id. at 597, 605–06.
the rights of persons in psychiatric institutions. I characterize these rights as "other institutional rights." 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 treatment and the development of the right to refuse treatment. 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; the right to sexual interaction; the right to freely practice religion; the right to be paid for institutional work; the right to free speech). I have written about all of these topics in a mental disability law treatise. By way of example, the section of the supplement to that treatise that deals with "other institutional rights" topics takes up only seven pages; the section that deals with the right to refuse treatment encompasses twenty-three pages, and the section that deals with sex offender laws spreads out to forty-three pages. 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 Oxymoron 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.


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

19. See id. at § 3C-3.1.

20. See id. at § 3C-37.1; 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.


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. 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. 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.

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. 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) and heuristic reasoning in an unconscious response to events both in everyday life and in the legal process.

Pretextuality can explain the ways in which courts accept (either


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).


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, blâse judging, and, at times, perjurious and/or corrupt testifying.\footnote{Perlin, She Breaks Just Like a Little Girl, supra note 30, at 25.}

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.”\footnote{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).} Recently, I have turned my attention to these concepts in the context of the relationship between international human rights and mental disability law.\footnote{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).} 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.”\footnote{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).} These stereotypes are the essence of sanism; vigorous, advocacy-focused counsel is needed to answer and rebut them.\footnote{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).}

Here, Professor tenBroek’s thoughtful voice demanding participatory justice for persons with disabilities—an eloquence matched by Professor Stein’s, both in this paper and elsewhere\footnote{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).}—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
disabilities and their clarion cry, "[N]othing about us, without us."

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."  

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." 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.

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

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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].


42. UN Convention, supra note 11, at art. 13.1.
"matters" to persons with mental disabilities. 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."

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." 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." This is a goal to which all of us who take this area of law and society seriously should aspire.


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