

Comments

STRATEGIC ADVOCACY IN FULFILLING THE GOALS OF DISABILITY POLICY: IS THE ONLY QUESTION HOW FULL THE GLASS IS?

By: Laura Rothstein*

In his excellent article assessing the current state of disability law in the United States,¹ Professor Robert Dinerstein evaluates the array of federal statutes (including the Americans with Disabilities Act (ADA),² the Individuals with Disabilities Education Act (IDEA),³ the Fair Housing Act (FHA),⁴ and Section 504 of the Rehabilitation Act (Section 504)⁵ and discusses whether we have come far enough. Professor Dinerstein focuses on the question of how full the glass is with respect to fully realizing the potential of existing laws. He notes that the answer depends on the perspective of the person asking the question—whether one is an outside observer or one directly affected by the fullness of the glass. This commentary is taken from my remarks responding to Professor Dinerstein’s presentation at the tenBroek conference.

In today’s society, to stay healthy, we drink more water. To be environmentally conscious, we try to reuse the plastic water bottles from which we drink. Recently there has been concern that some of these bottles may contain chemicals that leach into the water when the bottle is reused. So, the unintended consequence of trying to do good things—stay healthy and be environmentally conscious—may be that drinking the water actually causes health problems. Therefore, I suggest that perhaps we should focus not only on how full the glass is, but also from what the drinking vessel is made.

* Laura Rothstein is Professor of Law and Distinguished University Scholar at the University of Louisville Louis D. Brandeis School of Law. B.A., University of Kansas; J.D., Georgetown University Law Center. Professor Rothstein began her work in disability law in 1979 as a consulting attorney with the Developmental Disabilities Law Project at the University of Pittsburgh School of Law. That experience led her to teach, write, and lecture extensively on disability rights issues. She is the author of numerous books, book chapters, and articles on disability law.

1. Robert Dinerstein, *The State of Disability Law in the United States in 2008: How Full Is the Glass?*, Jacobus tenBroek Law Symposium Transcript (2008).

2. 42 U.S.C. §§ 12101–12213 (2000).

3. 20 U.S.C. §§ 1400–1491 (Supp. IV 2004).

4. 42 U.S.C. §§ 3601–3631 (2006).

5. 29 U.S.C. § 794 (2000).

My point is that often there are unintended consequences of well-intended policy decisions. It may be prudent, therefore, particularly in the area of disability policy, to consider those possible consequences before going too far in both legislative and litigation-based advocacy in various areas. Those who advocate on behalf of individual clients—especially for class actions—or in litigation on behalf of disability rights groups should consider the ultimate consequences of the advocacy.

My perspective comes from almost thirty years of work in disability discrimination law, beginning with advocacy for individual clients in a wide variety of legal matters—including employment, special education, and deinstitutionalization—in a law school clinic program at the University of Pittsburgh. From that experience, I became an “advocate through education.” Through my writing,⁶ teaching, and conference presentations, I try to educate various audiences about disability policy, why it is a good policy, and how to most effectively implement it.

This work has enabled me to see, in a broad perspective, how this set of laws and policies sometimes is not as effective as it might be in accomplishing equal opportunity. I concur with Professor Dinerstein’s general assessment that we have a very enviable “array of federal statutes” and the laws play a very “symbolic role . . . in galvanizing people with disabilities, their allies, and society at large.”⁷

I. WHAT IS GOING WELL AND WHAT IS NOT—WHERE IS THERE WATER IN THE GLASS?

The year 2008 marks the 35th anniversary of Section 504, the beginning of comprehensive disability discrimination law at the federal level. Advocates for equal opportunity for individuals with disabilities would certainly like to be further along in accomplishing the goal, but there has been progress. Since 1973, there has been substantially greater awareness of disability issues and a substantially greater presence of individuals with disabilities in almost all aspects of society.

Employers are doing a better job of identifying essential functions, providing accommodations, and implementing ways to resolve disputes without litigation. Many employment cases are not litigated, not because employees do not succeed often in court, but because many employment cases are resolved through negotiation, mediation, or settlement and because employers have changed their practices in the first place.⁸

The built environment is better. Architects and designers are much better at ensuring accessible design. This has been helped by the

6. LAURA ROTHSTEIN & JULIA ROTHSTEIN, *DISABILITIES AND THE LAW* (3d ed. 2006) [hereinafter *DISABILITIES AND THE LAW*]; LAURA ROTHSTEIN, *DISABILITY LAW: CASES, MATERIALS, PROBLEMS* (4th ed. 2006); LAURA ROTHSTEIN & SCOTT JOHNSON, *SPECIAL EDUCATION LAW* (4th edition in progress 2009).

7. Dinerstein, *supra* note 1.

8. See Sharona Hoffman, *Settling the Matter: Does Title I of the ADA Work?*, 59 ALA. L. REV. 305 (2008), for an excellent analysis of the role of settlements and other reasons why data on litigation should not be the sole basis for evaluating the effectiveness of the ADA.

increasing awareness that accessible features often benefit others, not just individuals with disabilities. For example, ramps and curb cuts help the person with roller luggage, a baby stroller, or a delivery cart as often as they provide access for wheelchair users.

Since the 1975 enactment of the special education mandate, IDEA, there has been a dramatic increase in the number of individuals able to enter higher education. These individuals have generally found a proactive and positive approach by most higher education institutions.

A great deal of technical assistance and guidance is available today. Much of it is assisted by the Internet. Government agencies, the Job Accommodation Network, the Association of Higher Education and Disabilities, and numerous other groups provide substantial guidance on accommodations, best practices, and templates for procedures. Often this information is only a few clicks away.

The improvements in technology have been positive. Not only is guidance and technical assistance much more accessible than it was in 1973, but individuals with mobility impairments can readily engage in activities such as online shopping and research that would have required significantly greater effort and challenge. Assistance is also available to support those designing websites to ensure that they are accessible to individuals with visual impairments or learning or other disabilities that make accessing the Internet difficult. Real time transcription for individuals who are deaf has allowed for greater participation. Kurzweil reading machines and other materials that allow an individual with a visual impairment or learning disability to access books and other literature much more easily have been developed over the years.

Although there have been gains, and life for individuals with disabilities is certainly much better than it was before 1973, there is much that is in need of attention.

In the area of education, amendments to the original 1975 statute and Supreme Court decisions have addressed a number of issues including attorneys fees, transition services, remedies, and disciplinary removal.⁹ There are, however, a number of areas where greater attention is needed. These include greater consideration to disciplinary removal and school choice. Greater clarity on these matters was provided in the 1997 and 2004 amendments to IDEA, but these issues still create great concern for both parents and schools. Unfortunately these amendments do not address all of the issues that arise in the array of school choice plans (including vouchers programs and magnet programs) that might affect a student with a disability.¹⁰ The No Child Left Behind policy under the Bush administration had laudable goals, and was intended to ensure better services and achievement measurements for all students, including those with disabilities. The woeful lack of resources, however, along with other concerns about the workability of that policy in a variety of ways—such as “teaching to the test”—has made revision of

9. For a review of the developments in special education law, see *DISABILITIES AND THE LAW*, *supra* note 6, at Chapter 2.

10. See generally Laura Rothstein, *School Choice and Students with Disabilities*, in 332 *SCHOOL CHOICE AND SOCIAL CONTROVERSY* (Stephen Sugarman & Frank Kemerer eds., 1999).

this policy essential.

Higher education is the area with the greatest experience and evolution in ensuring participation of individuals with disabilities.¹¹ Because Section 504 of the Rehabilitation Act applied to most colleges and universities, these institutions learned how, at an early stage, to ensure accommodations for students with disabilities.¹² Areas in need of attention include greater clarity on privacy of student records and balancing concerns about safety on campus for students with mental health problems. Student housing accessibility requirements and testing accommodation requirements need clarification. Although perhaps not a high priority, an issue increasingly facing higher education institutions is the documentation related to assistance and companion animals. This is true not only for higher education, but also for public accommodation and employment issues. A thoughtful assessment by the Department of Education about the balance between the needs of the individual and the impact on others would be helpful.

The built environment is certainly better, but thirty-five years after the Rehabilitation Act and eighteen years after the passage of the Americans with Disabilities Act, it is inexcusable that new facilities built by some major corporations are designed with major barriers to access. Because damages are not available under Title III of the ADA, there is insufficient incentive to litigate. Unfortunately, some of the most successful litigation involving public accommodations has the potential of backlash from the business community, particularly small businesses. The practice of some litigants seeking only monetary awards as a settlement rather than to remove the barriers, has caused the legal world and the business community great consternation. Courts have used a variety of procedural mechanisms to dismiss these cases, such as requiring proof that the individual demonstrate the likelihood of returning to the facility in order to demonstrate harm and the right to a remedy. These litigants and the decisions that result from vexatious litigation have the potential of reducing the effectiveness of the public accommodations requirements of the ADA. Such vexatious litigation may also reduce public support.

The fact that twenty years after the Fair Housing Act Amendments multi-unit dwellings are still being built without appropriate accessible design features is troubling.¹³ While litigation has increased in this area, that is not always the most effective way to accomplish the desired results.

Mass transit access improved after the ADA provided greater clarity than had been previously provided under a set of confusing federal requirements.¹⁴ Lack of resources, however, often means that

11. See generally, *DISABILITIES AND THE LAW*, *supra* note 6, at Chapter 3.

12. Laura Rothstein, *Southeastern Community College v. Davis: the "Prequel" to the Television Series "ER,"* in *EDUCATION STORIES* (Michael Olivas & Ronna Schneider eds., 2007) (includes a detailed discussion of the evolution of disability policy in higher education and its impact on other areas).

13. *DISABILITIES AND THE LAW*, at §§ 7:6-7:11.

14. *DISABILITIES AND THE LAW*, at §§ 8:4-8:14.

individuals with severe mobility impairments for whom paratransit is essential are often left with extremely inefficient means of transportation because of scheduling issues.

Resource challenges are a major barrier to the full implementation of the policies of the deinstitutionalization movement which gained momentum in the 1970s, and has resulted in an overarching policy of placement in the community.¹⁵ While the legal mandates are generally clear, implementing them at the state and local level has been challenged by lack of funding.

Myths, fears, and stereotypes still plague individuals with mental illness. They still face undue scrutiny in professional certification processes in most states.¹⁶ They still face challenges in the employment arena, in accessing health care, and in accessing services in a variety of other ways often related to employment and health care access.¹⁷

Technology has been a double edged sword.¹⁸ It provides a means for many with mobility impairments to do research and shop online, but the challenges of using a keyboard and a screen with only visual access and a mouse can mean that many with visual impairments and some mobility impairments face greater difficulty in accessing the world than they did before.

Two interrelated areas in need of attention are access to health care¹⁹ and the definition of disability, particularly in the employment sector. The fact that most Americans access health care through employer-provided health insurance has been problematic. Employers, who may be willing to make the accommodations for a variety of disabilities, are understandably concerned about some of the high costs of health care for certain conditions such as cancer, diabetes, and mental illness. An effective means of addressing that dilemma is needed. Other health care issues needing attention include the current disincentive for individuals receiving government medical benefits to seek employment because they will lose more comprehensive health care coverage.²⁰ And the lack of parity for individuals with mental illness is a serious problem.

The most important issue to be addressed, of course, is the definition of who is covered. This has been the primary obstacle to equal opportunity in employment.²¹ The Supreme Court narrowed the definition in 1999 in the *Sutton* trilogy²² by establishing that mitigating

15. DISABILITIES AND THE LAW, at §§ 7:12–7:13.

16. DISABILITIES AND THE LAW, § 5:8.

17. Laura Rothstein, *Protection for Persons with Mental Disabilities: Americans with Disabilities Act and Related Federal and State Law*, in LAW, MENTAL HEALTH CARE, AND MENTAL DISORDER (Brooks & Cole, 1995); Laura Rothstein, *Law Students and Lawyers with Mental Health and Substance Abuse Problems: Protecting the Public and the Individual*, 69 U. PITT. L. REV. (forthcoming Spring 2008).

18. DISABILITIES AND THE LAW, at § 9:5.

19. DISABILITIES AND THE LAW, at §§ 10:1–10:2.

20. Hoffman, *supra* note 8, at 332.

21. DISABILITIES AND THE LAW, at § 1:4 & Chapter 4.

22. *Sutton v. United Air Lines, Inc.*, 527 U.S. 451 (1999) (holding that individuals whose vision was corrected with eyeglasses or contact lenses were not disabled); *Albertson's, Inc. v. Kirkingburg*, 527 U.S. 555 (1999) (holding that a truck driver with correctable monocular vision was not disabled); *Murphy v. United Parcel Services, Inc.*, 527 U.S. 516 (1999) (holding that an

measures (such as medication or eyeglasses) that minimize the level of impairment caused by disabilities *should* affect the characterization of one's disability. Before 1999, courts almost automatically considered those with HIV, serious mental illness, and epilepsy (and often even those with cancer and diabetes) to be disabled, and focused on issues of whether the individual was otherwise qualified or whether the requested accommodation was reasonable. Since 1999, however, courts are regularly dismissing these cases because the complainant lacks standing as a person with a disability.²³ So, the individual whose medication for mental illness causes dry mouth who requests water at the work station does not have the opportunity in court to demonstrate that this is reasonable. This is not what the drafters of the Rehabilitation Act or the ADA intended.

Other employment issues needing attention are the definition of what constitutes a major life activity and immunity of state agencies from certain ADA remedies in employment discrimination cases.²⁴

This review of areas needing attention is certainly not exhaustive and most of them were also noted by Professor Dinerstein. My commentary focuses not only on what needs attention, but how major concerns might best be addressed. Certainly more water is needed in the glass, but how we fill it and what the glass is made of must be considered as well.

II. WHAT IS NEEDED TO ACCOMPLISH THE GOAL OF EQUAL OPPORTUNITY?

Professor Dinerstein correctly notes the importance of the relationship between societal acceptance of and attitudes towards individuals with disabilities and the effectiveness of legal policies in achieving goals of social change.²⁵ His recognition of the mixed reactions is why I think that great care should be given to how to best respond to deficiencies in existing policy. The avenues for accomplishing the goal of equal opportunity include legislation, regulation, interpretation, education, negotiation, mediation, litigation, and appropriation.

Equal opportunity starts with *legislation*, but it does not stop there. Regulations and agency guidelines interpreting the regulations are important. The *regulations* and agency *interpretations* of the statutes have been important in avoiding litigation. Program administrators and employers who understand what they are required to do are much less likely to intentionally violate discrimination law. Department of Education Office for Civil Rights opinion letters in the area of higher education and K-12 education have been quite helpful in addressing concerns without resorting to costly litigation. Guidance from other

individual with high blood pressure controlled by medication was not disabled).

23. DISABILITIES AND THE LAW, at § 4:9.

24. DISABILITIES AND THE LAW, at §§ 1:8; 4:8 & 4:21.

25. See generally Dinerstein, *supra* note 1.

federal agencies has also been valuable.

This guidance is one form of *education*. A proactive approach to avoiding disputes in the first place includes education. Federal agencies as well as a number of advocacy groups provide substantial technical assistance on how to implement a wide array of requirements. These range from accommodating individuals with mental illness to auxiliary aids for individuals with hearing impairments. With the ever-expanding World Wide Web, finding such assistance is often quickly available. Education not only includes providing information on how to implement policy, it also affects public attitudes towards disability policy.²⁶

The school setting, the workplace, and rental housing are all situations where adversarial parties are likely to have an ongoing close relationship. For that reason, alternative dispute resolution (including *negotiation* and *mediation*) can be an important part of resolving disputes while retaining a positive environment among the parties. Some states specifically provide for voluntary informal dispute resolution in special education cases. Employers who understand the value of an interactive resolution should and often do build in systems to resolve requests for accommodations and other concerns. In rental housing settings, a means of addressing disagreements other than litigation might prove useful. The benefits of using means other than litigation include reduced costs to all parties and often a less tense continuing relationship. Implementing these programs more broadly and developing more training for mediators, negotiators, and others should be a high priority.

Unfortunately, even with statutes, regulatory and agency guidance, and technical assistance about means of compliance, *litigation* is sometimes necessary. Such litigation not only enforces rights, but the court opinions provide critical interpretation about disability laws. In important Supreme Court decisions, involving issues such as access to courthouses,²⁷ deinstitutionalization and community placement,²⁸ and provision of health care to individuals with HIV,²⁹ litigation seems to be the only route to nondiscrimination and equal opportunity. Some cases are brought by plaintiffs whose primary focus is on the individual client. But others are brought on behalf of advocacy groups, with the goal of not only achieving a remedy for one individual, but to achieve a broader goal of affecting overall policy implementation or an entire class of individuals with disabilities.

26. Laura Rothstein, *Don't Roll in My Parade: Sports and Entertainment Cases and the ADA*, 19 REV. LITIG. 400–432 (2000) (discussing positive public attitudes towards the ADA as found in media coverage).

27. *Tennessee v. Lane*, 541 U.S. 509 (2004) (holding that access to state and local courthouses is not shielded by 11th Amendment immunity).

28. See *City of Cleburne v. Cleburne Living Center*, 473 U.S. 432 (1985) (holding that although mentally retarded individuals are not entitled to heightened scrutiny, the denial of a special use permit for a group home was unconstitutional); *City of Edmonds v. Oxford House, Inc.*, 507 U.S. 970 (1993) (holding that zoning ordinances that affect group homes are not exempt from examination under the FHA); *Olmstead v. L.C.*, 527 U.S. 851 (1999) (holding that in most circumstances mental health treatment should be provided in community settings rather than in institutions).

29. *Bragdon v. Abbott*, 524 U.S. 624 (1998) (holding that dental offices were subject to Title III of the ADA and that the plaintiff's HIV status was a disability because it interfered with her major life activity of reproduction).

And finally, there is a critical need for greater governmental *appropriation* at all levels and in all areas to ensure that equal opportunity goals are accomplished. Education, generally, and special education, in particular, are woefully underfunded today. In the area of health care, high costs associated with providing personal assistance to individuals with severe impairments often prevent independent living. Those who could live with substantial independence in the community too often remain in large institutions, nursing homes, or hospital settings because there are insufficient funds for staff and housing in group homes or in other independent settings. Appropriations for training personnel and for the facilities and programmatic costs themselves are critically inadequate.

III. A STRATEGIC APPROACH—ENSURING THAT THE GLASS IS MADE OF THE RIGHT MATERIAL

As the previous sections illustrate in broad strokes, while the goals of disability discrimination law are much closer to being met than they were thirty-five years ago, there is still much to be done. My concern is that zealous advocates may not always be strategic in seeking to accomplish those goals. Returning to Professor Dinerstein's metaphor about whether the glass is half full or half empty from the perspective of the inquirer, coupled with my twist on the question—asking what the glass is made of—I would suggest that if we think the container itself needs to be changed, that we ensure that we minimize unintended negative consequences. If we replace the container—by amending the statute—we may find that the container is too heavy or too slippery or too fragile. Then it will not matter whether the glass is half full or half empty because it is simply too difficult to pick up and use.

The ADA Restoration Act³⁰ is the most important current advocacy effort. While it rightfully attempts to amend the definition of who is covered, there is great danger in trying to go too far. Most would agree that individuals with HIV, epilepsy, diabetes, serious mental illness, and cancer should not have their claims summarily dismissed as being not currently substantially limited in major life activities. It is essential to find a reasonable way to return to the pre-*Sutton* interpretations of coverage.

By amending the statute to include a very broad spectrum of individuals, however, great burdens can be placed on programs that must then expend costly administrative effort to respond to requests for accommodations from individuals previously not covered even before *Sutton*. This may mean that those in greatest need of services will be less likely to get them because of resource challenges. For example, in higher education,³¹ the area with which I have the greatest experience and expertise, extending coverage to individuals with moderate

30. ADA Restoration Act of 2007, H.R. 3195, 110th Congress, introduced July 26, 2007.

31. See generally, Laura Rothstein, *Millennials and Disability Law: Revisiting Southeastern Community College v. Davis: Emerging Issues for Students with Disabilities*, 34 J.C. & U.L. 167–199 (2007–08).

impairments, such as anxiety and panic attacks, will surely stretch the resources of the disability service offices in providing accommodations. The funding spent on administrative costs in evaluating requests and implementing accommodations for individuals who are not in greatest need will surely make it much more difficult to ensure accommodations for those with substantial impairments. It is not that I think we should not try to work with students with anxiety and panic disorders in a reasonable way, but to mandate it within Section 504 and the ADA could create an extreme burden at most colleges and universities, even those with large offices. Anyone who thinks that colleges and universities can simply find these funds has not been paying attention to the massive budget challenges facing higher education today.

Attorneys representing advocacy groups (not individual clients) might give careful thought about whether in some areas litigation may ultimately lead to backlash, whereby Congress would seek to limit the statute in response. For example, the litigation involving websites rightfully raises a concern about ensuring access to technology for those with visual impairments. The unfortunate result might be, however, that not only are the major chain stores, hotels, and other large entities subjected to the reasonable accommodation mandates of the ADA, but the small start up “Mom and Pop” store, restaurant, or other business without the technical expertise or the financial means of acquiring it, would be shut down because they have inaccessible websites. The litigation in the public accommodations arena, which requires the complainant to demonstrate the probability of returning to the location,³² should possess a much greater evidentiary burden than litigation regarding websites. Everyone can easily claim an intent to return to a website to shop or get information. While it has been suggested that the cost of making these websites accessible is small, for a small business, it can be prohibitive. While technical assistance may help most small businesses comply, it will not save many from costly litigation in defending an ADA Title III action. This is an example of an area where federal agency guidance on what is required—before the courts act and public backlash results—would be quite helpful.

There are many other examples of good faith advocacy efforts to change the law creating unintended consequences that negatively affect equal opportunity. My perspectives should not be taken to mean that the status quo is fine, and that any change will only have negative effects. To the contrary, I think it is critical that issues such as the definition of who is disabled, the immunity of state agencies, and other issues noted above be addressed through statutory amendment. But I feel strongly that if these changes are not made carefully, we risk the “legislative fatigue” that occurs when Congress thinks that something has been taken care of and does not want to spend time on it again any time soon.³³

Civil rights leaders, including Martin Luther King, Jr., and Justice

32. DISABILITIES AND THE LAW, at § 6:17.

33. Mark Rothstein, *Genetic Exceptionalism and Legislative Pragmatism*, 35 HASTINGS CENTER REPORT 27 (2005) (raising concerns that broad policy reform may be lost in favor of genetic-specific legislation).

Thurgood Marshall were certainly strategic in deciding which battles to fight and how and when to fight them.³⁴ Justice Louis D. Brandeis,³⁵ an attorney advocate before he was a Supreme Court Justice, wrote the first Brandeis Brief in 1908, using social and economic factors in arguing for upholding the constitutionality of Oregon's law limiting women's working hours. Surely he would have preferred to argue for better working conditions for all workers. Politically, however, that argument was unlikely to succeed at the time, and he chose to fight the battle he could win. These are certainly strong exemplars, demonstrating the value of strategic and thoughtful advocacy. They were not individuals who were simply too cautious or lacked the courage to fight necessary battles. And because they were strategic, while the results of their efforts may not have been all that others wanted, they surely achieved more success than that of a collective attack and advocacy, heedless of the importance of societal acceptance and attitudes towards change.

So, I would encourage well-meaning advocates who are trying to fill the glass to focus not only on adding water, but to making sure that the vessel holding the water will not break, leak, leach chemicals, or be too heavy; and also to continue efforts to fulfill the goal of equal opportunity for all individuals with disabilities.

34. Richard Kluger, *SIMPLE JUSTICE: THE HISTORY OF BROWN V. BOARD OF EDUCATION AND BLACK AMERICA'S STRUGGLE FOR EQUALITY* (2004); Juan Williams, *THURGOOD MARSHALL: AMERICAN REVOLUTIONARY* (1998).

35. Philippa Strum, *LOUIS D. BRANDEIS: JUSTICE FOR THE PEOPLE*, Chapter 7 (1984). Justice Brandeis also knew how to use the media to garner public support for many of the causes on which he worked.