

## **Disability Discrimination in Health Care**

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When I was growing up in Canada, there were those very rare occasions when my first generation Chinese father and I would butt heads about something or other. During these *discussions*, my father, who refined his fluent English by going to movie theaters a lot as a young man in his 20s, would sometimes feel compelled to shake a finger in my face, and rhetorically ask in a bellicose tone “Who do you think you are?”

I would like to use this question as a way to frame my discussion of disability discrimination in health care, *within* the context of this year’s tenBroek symposium theme, “Disability Identity in the Disability Rights Movement.

### **Rights**

In the U.S., disability rights are generally recognized as hard-fought civil rights. When I first started working at DREDF in 2000, I often heard my Directing Attorney Arlene Mayerson explain to people that we only did disability civil rights, not “benefits.” By that, she meant that we do not generally take on individual administrative appeals for federal or state welfare benefits, instead focusing on impact litigation brought under such recognized cross-disability, civil rights statutes as the Americans with Disabilities Act of 1990 or Section 504 of the Rehabilitation Act of 1973. In addition to the *type* of case, however, she was also drawing a distinction between laws that are primarily aimed at redressing discrimination and prejudice experienced by PWD (I’ll call them “level playing field laws”), and long-existing laws that in practice, if not necessarily specific intent, provide many people with disabilities (PWD) with the material means of existence: income, accessible affordable housing, health care services, etc. This distinction has underlain our work for a long time. For example, we brought a case against the U.S. Social Security Administration, but it was not a case about benefits, per se. It didn’t directly question SSA’s qualifying standards for benefit payments, or whether the benefits comprise an actual living wage across the country. Rather, it was directed at getting notices and information in alternate formats for SSA beneficiaries, recipients, and applicants with visual impairments because inaccessible formats are a critical barrier to equally effective program participation. Our case was about leveling the playing field.

Over the last few years, as I have been working more in the area of disability health care discrimination and policy for PWD, I have been wondering if this underlying distinction, a foundational one at DREDF, between rights laws and benefits laws continues to make sense.

## Disability Discrimination in Health Care

I will be looking at disability discrimination in health care using three different lenses. There is not a watertight distinction between the lenses, of course, but it is useful for my purposes to use these three modes to examine health care discrimination.

The first involves the physical and programmatic accessibility of health care delivery and services. This is the category that is most linked with traditional civil rights laws. We know from published qualitative research, patient focus groups, anecdotal evidence, and such landmark litigation as *Metzler v. Kaiser*, a case brought by Disability Rights Advocates that settled in 2001, as well as our own work in this area that health care services remain deeply inaccessible, from clinic restrooms that do not have grab bars or reachable faucets to health plans that do not have benefit information or notices in alternate formats, from providers that refuse to provide ASL interpretation to insufficient appointment times to enable a person with speech impairments or some developmental disabilities to communicate and follow directions.

I'm going to focus today on the area of height-adjustable exam and diagnostic equipment, because I think of it as a discrete area of health care discrimination that combines physical accessibility issues and "programmatic issues" – a phrase that I use as a shorthand for issues concerning the need for modified policies, practices and procedures. Since most diagnostic and exam equipment is not designed for independent use, the effectiveness of accessible equipment depends in great part on staff training, exam room and diagnostic booking procedures, the availability of trained lift assistance policies, and so forth. Equipment issues also overlap with problematic provider attitudes and prejudice, since, for example, OB-GYNS who don't think that women with disabilities engage in sexual activities also tend to think that women with disabilities do not need full examinations or pap smears and can more easily dismiss the necessity for a woman getting, and safely staying, on an exam table in the first place. A provider that lacks accessible equipment such as exam tables and scales is very unlikely to be offering equally effective health care to people with a wide range of mobility, musculoskeletal, and balance impairments.

In California, Medicaid managed care plans are required by the state to administer a "facility site review" (FSR) to all their network primary care providers. The FSR originally had little to do with accessibility. It measured things like the temperature of the refrigerators where medication was stored and staff training on obtaining patient consent; plans often used nurses to administer the FSR. Providers would have to undergo the FSR when they first joined a plan, and every 3 yrs. In 2000, a couple of disability consultants started to work with four Medicaid managed care plans to develop a 55-item physical access survey that would be administered as a part of their FSR process. Beginning in 2006, these plans would administer the 55-item physical access survey in any primary care provider office where they were going through the FSR. A fifth plan also was persuaded to add the physical access survey to their FSR process. DREDF and a close colleague, Professor Nancy Mudrick at Syracuse University,

recently drew on this data to get the first hard statistics on the architectural accessibility of a large number of provider offices.<sup>1</sup> The data is derived from reviews of over 2300 primary care provider facilities in 18 of California's 58 Counties, serving about 2.5 million Medicaid enrollees and an unknown number of non-Medicaid enrollees since most providers do not see Medicaid patients exclusively. Moreover, because the 55 item survey contained one question relating to height-adjustable exam tables, and one question relating to accessible weight scales, the information gathered provides an accurate picture of the availability of accessible medical equipment.

The results for the medical equipment will not shock anyone here, but they are still a little stunning. Previous published literature had found that height-adjustable exam tables were present in 17-44% of provider offices, but those were studies with small numbers of participants (40 in 1 study, 68 offices in another), using sites that had essentially self-selected. From the California surveys, we found that 8.4% of provider sites have a height-adjustable exam table, and 3.6% have an accessible weight scale. We are talking about tables and scales, the two most basic pieces of equipment used in any routine patient visit. Also keep in mind that these are findings made in California, which has some of the oldest state disability rights laws in the country, arguably some of the most enlightened public attitudes about civil rights, and some of the newest architecture – which could well be spacious enough to hold accessible equipment, but apparently that theory is rarely tested. I very much doubt that there is any state in the country that has greater primary care availability of accessible exam tables and scales.

What are the alternatives when accessible tables and scales are not available? Wheelchair users are examined in their chair or offered a rug on the floor. Individual patients and medical staff risk injury in lifts, or patients are just turned away and told to bring someone to lift them next time. Medication is administered to people according to an obsolete weight measure, or patients are weighed on laundry scales. The fear of injury and indignity experienced by people with disabilities in the face of these so-called “alternatives” deeply discourages the scheduling of regular provider visits and preventive exams.

Title III of the ADA applies to places of public accommodation such as “the professional office of a health care provider.”<sup>2</sup> An individual who uses a wheelchair and visits a provider for health care services, is not given the use of the height-adjustable table she needs for an independent transfer, is not offered transfer assistance or cannot safely be transferred to the inaccessible table, and is given an examination in her chair, has the right to sue that provider because she has not been given an equally effective health care service. She has also likely not been weighed. The problem is how to effect needed systemic change by suing one provider at a time. And even the wheelchair user who would not balk at bringing a dozen Title III cases against “those poor little mom and pop” stores might hesitate before suing the provider that he already has a relationship with, or the specialist from whom he needs urgent ongoing treatment. Anywhere, where else is he going to go when over 91% of provider offices don't have a height-adjustable table? The fact is, over 83% of outpatient facility visits take place in these smaller practices and clinics owned by a physician or physician group. For me,

individual providers and clinics are a lot like small businesses. They both tend to be insulated and highly individualistic, they tend to listen only to their own, in this case, other providers or medical associations, and they can be a powerful lobby.

In some ways, however, health care is a uniquely bad arena for the application of disability civil rights. It is, after all, the cradle of the “medical model” of disability. Providers can assume they know all about *people* with disability because they are trained in how to fix and treat *disabilities*, but they are not nearly as well trained in how to maintain health and function, and respect the dignity, of people who have impairments that are not “fixable.” As Professor Elizabeth Pendo has pointed out in her 2008 article, health care professionals have attitudes that are as negative, if not more negative, toward people with disabilities as those held by the general public.<sup>3</sup> Professor Carol Gill, who directs the Chicago Center for Disability Research, found that “[i]n a survey study of attitudes of 153 emergency care providers, only 18% of physicians, nurses, and technicians imagined they would be glad to be alive with a severe spinal cord injury. In contrast, 92% of a comparison group of 128 persons with high-level spinal cord injuries said they were glad to be alive.”<sup>4</sup> These attitudes on the part of health care workers might be reassuring if one were taken to an emergency room *because* of a spinal cord injury, but they are much less reassuring if you go as a person *with* a spinal cord injury who is seeking treatment for a serious injury or illness. This is an older study, from before 2000, but professional cultures do not tend to change quickly, even with active encouragement from top leadership levels, and unfortunately, disability cultural awareness has not enjoyed such a high profile in the medical profession.

Let us be very clear. Health care providers may not “intend” to discriminate or hold active malice, but just as with small business owners or small hotel owners with pools, ignorance and willful blindness are no excuse. Inadequate examinations lead to failures to diagnose, worsening health, reduced function, and possible institutionalization and death for people with disabilities who cannot obtain the care they need. All civil rights are high stakes, and disability civil rights are no different.

Next I would like to look briefly at disability discrimination in health care through the lens of health care reform, and specifically the Affordable Care Act (ACA).

While the ACA does explicitly incorporate anti-discrimination laws within its provisions, and a number of the regulations proposed or already enacted under the ACA also generally require states or the state health exchanges to adhere to the requirements of federal anti-discrimination statutes, overall the ACA is not really thought of as a “civil rights statute.” Rather it is clearly considered, and criticized as, a health care law, and it is a “benefits statute” to the extent that it seeks reform and expansion of such longstanding public health care programs as Medicaid and Medicare.

And yet, I would like to draw attention to two particular provisions of the ACA that fit the disability civil rights mold pretty handily.

The first is s. 4203 of the Act, which directs the Access Board to develop standards for accessible medical equipment used in health care settings, including “examination tables, examination chairs . . . weight scales, mammography equipment, x-ray machines, and other radiological equipment commonly used for diagnostic purposes by health professionals.” In fact, the Access Board has issued those standards, and a call for public comment is due June 8. Those standards, of course, are not law in themselves, but the Department of Justice (DOJ) previously issued an Advance Notice of Preliminary Rulemaking relating to accessible medical equipment on the anniversary of the ADA in 2010, and is also a member of the Access Board. There is an expectation that the DOJ will adopt the recommendations of the Access Board, and go on to develop the scoping requirements that the Access Board did not. While we cannot predict when this will happen, its occurrence, and even the steps taken so far, give persuasive weight to the arguments of lawyers who are involved in complaints, lawsuits, or structured settlements addressing the absence of accessible equipment.

The other section I would like to highlight is, handily enough, s. 4302, and it concerns data collection. Specifically, it calls for the collection of additional information related to specific, known barriers to health care that affect individuals with disabilities, and that contribute to the health and health care disparities that such individuals experience. DREDF had a hand behind the scenes on just a couple of the ACA bill provisions, and funnily enough, the data collection standards include a requirement to “survey health care providers and establish other procedures in order to assess access to care and treatment for individuals with disabilities and to identify . . . the number of providers with accessible facilities and equipment to meet the needs of the individuals with disabilities, including medical diagnostic equipment that meets the minimum technical criteria.”

DOJ’s regulation of accessible equipment standards are clearly related to civil rights, but data gathering requirements can also play a crucial role. Key data both helps advocates to encourage providers to *meet* the accessibility civil rights of PWD, and provides information needed to bring effective litigation when encouragement just is not enough. Unfortunately, s. 4302 depends on HHS having or acquiring sufficient funds. That is, no appropriations were clearly connected to this section, and HHS’s notice of proposed rulemaking relating to implementation of this section did not have an identified plan for how this data would be obtained. But then this is, possibly, where our next lens could come into play.

The third and final lens through which I will view disability discrimination in health care relates to new and existing authority given to the Centers for Medicare and Medicaid (CMS) to waive the general Medicaid and Medicare rules. To put it very briefly, beneficiary freedom of choice is a basic Medicaid and Medicare requirement, and it is the ability to go to any provider that will take your public health insurance as payment. States have long had the ability to apply to CMS for a waiver of this requirement, along with a number of others, and mandatorily enroll Medicaid beneficiaries into managed care plans which can then limit the managed care enrollee’s choices to the plan’s available provider network. The ACA created a new office within CMS which has the additional authority to waive freedom of choice, along with a number of other

requirements, for Medicare beneficiaries. This enabled the new office to encourage and financially incentivize states to create new integrated health care delivery and financing systems for the approximately 9 million people nationwide who are dually eligible for both Medicare and Medicaid. These so-called “dual eligibles” include seniors, many of whom have disabilities, as well as younger PWD who have worked enough to qualify for Medicare. Dual eligible also include people who are often described as “the poorest, sickest, most vulnerable, and most frail” individuals enrolled in public health care – note the stereotypical descriptors that tend to make disability rights advocates cringe.

For a state like California, which has long invested in managed care, is in the midst of a budget crunch, and is convinced that capitated managed care payments are *the* way to both save money and provide better coordinated care, mandatory managed care for seniors and PWD is the ticket to the future.

Wait, one might ask, what does getting into the weeds on Medicaid and Medicare have to do with disability civil rights? Well, plenty, if we’re talking about the fact that in California, the state is proposing putting a decades old consumer-driven home and community-based supportive services program under the administration of managed care plans. In-home Supportive Services (IHSS) are the house-keeping and personal assistance services that allow many PWD to stay safely in the community, and they are primarily Medicaid-funded. Olmstead is the legal right to get out, but in California, IHSS has been critical to sustainably staying out. PWD, and anyone in California who believes in Olmstead, knows that there is a tremendous risk to putting managed care organizations, which have little or no experience with home and community-based services, and a background in delivering health care to mostly healthy families and children, in charge of IHSS.

At the same time, there is an extremely interesting opportunity here. If managed care organizations become the single entity that is financially responsible for both home and community based services and institutional care, we will have created a very direct way to **rebalance** the traditional public health care bias toward institutional care and nursing homes. Most managed care organizations will figure out, and a number have already figured out, what the disability community and Olmstead advocates have said for years, it is less expensive to provide PWD with services and supports to live in the community than to institutionalize PWD. Self-interest should therefore lead managed care organizations to focus less on nursing home services and more on home and community-based services. Call it the theory of the “Reptilian managed care company” if you will.<sup>5</sup>

Moreover, there is at least one additional opportunity presented by the movement to managed care. In June of last year, California started implementing a waiver obtained from CMS that placed 850,000 Medicaid-eligible seniors and PWD into mandatory managed care in 16 counties. The lead-up to the application for the waiver involved a lengthy process of consumer and advocate input and negotiation with the state that actually achieved some unprecedented consumer protections. One of these protections among the final waiver terms and conditions granted by CMS relates to the need for

physical and programmatic accessibility. A more refined version of the 55-item physical access survey that I mentioned before is now a required part of the facility site review for all plans participating in the waiver. The information obtained from those reviews is supposed to be placed on the plan web pages and made available to beneficiaries over the phone, and yes, the web pages are required to be accessible. At least, these are the requirements on paper. As usual, effective state and federal monitoring and enforcement of these requirements is an issue that advocates must continue to press on.

While I have been speaking primarily about California, the managed care lens applies to many of the almost 20 states that have taken up CMS's challenge to create integrated dual eligible programs, and the fact that managed care has done physical accessibility surveys in California shows that it can be done in other states. Third party managed care surveys *could* provide the heretofore missing infrastructure for gathering the disability health care data requirements of s. 4302 of the ACA. (Now we just need to work out a mechanism for administering programmatic surveys . . .)

Is this civil rights? It does not fit the traditional mold. Is this only about getting better benefits? And yet it has the capacity to systemically, slowly, improve accessibility in individual provider offices without suing every one; or at the very least, it has the potential to get a big pool of information about provider accessibility that may be subject to a public records act request because the plans directly contract with the state to administer Medicaid. And it has the capacity to effect a broader transformation of home and community-based services across the country than any single Olmstead case.

## **Conclusion**

PWD and their advocates and lawyers have had to work very long and very hard to try and dispel stereotypes: we live in the community, we hold jobs, we shop, see movies, and go to restaurants, we travel (and use hotel pools . . .), we have spouses and partners and children, we aren't all sickly and unhealthy, we aren't all on public welfare, and we can and do lead damn good lives. This is all true. And yet, it is also true that PWD are disproportionately poor. One 2009 study 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)."<sup>6</sup> PWD who are employed, as well as many of those on public health care programs, tend to have high out-of-pocket health care-related expenses such as personal assistance, durable medical equipment and supplies that simply are not sufficiently covered by insurance, or at least, not by affordable insurance or the insurance generally available through employment. PWD often could not afford to live in the community without such benefits as general assistance, Medicaid home and community-based services, food aid, and housing vouchers. Some PWD can independently handle the heavy demands of care coordination that come with multiple medical conditions and functional impairments, and some PWD need assistance. Some PWD have a network of family, friends and financial means, and many do not.

Can we integrate all these facts, and insist on a leveling of the playing field while also demanding a place at the decision-making table as benefit recipients? The ground feels far less steady here, not so level, but it is critical ground for us to defend as a community and as advocates.

Who do we think we are? As disability attorneys? As a disability community? (Take away the pointing finger and the bellicose tone.) Are we **only** about getting a level playing field? What if that playing field, one where health care is privatized and for profit, where health insurance is profoundly and *inexplicably* (I told you I was Canadian right?) linked with employment, where the public loves the idea of a universal public safety net but hates the idea of paying for it, and where popular culture continues to idolize youth and physical perfection, remains a highly unfriendly place for many, many PWD: those who are poor, those with mental disabilities, those with multiple chronic conditions, those who are seniors and newly acquiring disabilities after having worked all their lives in jobs where they simply could not save the amount needed to retire comfortably and well.

I am NOT calling for an “either/or” approach here – for choosing between what we have long accepted as civil rights litigation and involvement in benefits policy work and litigation. I am not asking us to choose between telling the stories of powerful, fully integrated individuals with disabilities and the stories of low-income people with disabilities who are one state or federal budget cut away institutionalization. As much as we may have felt a need in the past to distance ourselves from being poor, vulnerable, frail PWD on public benefits, “Who we are” as a community encompasses the stories of those counted successful in the world as well as those the world dismisses as failures, as well as all the myriad stories between. Who we are as disability rights lawyers increasingly must encompass both civil rights and benefits policy. I do not necessarily mean that the same people must do all the work – my father used to admonish me to not be “a woman with a hundred knives, all of them dull.” (Great way to school your children, those Chinese proverbs). No one can do everything. But at least we can equally value and celebrate the full gamut of disability rights work that we do.

Thank you. It has been an honor to be here and to speak today.



## Endnotes

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<sup>1</sup> These findings are published in N.R. Mudrick, M.L. Breslin, M. Liang and S. Yee, *Physical Accessibility in Primary Health Care Settings: Results from California On-Site Reviews*, 5 DISABILITY & HEALTH J. (2012) (forthcoming).

<sup>2</sup> 42 U.S.C. § 12181(7)(F).

<sup>3</sup> Elizabeth Pendo, *Disability, Equipment Barriers, and Women's Health: Using the ADA to Provide Meaningful Access*, ST. LOUIS U. J. OF HEALTH L. AND POL'Y 15, 43 (2008).

<sup>4</sup> Carol J. Gill, *Health Professionals, Disability, and Assisted Suicide: An Examination of Relevant Empirical Evidence and Reply to Batavia (2000)*, 6 PSYCHOL. PUB. POL'Y & L. 526, 520 (2000).

<sup>5</sup> This is a reference to the work of David Ball, who presented his fascinating work on jury selection and damages on a panel that took place April 19 at the 2012 tenBroek Symposium. , As I understand it, the "reptilian" brain refers to that portion of the brain that is devoted to primal survival and self-interest.

<sup>6</sup> Shawn Fremsted. *Half in Ten: Why Taking Disability Into Account Is Essential to Reducing Income Poverty and Expanding Economic Inclusion*. Washington, D.C.: Center for Economic and Policy Research (2009).