

Achieving accessible health care for people with disabilities: Why the ADA is only part of the solution

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Abstract

People with various disabilities encounter numerous physical and programmatic barriers to receiving health care of equal quality and effectiveness as that received by people without disabilities. Litigation and settlement negotiations under such federal laws as the Americans with Disabilities Act of 1990 have resulted in the removal of access barriers in specific instances, but have not yet resulted in the kind of systemic change needed in the health care delivery system. This article analyses some of the factors that make accessible health care so difficult to achieve. Accessible health care is viewed through a public health lens by which changes in public policy and social views of disability are necessary for achieving sustainable long-term success. The advantages and disadvantages of judicial policy making in the analogous contexts of tobacco cessation and Title VI medical discrimination in the United States is briefly discussed. The powerful but blunt tool of litigation is analyzed as only one tool among an array of public policy and legislative tools needed to effect barrier removal in the field of health care, especially among the smaller provider clinics and practices where a majority of outpatient visits take place. Lawsuits and other policy tools, such as enacting further legislation to link accessibility standards to federal agency enforcement, creating federally funded technical assistance centers that will disseminate practical policy and procedural tools to providers, and mandating the gathering of disability-specific disparities and effectiveness data, must work in concert to transform our health care system. © 2010 Elsevier Inc. All rights reserved.

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Health care and the broad sweep of the ADA

The rise of the disability rights movement, both in the United States and internationally, has been founded in large part on a change in how people with disabilities understand themselves. The concept of disability developed by many pioneers in the disability rights movement posits that disability cannot simply be equated with a physiological or mental condition defined by a medical category. Rather disability arises from the fact of an individual's impairment and how that impairment interacts with both the built environment and the social, cultural and economic norms, perceptions and stereotypes of the society in which the individual lives. Commonly called the "social model" of disability, its proponents advanced its tenets in opposition to the traditional "medical model," in which a diagnosis would fully define what people with disabilities could and

could not do, where and how they could live, and their capacity to make life decisions for themselves.

The enactment of the Americans with Disabilities Act of 1990 [42 U.S.C. § 12101 *et seq.*, Pub. Law 101-336, hereinafter ADA] was the first attempt, both in the United States and internationally, to imbed the social model of disability in to law [1]. The "three prongs" of the ADA's definition of disability are:

- (a) a physical or mental impairment that substantially limits one or more of the major life activities of such individual;
- (b) a record of such an impairment; or
- (c) being regarded as having such an impairment [42 U.S.C. § 121021].

The third prong is based on the understanding that an individual is discriminated against and "disabled" when he is treated by those around him *as if* that individual has an impairment. In other words, subjection to the stereotypes, misperceptions, and assumptions of others about disability can be as disabling as the functional limitations arising from a physiological or psychological impairment

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or its treatment.¹ A second revolutionary aspect of the ADA is its requirement that entities covered by the law must provide “reasonable accommodations” to qualified applicants or employees with disabilities and/or make “reasonable modifications in policies, practices, or procedures” to enable people with disabilities to fully and equally enjoy goods, services and facilities available to the public [42 U.S.C. § 12112(b)(5)(A)]. The requirement for reasonable accommodation or modification captures the understanding that people with disabilities are impeded by society’s structural and procedural assumptions about how human beings do things. With respect to construction, the ADA puts forth a schedule for accessibility in the built environment that prioritizes compliance with accessibility standards in newly built and newly altered facilities, but also requires some degree of accessibility in existing older facilities.

Together, the imbedding in the law of the social model of disability and the concept of reasonable accommodation or modifications are meant to ensure that people with disabilities can fully enter the mainstream of American life. The ADA is also remarkable for the scope of its nondiscrimination mandate. The federal law applies broadly to telecommunications, and the activities of both state and local governments and privately owned entities. Intended to cover such varied aspects of daily life as employment, transportation, recreation, shopping, and civic engagement, the act also explicitly covers the private entities of a “pharmacy, insurance office, professional office of a health care provider, hospital, or other service establishment” [42 U.S.C. § 12181(7)(F)].

In terms of enforcement, individuals with disabilities have the right to file administrative complaints about providers and/or health care programs that receive federal funds² to the Office of Civil Rights (OCR) in the Federal Department of Health and Human Services (HHS) [28 C.F.R. § 35.170–172], and the right to bring private litigation against state/county operated health care entities, health care entities that receive federal funds, and privately owned entities of any size [28 C.F.R. § 35.172(b) and 28 C.F.R. § 36.501 (T III lawsuit)]. The U.S. Department of Justice (DOJ) may also initiate and investigate complaints against private health care entities,

and file a lawsuit where it reasonably believes there is “a pattern or practice of discrimination in violation of the Act” and/or “the discrimination raises an issue of general public importance” [28 C.F.R. § 36.502–503]. As complaints and lawsuits are filed against inaccessible providers and health care entities, provider awareness about inaccessibility and the physical and programmatic (those involving practices, policies, and procedures) barriers to health care [2] faced by people with disabilities should increase and the barriers themselves should steadily decrease.

Unfortunately, 20 years after the passage of the ADA, health care is far from accessible for people with various disabilities. Research and reports from the U.S. Surgeon General, the Institute of Medicine, The National Council on Disability, the Centers for Disease Control and Prevention, and other private health research organizations show the accumulating evidence that people with disabilities are underserved and poorly served in a health care system that is rife with physical and programmatic barriers for people with various disabilities, and peopled by providers with little or no awareness of disability culture who are not even aware of how these barriers profoundly compromise the quality of care they provide [3–7]. Such common health care performance and consumer satisfaction measures as the Healthcare Effectiveness Data and Information Survey (HEDIS) and Consumer Assessment of Healthcare Providers and Systems (CAHPS) surveys have only recently developed and tested disability-specific questions [8,9]. Disability is still not recognized as a group characteristic for qualification as a Medically Underserved Population or Health Professions Shortage Area under the criteria established under the Public Health Services Act [42 U.S.C.A §§ 330(b)(3) and 332], or a health disparity population under the Minority Health and Health Disparities Research and Education Act of 2000 (Pub. Law 106–525, hereinafter MHDREA).

People with disabilities and the use of litigation in the context of the U.S. health care system

Obtaining quality care in the complex and fragmented American health care system is a challenge for everyone and not only people with disabilities. The U.S. delivery and administrative system features myriad actors subject to often competing motives such as public health and safety, cost control, the search for new treatments, profit maximization, the push for evidence-based medicine, and the imperative to reduce gaps in coverage [10].

The average health consumer, especially one who does not or can not obtain health insurance through employment, is faced with a bewildering array of insurance, organizational, and provider choices that all come with fine print conditions and exception clauses. The ADA’s reference to “the professional office of a health care provider” [42 U.S.C. § 12181(7)(F)] as an entity that is subject to the law’s nondiscrimination mandate seems almost quaint 2

¹ The original wording of the definition of disability has not been altered by the *ADA Amendments Act* of 2008 (P.L. 110–325), which came into effect January 1, 2009. Instead, the *ADA Amendments Act* clearly directs a change in how the words of the definition should be interpreted and corrects prior overly strict and narrow judicial interpretations of the definition.

² Note that while this article speaks mainly in terms of the ADA, references to federal law include Section 504 of the Rehabilitation Act of 1973 (“Section 504”), U.S.C.A. 29, § 794, predecessor legislation to the ADA. Section 504 prohibits discrimination in federally funded programs and activities and its application is particularly important in health care as most providers and health care facilities, including private entities, receive federal funding through Medicare, Medicaid, and/or federal block grants. See *United States v. Baylor Univ. Med. Ctr.*, 736 F.2d. 1039, 1042, 5th Cir (1984), *cert denied* 469 U.S. 1189, 105 S.Ct. 958 (1985).

decades later, when providers practice within professional, regulatory, and administrative layers that determine how providers get paid, establish managed care systems and goals, set rules for insurance eligibility, and oversee office management.

People with disabilities are also not the only minority groups to encounter problems with gaining and maintaining access to health care. As a cross-cutting population group, people with disabilities of different racial and ethnic minorities, socioeconomic, status and genders face the same access and service problems that other minority groups face [11–14], as well as numerous unique challenges to obtaining the health care services that are generally available to people without disabilities.

First, people with various functional limitations, including seniors and people with chronic conditions who may not self-identify as a “person with a disability” or be considered such by a provider, must contend with pervasive physical and programmatic access barriers that arise from the preliminary step of obtaining needed health coverage or making an appointment [3–7,15,16]. Providers, physician groups, health maintenance organizations, country/state/federal government agencies, and other intervening administrative layers between the payer and the provider have little or no idea of how to handle or answer requests for information about the existence of physical and programmatic barriers. People with disabilities therefore cannot even make informed choices about where to seek accessible care.

It also cannot be assumed that people with disabilities no longer encounter instances of outright startling prejudice: women with disabilities who are not given reproductive counseling or services because of the assumption that they are not sexually active [17,18]; doctors “reassuring” the parents of a baby with developmental disabilities that they need not take the baby home [19]; failing to give treatments, procedures, or advice to people with disabilities that would be given to similarly aged nondisabled persons on the assumption that the former has less to live for and therefore should go “gentle into that good night” sooner rather than later [20].

It can be argued that if people with disabilities face special problems in obtaining health care, then they also have a “special solution” in the ADA. Like all civil rights laws, including state laws where they exist, the ADA gives individuals covered by the law the right and responsibility to act as a “private attorney general” who can bring a private lawsuit to enforce the nation’s nondiscrimination goals. However, even the strongest rights-oriented person with a disability can find it especially difficult to bring a lawsuit in the health care context. Administrative complainants and plaintiffs can fear reprisal from a provider or specialist with whom they need an ongoing relationship. People typically would not choose to engage in the time-consuming and taxing activity of bringing a lawsuit if they are ill or not feeling well for the reason(s) that originally prompted them to seek health care. Complaints and

lawsuits rarely resolve quickly enough to provide any relief for those who need immediate barrier removal to receive a needed service [18]. Furthermore, the limited systemic impact of lawsuits brought against individual providers and even larger hospitals and clinics can further magnify these difficulties, because the individual with a disability who brings a suit is also very likely to encounter the same barriers elsewhere (e.g., lack of sign language interpreters [21], inaccessible medical diagnostic equipment), which will make finding another provider or obtaining quality care from a new provider problematic.

A second challenge that is unique to people with disabilities in the health care context is the fact that the “medical model” of disability remains deeply imbedded in the health care profession where the focus on a patient’s presumably inherent deficits can also justify a traditional medical paternalism that still can be absorbed from superiors and colleagues. While a few innovative disability education courses for medical professions have been developed, medical school in general still emphasizes clinical treatment of a condition, not a person [22–24]. As a result, health care providers may be confident that they are fully equipped to handle the primary condition(s) that a person with a disability is identified with, but have little or no idea of how to work with that individual to maximize his or her overall health and level of functioning.

As one commentator noted in a special 2009 issue of *The Lancet* that tried to look beyond the medical model, “one of the biggest barriers to accessing appropriate health care is the attitude of health professionals, which might further isolate and stigmatize people with disabilities. Despite what many health professionals might assume, people with disabilities can be healthy, do not necessarily need to be “fixed”, are often independent, and might well be consulting for a reason unrelated to their disability” [25].

Paternalistic or patronizing provider attitudes and adherence to the medical model do not merely lead to insult and reduced choice. They lead to inadequate examinations, failures to diagnose, worsening health, and possible institutionalization or death for people with disabilities who cannot obtain the care they need because providers locate the problem in the person. It is the patient who cannot get on the table or hold still in the MRI machine, cannot communicate quickly or well enough for an assigned exam slot, or cannot read the printed materials warning of drug interactions. It is too easy to forego the interactive effort needed to find a procedural, technological, or mechanical solution, and there is insufficient targeted dissemination of disability technical assistance and best practices for providers, clinics, and hospitals to follow. Above all, there is no clear authoritative call *within* the health care system directing all levels of the system to work together on barrier removal and provide equally effective care to people with disabilities.

A third challenge that is related to the second is the specialized and fragmented nature of health care delivery, where providers are often categorized according to the

specific body part or psychosocial issue that she or he treats. Individuals who have multiple disabilities or who develop conditions unrelated to their known primary diagnosis face tremendous challenges getting effective and sufficient care coordination that will enable providers to, at the very least, avoid treatments and/or medications that work at cross-purposes, or at best, facilitate the exchange of expertise needed for holistic health maintenance. The almost half million children with intellectual and developmental disabilities who annually become young adults and must transition out of the independent interdisciplinary system of care that they and their families have negotiated since their birth face similar care coordination issues when seeking adult health care services [26]. These ongoing care coordination issues raise an additional layer of access problems for people with disabilities.

Finally, obtaining equally effective health care for people with disabilities requires the conceptual understanding that we must recognize and fight physical and programmatic barriers and discriminatory attitudes and actions that *commonly* affect people with disabilities, while also fighting *for* the development, dissemination, and use of specific modifications, specialized knowledge, and clinical experience that people with various disabilities and conditions require. It is easy to see how ADA complaints and lawsuits can be wielded to achieve barrier removal, especially in a straightforward case brought against a single provider who is intransigent on barrier removal or prejudicially denies services. It is harder to see how the ADA can be directly used to encourage the education on disability culture, provision of equal health care, and exchanges of specialized information that people with disabilities also need to maintain their health. Even putting aside the difficulty of bringing a lawsuit or complaint, this specificity of modifications or level of health care accommodations can easily fall outside of the knowledge and experience of the typical attorney, mediator, or judge involved in an ADA lawsuit.

Accessible health care as a public health concern and a social imperative

The removal of structural and programmatic barriers would only be a critical first step toward achieving the broad public policy change needed for sustainable and equal health care for people with disabilities. For example, effective barrier removal does involve providers taking proactive steps such as training staff to offer accommodations, determining what structural changes are required under federal and state law, and developing detailed office accommodation procedures and policies. However, long-term benefit will not accrue from these changes until every part of the health care system acknowledges that it does a poor job of maintaining health and wellness for those who do not fit into a physical or mental “norm” and accepts ongoing responsibility for altering the status quo. Provider education faculties and professional associations, regulatory and quality control

agencies, federal and state Medicaid and Medicare entities, managed care organizations, and insurers, in concert with people with disabilities, are among the groups that have important roles to play in creating an accessible health care system, irrespective of any single entity’s awareness or analysis of its liability under the ADA.

As is the case with all civil rights laws, the ADA’s enforcement mechanisms generally rely upon the violation of a single individual’s rights, or in the case of a class action, the rights of a legally and factually similarly situated group. This legal emphasis on the wrongs suffered by one person may obscure the numerous public health aspects of accessible health care, including the many correlations between disability and older Americans, those who are poor, minorities, and those who are uninsured [27–30].

The link between poverty and disability is especially startling, with disability acting as both a cause and a result of poverty. One recent research report found that “[p]eople with disabilities account for a larger share of those experiencing income poverty than people in any single minority or ethnic group (or, in fact, all minority, ethnic and racial groups combined)” [31]. The prevalence of disability is also higher among working-age African Americans (17%) and Native Americans (22%) than among whites (12.6%) [32]. Health care for people with disabilities is therefore a public health concern in the same way that the availability and quality of health care for other vulnerable groups has public health dimensions, with the *additional* factor that unlike many underserved groups, disability is not a closed category. As the American population ages (and/or engages in armed international conflict), greater numbers of people will acquire functional impairments and encounter physical and programmatic barriers to needed health care services.

The Institute of Medicine raised disability as a topic of public health in its 1991 and 1997 reports [33,34], and in its 2007 report focused entirely on the health and wellness of people with disabilities, highlighting the interrelationship between the public and private aspects of disability:

In considerable measure, the future of disability in America will depend on how this country prepares for and manages a complex array of demographic, fiscal, medical, technological, and other developments that will unfold in the next several decades. Much can be done now to make this future one that enables people with disabilities to lead full and productive lives. Inaction will lead to individual and societal costs—avoidable dependency, diminished quality of life, increased stress on individuals and families, and lost productivity....

Over their life spans, the majority of Americans will experience disabilities or will have family members who do. People may not realize it, but the support that they give today for policies that affect future funding for disability-related programs is a statement about

the level of support that they can expect at later stages in their own lives.

This report underscores the growing evidence that disability is not an unavoidable consequence of injury and chronic disease but is substantially affected by the actions that society takes—in the public arena and in commerce and other private domains [4].

The use of litigation, either in tort or under civil rights law, to pursue broad public policy goals is hardly unprecedented. Public health campaigns against smoking, on AIDS awareness, and aimed at obesity prevention [35] have all invoked an array of public awareness and policy tools, and litigation is often brought or proposed for a specific tactical purpose. Analysis of such strategies in smoking litigation has found mixed results and yielded the conclusion that “[w]e should not underestimate the ability of litigation to captivate public attention and force an issue onto the policy agenda,” but “we must be careful not to overestimate the ability of litigation to result in desirable policy changes” [36]. Any analogy drawn between ADA cases and smoking and gun litigation is imperfect. Tort actions have a long common law history overlaid in the United States with a complex web of state regulation. The ADA confers statutory civil rights and remedies. Tobacco litigation is aimed at damage recovery and getting the industry primarily to *stop* doing something (e.g., marketing to youth), while ADA health care litigation is aimed more toward injunctive relief that impels the health care system to deliver barrier-free health care.³

Nonetheless, it is interesting to note that the shifting interplay between society’s views of individual responsibility and industry responsibility for behavioral harm is significant in both tobacco/gun cases and ADA cases. Historically individual tobacco litigants lost their cases because courts and juries agreed with the industry that individuals knew the risks of smoking and assumed them willingly. More recent tobacco class actions forced the tobacco industry to disclose highly damaging internal documents on the degree to which information about smoking’s health impacts had been withheld from the public, and eventually resulted in a “master settlement agreement” which explicitly sought to change public health policy by placing various restrictions on industry marketing and event sponsorships and creating an antismoking advertisement fund [36]. The entire course of litigation led to “changes in juror attitudes and public opinion generally regarding the industry’s veracity,” leading in turn to more successful litigation outcomes” [36].

³ Ironically, a successful 1995 case brought under the ADA by three children with asthma against McDonald’s had a successful tobacco policy outcome. In *Sharon v. McDonald’s*, 51 F.3d 353 (2d Cir. 1995), the court ruled that plaintiffs could show on a case-by-case basis if a smoking ban would be a reasonable accommodation. “In part as a response to this litigation, the defendants instituted no-smoking sections at their restaurants” [37] at 231.

In ADA cases, disability is usually not attributed as a matter of individual “fault,” but the medical model remains significantly imbedded in public attitudes. Encounters with physical and programmatic barriers can be viewed simply as the unfortunate but unavoidable consequence of having an impairment. Public attitudes about disability need to shift before there will be widespread recognition and support for the systemic changes needed in all levels of the health care industry. While lawsuits are unlikely to uncover conspiratorial documents among health care providers concerning the erection of physical and programmatic barriers, it is imperative to bring research findings concerning the inaccessibility of health care delivery to, and health disparities among, people with disabilities to public attention, through litigation or otherwise. Finally, disability advocates and attorneys should seriously consider the need to include explicit public health policy goals in ADA litigation settlements, such as requiring defendants to inform all patients of their ADA and 504 rights, establishing a common professional fund for providers who work in underserved areas to obtain accessible equipment, and disseminating best practices information as appropriate to fellow providers and sister organizations in the health care “chain” of delivery.

Some of the criticisms that commentators have leveled at judicial policy making [37] are among the factors that make litigation attractive in the health care context in the U.S. Civil rights-based laws are enacted in part to redress historical and ongoing power imbalances in those policy-making and legislative contexts where minority individuals have less political influence and decidedly less economic clout than industry interests. A single health care provider, a large health maintenance organization, and a state government may all have cost concerns that impede taking action quickly or at all to provide required accommodations, and the law already takes these concerns into account when accommodations and programmatic modifications are limited to those that are “reasonable” or that do not “fundamentally alter” the service provided. Courts should not be required to consider evidence on and fashion the cheapest solution for civil rights defendants.

Furthermore, an emphasis on a national standard for the provision of physical and programmatic accessibility would be welcome to people with disabilities so, for example, a person using a wheelchair in one state could be assured that his or her right to lift assistance would not be lost or unknown with a move to a neighboring state. Finally, it is important to note that ADA litigation in the area of health care is not an attempt to completely circumvent or substitute for the political or legislative process. Fears that litigation encourages “piecemeal rather than coordinated policy solutions” [37] are overstated if each case is viewed less as a goal in itself, and litigation is understood as a policy tool that can advance broader ongoing policy negotiations for more comprehensive solutions by equalizing the bargaining position of people with disabilities.

Litigation in general is a very effective but very blunt and narrow tool. It can force defendants to stop doing certain things and has a mixed record when it comes to forcing Defendants *to do* something. In Title VI medical discrimination cases, one commentator specifically notes the limited nature of the health care “victories” obtained by African Americans using federal antidiscrimination law, but goes on to argue that the importance of such litigation lay in “the threat litigation has played in negotiations conducted in the pursuit of equitable health care, even when an outright victory was not possible... viable litigation provides negotiation leverage where a courtroom victory is ultimately not possible for nonmeritorious reasons, such as the lack of resources to cover the expense of litigation and an inability to obtain adequate counsel” [38]. The author goes on to argue that two unfavorable court rulings nonetheless “helped to bring about access to health care for African Americans and to delay the departure of hospital facilities from poor minority communities” [38]. In the case of people with disabilities, litigation is being used as a means of speeding up the provision of accommodations and barrier removal among a recalcitrant health care system where providers and insurers are much more aware of malpractice liability than of their ADA obligations.

In light of the above analysis, it is fascinating to note that virtually all of the class action “impact” cases that have been brought under disability rights laws in health care have resulted in settlement or structured negotiations⁴ and *not* in a court decision. The first of these was a private lawsuit initiated in 2000 by three wheelchair users against Kaiser Permanente, the largest nonprofit health management organization (HMO) in the United States, in California state court under state access laws. The lawsuit alleged that inaccessible examination equipment and ubiquitous barriers prevented the plaintiffs and other people with physical disabilities from receiving equal and adequate health care services. The parties entered a settlement agreement in March 2001 [39]. In part due to the sheer size of the defendant, the Kaiser lawsuit unquestionably had a positive impact by prompting medical equipment manufacturers to develop accessible equipment such as height-adjustable examination tables to cater to Kaiser’s settlement obligation to procure and install accessible equipment. The equipment has since become more widely known, available, and affordable for all providers. The settlement’s requirement that Kaiser develop access policies and procedures over the 7-year term of the settlement also provides possible best practices for other HMOs and providers. At the same time, the Kaiser settlement did not have as wide a national influence on hospital and

HMO practice as might have been expected. Subsequent major hospital settlements include the 2005 settlement involving the private Washington Hospital Center complex, brought on behalf of four former patients and an organizational plaintiff, and particularly notable for the involvement of the DOJ [40], and the more recent 2008 *Olson v. Sutter Health* Class Action Consent Decree [41]. As in Kaiser, the settlements required the health care entity to acquire accessible diagnostic equipment, engage in barrier removal in physical facilities, and develop procedures and staff training for achieving programmatic accessibility for people with physical and sensory disabilities.

Similar results have been achieved through structured negotiations. The UCSF Medical Center Settlement Agreement was reached in 2008, with UCSF agreeing to evaluate its facilities, effective communication policies, and equipment, and remove barriers where necessary [42]. Disability advocates and attorneys in Boston deliberately engaged Massachusetts General Hospital and Brigham and Women’s Hospital for their leadership within the medical community, in the hope that their eventual commitment to remove barriers in their facilities and procedures would influence health care facilities beyond Boston and Massachusetts [43].

Given the deep-rooted complications of achieving barrier removal in the health care system, it is perhaps unrealistic to expect what has effectively only been a decade of higher-profile ADA health care litigation to achieve voluntary ADA barrier removal and compliance by providers who have not been directly sued. As the Mudrick and Schwartz paper in this issue shows, cases and complaints continue to be brought, and favorable settlements are being achieved perhaps more easily, especially in those areas such as accessible equipment acquisition and physical and programmatic barrier removal for people with physical disabilities where successful settlements have established certain “ground rules.” In effect, taken together the above settlements now serve as a kind of “national standard” on the accessibility areas and entities that are their focus (i.e., physical and programmatic barrier removal at hospitals and HMO-owned clinics for people with physical disabilities and effective communication needs). At the same time, the settlements do not appear to have had a widespread impact on the general public’s awareness of the barriers and health disparities experienced by people with disabilities. This is possibly a downside of settlement as opposed to an actual court victory (or even loss). In a settlement, a defendant entity’s desire to avoid publicity, as well as its concerns over cost, can have a greater influence over the negotiated outcome than over a court.

The ongoing inaccessibility of the smaller practices and clinics owned by a physician or physician group where over 83% of outpatient facility visits take place [44] remains a major problem. However, it may not be one that litigation can be expected to solve quickly or on its own, even if more cases were being brought, which scenario also raises concerns about the available allocation of HHS-OCR or DOJ attorney resources as well as the availability of

⁴ The structured negotiation approach, developed by Bay area attorneys Lainey Feingold and Linda Dardarian, involves entry into formal talks *before* filing a lawsuit. The putative plaintiff attorneys work together with the potential defendants to undertake reviews of the latter’s facilities and procedures and agree on policies that will improve access for people with disabilities in accordance with ADA standards.

experienced disability attorneys to bring private lawsuits. Clearly, disability health care advocates continue to need as broad a range of policy tools as possible.

Additional needed policy tools and responses

Arguably the most significant responses thus far to some of these longstanding access problems are contained in the recently enacted Patient Protection and Affordable Care Act (Pub. Law 111-148, hereinafter PPACA). For example, the nondiscrimination provisions of the new law ensure that people with disabilities and preexisting conditions will eventually have access to private health insurance. This provision addresses a significant gap in the ADA and will help ensure that people with disabilities will be able to obtain health insurance coverage after 2014. For the first time, the PPACA also identifies disability as a bona fide health disparity demographic for research and data collection, which will eventually promote research that may lead to a better understanding of the reasons for health and health care disparities among people with disabilities. The PPACA directs the U.S. Access Board, an independent federal agency that develops and maintains design criteria for the built environment, to develop new access standards for medical diagnostic equipment, which may eventually spur medical facilities and practitioners to purchase such equipment. Also, new funding provisions of the PPACA enable hospitals and schools of medicine and dentistry to develop educational curricula on disability competency, a critically important step to improving provider knowledge and awareness and that should ultimately help improve patient care. Moreover, federally conducted or supported health care and public health programs now must collect data on beneficiaries' disability status; survey health care providers in order to assess the number of providers with accessible facilities and equipment; and survey the number of employees of health care providers trained in disability awareness and patient care.

Although the new legislation holds great promise, the extent to which potential reforms will become a reality depends on numerous factors, including the content of implementing regulations being developed by various federal agencies that will “flesh out” details and gaps in the legislation, and the response of states to the new mandates. For example, while the PPACA calls for medical diagnostic equipment access standards, the law itself does not relate the standards to the ADA and its enforcement mechanisms. Health care entities covered by the ADA, therefore, are not strictly required to purchase the equipment, thus manufacturers may determine that they have no incentives to produce equipment that adheres to the standards. This gap can be closed through additional legislation that directs federal agencies responsible for ADA enforcement to issue regulations consistent with the standards, and directs providers and hospitals to purchase accessible equipment as they turn over all their diagnostic equipment over time.

In another example, while the new law calls for data collection on health care provider facility accessibility and disability awareness, it does not specify how that information will be obtained. Methods and procedures must be devised to determine the meaning of such terms as “access” and “disability awareness,” as well as to guide health providers who conduct patient, architectural, and programmatic access surveys, and report data.

Additional gaps relate to amending existing laws to include disability, increasing and coordinating research, developing technical assistance capacity, and promoting professional training. For example, the National Council on Disability (NCD) has specifically recommended that Congress amend the MHHREA to broaden the definition of “health disparity population” [5]. While the PPACA identifies disability as a disparities population, most research funding is allocated through the MHHREA; therefore, disability should be explicitly identified in the Act in order to ensure robust access to research resources. NCD also recommends that Congress amend the Public Health Services Act, which established the Substance Abuse and Mental Health Services Administration (SAMHSA), to include an emphasis on people with disabilities [5].

For health care providers, lack of access to information about the range of issues people with disabilities face as well as to a menu of possible policies and procedures, solutions, and accommodations also remains a significant challenge. Disability experts and opinion leaders who participated in a 2008 Health Care Summit sponsored by NCD recommended that federal legislation be enacted to establish a publicly funded system of technical assistance centers to disseminate easily obtained centralized information on defined standards of care and related practical resources on providing accessible care [5].

A new technical assistance guide, *Access to Medical Care for Individuals with Mobility Disabilities* [45], is an excellent illustration of an additional resource that may help remove barriers to health care for people with disabilities. Not only will this tool aid health care access litigation and enforcement, it instructs health care providers on how to ensure that lifting assistance is provided in a manner that achieves equitable care for people with certain mobility impairments. For these reasons, it should be readily available through a coordinated system of technical assistance.

While the PPACA includes funding for medical education that encompasses disability awareness, fully integrating disability content into the curricula of professional training and education, licensing and certification, continuing education, and accreditation programs remains an important challenge.

Conclusion

Perhaps the most important idea to take away from this article is the fact that litigation and other policy tools can

and should work in a complementary fashion to improve health care access for people with disabilities. Better disparities research and data will help support lawsuits [46]. Over time, increased barrier removal will encourage complainants who will be less afraid that they have no other provider options. The development, dissemination, and use of best practices and accessible diagnostic equipment through policy and legislative means will also slowly raise the “common provider” practice bar. As litigation prospects improve, positive court cases and settlements will in their turn provide greater impetus and support for further needed policy and legislative changes. Ultimately the disability community can hope for a “snowball” effect—one which does not forecast the accumulating factors for a disaster, but mitigates the injustice of a health care system that all too often remains closed to people with disabilities.

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