

# Shifting the Conversation: Disability, Disparities and Health Care Reform

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In keeping with the theme of this symposium, I would like to invite you to consider health care reform as a political shift in our thinking about the barriers and inequalities experienced by people with disabilities in our health care system. Traditionally, when these issues have been addressed, the predominant approach has been through a civil rights framework, specifically the Rehabilitation Act of 1973<sup>1</sup> and the American with Disabilities Act of 1990 (ADA).<sup>2</sup> Now, the Patient Protection and Affordable Care Act of 2010 (PPACA)<sup>3</sup> offers a new approach. This essay will outline the barriers to health and health care experienced by people with disabilities, drawing upon my ongoing research into the impact of inaccessible medical equipment.<sup>4</sup> I will then examine the role of civil rights law and of health care reform in addressing those disparities, and recommend the development of these as complementary, rather than competing, approaches.

## I. THE IMPORTANCE OF DEFINING “DISABILITY”

When I teach my class on disability law, I like to start the semester with a discussion of the definition of disability. It is always an interesting way to begin because we all think we know to whom

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<sup>1</sup> Rehabilitation Act of 1973, Pub. L. No. 93-112, 87 Stat. 355 (codified as amended at 29 U.S.C. § 701 (2006)).

<sup>2</sup> 42 U.S.C. §§ 12101–12213; ADA Amendments Act of 2008, Pub. L. No. 110-325, 122 Stat. 3553 (codified as amended in scattered sections of 42 and 29 U.S.C.).

<sup>3</sup> Patient Protection and Affordable Care Act, Pub. L. No. 111-148, 124 Stat. 119 (2010) [hereinafter PPACA]. PPACA was amended by the Health Care and Education Affordability Reconciliation Act of 2010, Pub. L. No. 111-152, 124 Stat. 1029 (2010).

<sup>4</sup> See generally Elizabeth Pendo, *Disability, Equipment Barriers and Women's Health: Using the ADA to Provide Meaningful Access*, 2 ST. LOUIS U. J. HEALTH L. & POL'Y 15 (2008) [hereinafter *Equipment Barriers*]; Elizabeth Pendo, *Reducing Disparities through Health Care Reform: Disability and Accessible Medical Equipment*, 4 UTAH L. REV. 1057 (2010) (forthcoming) [hereinafter *Reducing Disparities*].

“people with disabilities” refers. But we quickly discover that we have widely divergent definitions from each other, and even within our own thinking once we consider the definition in different contexts. Definitions do matter, as estimates of disability prevalence can vary widely based upon the questions asked.<sup>5</sup> So I think it is helpful to clarify who we might be talking about.

“People with disabilities” can encompass a large, incredibly diverse group. For example, my recent research focuses on people with mobility disabilities, but there are many other types of disabilities that impact health and access to health care. Disabilities can be physical, mental, sensory, developmental, intellectual, or any combination of these.<sup>6</sup> They also can be visible or hidden, congenital or acquired, or stable, progressive or episodic. There is also variation in the degree to which a given disability may be stigmatized, and in what context.

How many people might we find in this large and diverse group? According to the U.S. Census, one in five people in the United States – or 54.4 million of us – reported some level of disability in 2005.<sup>7</sup> Of those, 35 million, or 12 percent of the population, were classified as having a severe disability. Both the number and percentage of people who reported impairments or disabilities were higher than the last time the census information was taken in 2002.

The U.S. Census definition is broad, and includes anyone who reported using a wheelchair, crutches, cane, or any sort of mobility aid; had difficulty performing one or more basic functions of daily living such as caring for self or working; had a specific mental or emotional condition that seriously interfered with everyday activity; if working age, had a condition that made it difficult to work; or re-

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<sup>5</sup> Barbara M. Altman and Stephen P. Gulley, *Convergence and Divergence: Differences in Disability Prevalence Estimates in the United States and Canada Based on Four Health Survey Instruments*, 69 SOC. SCIENCE & MED. 543 (2009) (finding that in surveys of the U.S. non-institutionalized adult population, disability prevalence ranged from 15.3 percent to 36.4 percent depending on the survey questions asked). You can also find multiple definitions of disability in various federal programs. See, e.g., Cherry Engineering Support Services, Inc., *Federal Statutory Definitions of Disability*, Prepared for The Interagency Committee on Disability Research, McLean, Virginia (July 1, 2003) (on file with author) (collection of federal statutory definitions of disability).

<sup>6</sup> According to a poll by the Kaiser Family Foundation, just over 61 percent of those surveyed reported physical disabilities, about 15 percent reported mental disabilities, and 24 percent reported both physical and mental disabilities. Kristina Hanson et al., The Henry J. Kaiser Family Foundation, *Understanding the Health-Care Needs and Experiences of People with Disabilities: Findings from a 2003 Survey*, 4 (2003), <http://www.kff.org/medicare/upload/Understanding-the-Health-Care-Needs-and-Experiences-of-People-with-Disabilities-Findings-from-a-2003-Survey.pdf>.

<sup>7</sup> Matthew W. Brault, U.S. Census Bureau, *Current Population Reports, Americans with Disabilities: 2005 Household Economic Studies* 4 (2008), <http://www.census.gov/prod/2008pubs/p70-117.pdf>.

ceived federal benefits based on an inability to work.<sup>8</sup> This is potentially much broader than, for example, the definition of disability in the ADA, “a physical or mental impairment that substantially limits one or more of the major life activities.”<sup>9</sup>

## II. BARRIERS TO CARE AND HEALTH DISPARITIES

When I started researching the effect of inaccessible medical equipment on access to basic health care for people with disabilities a few years ago, I quickly discovered that the health status and health care experiences of people with disabilities had not received a lot of attention. In fact, several disability activists and advocacy groups have noted the lack of large, population-based studies on the health status and health experiences of people with disabilities.<sup>10</sup>

However, this trend does appear to be changing. For example, a 2009 report by the National Council on Disability, *The Current State of Health Care for People with Disabilities*, concluded that people with disabilities experience significant health disparities and barriers to health care; encounter a lack of coverage for necessary services, medications, equipment, and technologies; and are not included in the federally funded health disparities research.<sup>11</sup> It also noted the absence of training in disability competence issues for health care practitioners.<sup>12</sup>

I think there could be several reasons for the increased attention. One is the recent amendment of the ADA in 2008 and the renewed interest in people with disabilities and their experiences as a civil rights issue, generally. The passage of the Genetic Information Non-

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<sup>8</sup> *Id.*

<sup>9</sup> Americans with Disabilities Act of 1990, 42 U.S.C. § 12102(A) (2006) (amended 2008). An individual may also be considered disabled within the meaning of the ADA if he or she has a “record of such an impairment” or is “regarded as having such an impairment.” *Id.* at § 12102(2)(B)-(C). Although this definition was interpreted narrowly by the courts, Congress reestablished a broader interpretation through the ADA Amendment Act of 2008. Americans with Disabilities Act of 1990, as Amended, Pub. L. No. 110-325, § 2, Sept. 25, 2008, 122 Stat. 3553, also in Americans with Disabilities Act of 1990, 42 U.S.C. §12102(4)(A) (2006) (amended 2008). While the statutory definition of disability remains the same, the ADA Amendments Act added clarification to the meaning of “major life activity,” “impairment” and “substantially limits” by including broad definitions of the three. US Equal Employment Opportunity Commission, Notice Concerning The Americans With Disabilities Act (ADA) Amendments Act of 2008, available at [http://www.eeoc.gov/laws/statutes/adaaa\\_notice.cfm](http://www.eeoc.gov/laws/statutes/adaaa_notice.cfm) (last visited Jan. 3, 2011).

<sup>10</sup> See *Reducing Disparities*, *supra* note 4, at 1059-65.

<sup>11</sup> Nat'l Council on Disability, *The Current State of Health Care for People with Disabilities* 1 (2009), <http://www.ncd.gov/newsroom/publications/2009/pdf/HealthCare.pdf> [hereinafter *The Current State of Health Care*].

<sup>12</sup> *Id.*

discrimination Act in 2008<sup>13</sup> also sparked discussion about the relationship between genetic information, illness, and disability, and how those can or should be accounted for at work and in health insurance. And the national discussion around health care reform invited conversations about access and fairness overall, including for people with disabilities and chronic illnesses.

Although the increased attention is welcome, there is already powerful evidence of serious inequalities. For example, it is well known that people with disabilities face multiple barriers to quality health care services.<sup>14</sup> According to a recent review of the available evidence, people with disabilities use fewer preventive services, have poorer overall health outcomes, experience more preventable emergency room visits, and report more unmet needs and dissatisfaction in the services they do receive.<sup>15</sup> The 2009 report by the National Council on Disability referenced above confirmed these findings, adding that people with disabilities use health care at a significantly higher rate than people who do not have disabilities, experience a higher prevalence of secondary conditions, and experience more problems accessing health care than other groups.<sup>16</sup> In addition, the literature reveals that people with disabilities are less likely to receive basic preventive health care services, such as screening for breast and cervical cancer,<sup>17</sup> screening for prostate cancer,<sup>18</sup> screening for cardiovascular

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<sup>13</sup> Genetic Information Nondiscrimination Act of 2008, Pub. L. No. 110-233, 122 Stat. 881 (codified in scattered sections of 26, 29, and 42 U.S.C.).

<sup>14</sup> *Equipment Barriers*, *supra* note 4, at 16.

<sup>15</sup> Karen Hwang et al., *Access and Coordination of Health Care Service for People with Disabilities*, 20 J. DISABILITY POL'Y STUD. 28, 29-30 (2009) (collecting results of population-based surveys).

<sup>16</sup> *The Current State of Health Care*, *supra* note 11, at 10. Prior to this report, the Surgeon General published *Call to Action to Improve the Health and Wellness of Persons with Disabilities* in 2005. U.S. Dept. of Health and Human Services, *The Surgeon General's Call to Action to Improve the Health and Wellness of Persons with Disabilities*, at 22-24 (2005). Other sources include the first national survey of women with disabilities on their experiences with women's health care conducted in the years immediately following passage of the ADA by the Center for Research on Women with Disabilities at Baylor College of Medicine, Ctr. for Research on Women with Disabilities, *Health Disparities Between Women with Physical Disabilities and Women in the General Population*, Baylor College of Med., [www.bcm.edu/crowd/?PMID=1331](http://www.bcm.edu/crowd/?PMID=1331) (last visited Nov. 3, 2010) (footnotes omitted) (citing studies), and the screenings and evaluations of people with developmental and intellectual disabilities conducted by the Special Olympics, Corbin, S.B., Malina, K., and Shepherd, S., *Special Olympics World Summer Games 2003—Healthy Athletes Screening Data* (Washington, DC: Special Olympics (2005)); *Changing Attitudes: Changing the World. The Health and Health Care of People with Intellectual Disabilities*, 2 (Washington, DC: Special Olympics, Inc., 2005).

<sup>17</sup> *The Current State of Health Care*, *supra* note 11, at 57-59.

<sup>18</sup> Kristina Hanson et al., *supra* note 6, at 9.

disease for women,<sup>19</sup> and bone mineral screenings.<sup>20</sup> This is especially troubling since we know that many people with disabilities have what some researchers have called “thinner margin[s] of health” meaning many have greater health care needs and could experience worse outcomes in the absence of basic care.<sup>21</sup>

The literature reveals that people with disabilities experience a variety of barriers to care. I’ll use my current research into accessible medical equipment as an example. In 2008, I was participating in a symposium devoted to disability, reproduction and parenting and I thought I would talk about access to assisted reproductive technologies for women with disabilities.<sup>22</sup> I started to research the issue, and quickly discovered that women with mobility disabilities have trouble getting basic women’s health care – let alone using assisted reproductive technologies – because of inaccessible tables, chairs, scales, and mammography equipment.<sup>23</sup> Indeed, women reported inaccessible medical equipment as a significant and fundamental barrier to basic women’s health services.<sup>24</sup> I have since expanded my research to include barriers to basic preventative services for men and women with disabilities, focusing on common types of medical equipment such as examination tables and chairs, X-ray and imaging equipment, and weight scales.<sup>25</sup>

Examination tables are used for general examinations, pelvic examinations, and often for prostate exams. Examination chairs are mostly used for dental and eye exams, but they can be used for other types of exams as well. A standard table or chair is generally too high for a safe self- or assisted transfer of a person in a wheelchair to the table. Also, if you have any sort of mobility impairment, loss of grip or strength in your hands or arms, tremors, or even just something very temporary like a broken arm, you might need supports such as

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<sup>19</sup> Hwang et al., *supra* note 15, at 29; Thilo Kroll et al., *Barriers and Strategies Affecting the Utilisation of Primary Preventive Services for People with Physical Disabilities: A Qualitative Inquiry*, 14 HEALTH & SOC. CARE IN COMMUNITY 284, 285 (2006).

<sup>20</sup> Ashley Duggan et al., *What Can I Learn From this Interaction: A Qualitative Analysis of Medical Student Self-Reflection and Learning in a Standardized Patient Exercise About Disability*, 14 J. HEALTH COMM. 797, 798 (2009).

<sup>21</sup> *Reducing Disparities*, *supra* note 4, at 1060. (citing Gerben DeJong, *Primary Care for Persons with Disabilities: An Overview of the Problem*, 76 AM. J. OF PHYSICAL MED. & REHAB., May-June 1997, at S2, S3).

<sup>22</sup> Videotape: Session Two: Elizabeth Pendo - Ensuring Equal Access to Reproductive Health Care for Women with Disabilities, held by the St. Louis University School of Law Center for Health Law Studies (April 4, 2008), available at [http://law.slu.edu/news\\_center/multimedia/conferences/HL2008\\_disability.html](http://law.slu.edu/news_center/multimedia/conferences/HL2008_disability.html).

<sup>23</sup> *Equipment Barriers*, *supra* note 4, at 16-28.

<sup>24</sup> *Id.* (collecting sources).

<sup>25</sup> *Reducing Disparities*, *supra* note 4, at 1060-65.

rails or bolsters to allow you to safely stay on the table. If a patient cannot safely get or stay on an examination table or chair, a physician cannot perform an appropriate examination, and the patient may suffer discomfort, injury, or the delay or denial of treatment.<sup>26</sup>

X-ray and imaging equipment also present issues of accessibility for a variety of people with disabilities, as examinations typically require the patient to be standing or lying still while images are taken from specific angles.<sup>27</sup> Traditional mammography equipment, for example, requires the woman to stand still while images of each compressed breast are taken.

Scales are also important as weight gain and obesity can be linked to a lot of different diseases.<sup>28</sup> Weight measurement is also important to determine the appropriate dosages of many medicines, and as a basic part of prenatal care.<sup>29</sup> However, in a national survey of people with disabilities 60% of people who used wheelchairs reported not being weighed because there was never an accessible scale anywhere they received treatment.<sup>30</sup>

So, although the ADA requires that health care institutions and offices be accessible,<sup>31</sup> twenty years after passage of the Act, many people with mobility impairments cannot get on examination tables and chairs, cannot be weighed, and cannot use x-ray and other imaging equipment. What is going on here? Part of it is stereotypes and assumptions about people with disabilities. The problem is more than simply not having an accessible examination table – it is realizing that you need an accessible examination table. In the context of women's health, for example, surveys of health care providers indicate that many providers believe that women with mobility disabilities are not sexually active, and are not or should not be mothers. Of course, women with mobility disabilities are often sexually active and frequently do parent. However, if a provider does not perceive that a patient is in need of certain kinds of care – such as screening for sexually transmitted infections, or discussion about birth control or enhancing fertility depending on the patient's desires – then that care

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<sup>26</sup> *Equipment Barriers*, *supra* note 4, at 25.

<sup>27</sup> *Reducing Disparities*, *supra* note 4, at 1064-65.

<sup>28</sup> *Equipment Barriers*, *supra* note 4, at 25.

<sup>29</sup> *Id.* at 25, 26 (“Accurate weight measurement is also important to establish medication dosages. . . . Barriers to weight measurement are also problematic for pregnant women, as monitoring weight gain is an important aspect of basic prenatal care.”).

<sup>30</sup> *Id.* at 25 (“In a national survey of people with disabilities, sixty percent of the respondents who used wheelchairs reported problems being weighed due to lack of an accessible scale.”).

<sup>31</sup> *Id.* at 18.

will not be provided. Therefore stereotypes, false beliefs and invisibility are a significant part of the problem.<sup>32</sup>

### III. A CIVIL RIGHTS APPROACH: THE ADA

Traditionally, when these issues have been addressed, the predominant approach has been through a civil rights framework using the Rehabilitation Act and the ADA. As noted above, the ADA requires that health care institutions and offices be accessible.<sup>33</sup> Specifically, Title II and the Rehabilitation Act apply to all public entities including state and local public health care programs such as Medicare and Medicaid programs,<sup>34</sup> and Title III reaches private health care offices.<sup>35</sup>

There are several recent cases brought by private parties against medical facilities or doctors' offices in this context. The first was the 2001 California class action *Metzler v. Kaiser*,<sup>36</sup> in which three named plaintiffs raised claims of inaccessibility in the Kaiser Permanente system, all based on inaccessible medical equipment. The case was resolved with a comprehensive settlement, with Kaiser Permanente agreeing to surveys, self-study, training, changes to policies, practices and procedures to ensure access and equal care for people with disabilities, and of course, a plan to acquire and maintain accessible medical equipment.<sup>37</sup>

I was interested in this case because it was the first of its kind, so I searched for other private actions challenging inaccessible medical equipment. I found three others, *Equal Rights Center v. Washington*<sup>38</sup>

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<sup>32</sup> For example, women with disabilities are not seen as sexually active.

As one researcher put it, "[p]eople may wonder how a woman confined to a wheelchair can participate in intercourse, or how a woman with sensory loss can feel her genitals. More usually, people assume a disabled woman has no sexuality" (quoting Carrie Killoran, *Women with Disabilities Having Children: It's Our Right Too*, 12 SEXUALITY & DISABILITY 121, 123 (1994)). Of course, women with disabilities are sexually active. According to the CROWD Study, ninety-four percent of the women surveyed were sexually active at some point, and report as much sexual desire as women in general (citing M.A. Nosek et al., *National Study of Women with Physical Disabilities: Final Report*, 19 SEXUALITY & DISABILITY 5, 8 (2001)).

*Id.* at 42-47.

<sup>33</sup> *Equipment Barriers*, *supra* note 4, at 18.

<sup>34</sup> *Id.* at 49-54; 42 U.S.C. § 12132 (2000).

<sup>35</sup> *Equipment Barriers*, *supra* note 4, at 33-34; See 42 U.S.C. § 12181(7)(F) (2000); 42 U.S.C. § 12182(a) (2000).

<sup>36</sup> See *Settlement Agreement Metzler et al v. Kaiser Found. Health Plan, Inc., et al.* (Mar. 26, 2001), <http://www.drakelegal.org/downloads/cases/metzler/settlement.pdf>.

<sup>37</sup> *Id.*

<sup>38</sup> See *Settlement Agreement Among the United States of America Plaintiffs Equal Rights Center, Dennis Christopher Butler, Rosemary Ciotti, George Aguehounde, and Marsha Johnson and Washington Hospital Center Dep't of Justice Complaint No. 202-16-120*, [www.ada.gov/whc.htm](http://www.ada.gov/whc.htm) (last updated Dec. 29, 2005).

filed two years later in 2003, *Olson v. Sutter Health* filed in 2008,<sup>39</sup> and *Longo and USCF Medical Center* a structured settlement reached in 2008.<sup>40</sup> Each case was brought against a hospital chain, and reached a comprehensive settlement beyond what could reasonably be expected in court.

In addition to those four private actions, I was also curious about public enforcement activity by the DOJ on this issue. With the help of a research assistant, I reviewed all of the quarterly DOJ reports since they have been published in 1994 up through September 2009 and looked for instances of any kind of involvement in cases challenging architectural or physical barriers in a health care setting, and then those specifically involving medical equipment. I then summarized them into a chart (as I did with the private settlements), which suggested that the DOJ has been involved in a small but increasing number of cases during the past two decades.<sup>41</sup> Specifically, between 1994 and September 2009, the DOJ was involved in fifty-five actions involving architectural barriers in a health care setting, and twelve actions involving inaccessible medical equipment.<sup>42</sup> In addition, in October of 2009 the Department entered into a settlement with Beth Israel Hospital, a teaching hospital affiliated with Harvard University.<sup>43</sup> Interestingly, the Beth Israel settlement appears to have incorporated much of the language and findings that I had observed developing in the private settlements.

There have been other developments, as well. In July 2010, the DOJ also issued a guidance document about physical accessibility to places where health care is provided that included a discussion of

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<sup>39</sup> See [Proposed] Order Certifying a Settlement Class and Finally Approving Class Action Settlement, *Olson v. Sutter Health*, No. RG06-302354 (Cal. Super. Ct. July 11, 2008), [www.dralegal.org/downloads/cases/sutter/order\\_7-11-08.pdf](http://www.dralegal.org/downloads/cases/sutter/order_7-11-08.pdf).

<sup>40</sup> See Law Office of Lainey Feingold, *USCF Medical Center Settlement Agreement*, <http://llegal.com/2008/09/ucsf-settlement-agreement> (last visited Nov. 1, 2010) [hereinafter *UCSF Medical Center Settlement Agreement*]. Structured Negotiations combine both advocacy and dispute resolution methods and do not require litigation. “If all parties agree to participate, a legally binding written settlement agreement is negotiated and signed.” See Law Office of Lainey Feingold, *Frequently Asked Questions*, <http://llegal.com/faqs/#structured-negotiations>.

<sup>41</sup> *Reducing Disparities*, *supra* note 4, at 1067-71 (see Table 1, “Private Actions Challenging Inaccessible Medical Equipment,” and Table 2, “DOJ Involvement in Actions in a Health Care Setting”). Thank you to Stacy Connelly, J.D./M.B.A. (2010), Saint Louis University School of Law and Saint Louis University John Cook School of Business for his excellent assistance with this research.

<sup>42</sup> *Id.*

<sup>43</sup> *Settlement Agreement Among the United States of America and The Beth Israel Deaconess Medical Center Under Title III of the Americans with Disabilities Act* DJ# 202-36-195 (Oct. 27, 2009), <http://www.ada.gov/bidmsa.htm>.

equipment.<sup>44</sup> That same month, the DOJ issued a Notice of Proposed Rulemaking and invited public comment on the adoption of standards and scoping requirements for accessible medical equipment under Titles II and III of the ADA.<sup>45</sup>

Despite what looks like a promising increase in public and private enforcement activity, ADA litigation has yet to generate what I would consider a meaningful and widespread change in access, including the provision of accessible equipment. While I believe that the right to nondiscriminatory access to health care provided by the ADA can and should be protected, I am also interested in exploring how health care reform might support and advance those same goals.

#### IV. A NEW APPROACH: PPACA

The provisions of PPACA focus on expanding coverage, controlling costs, and improving the quality of the health care system. I would like to focus on three lesser-known provisions that relate most directly to people with disabilities, and the problem of inaccessible medical equipment that I have identified.

First, PPACA calls for the establishment of standards for accessible medical equipment, including “examination tables, examination chairs . . . , weight scales, mammography equipment, x-ray machines, and other radiological equipment commonly used for diagnostic purposes by health professionals.”<sup>46</sup> Specifically, it requires the United States Access Board to establish regulations and specific standards relating to accessible medical equipment in various health care settings.<sup>47</sup>

The Access Board is an independent federal agency charged with developing guidelines through a collaborative process. It follows a process common to most Federal regulations which provides an opportunity for public comment, and allows interested groups, including those representing designers, industry, and people with disabilities, to

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<sup>44</sup> *Americans with Disabilities Act: Access to Medical Care for Individuals with Mobility Disabilities*, [http://www.ada.gov/medcare\\_mobility\\_ta/medcare\\_ta.pdf](http://www.ada.gov/medcare_mobility_ta/medcare_ta.pdf).

<sup>45</sup> I submitted a Public Comment by letter dated January 24, 2011, supporting the DOJ’s adoption of standards and scoping requirements for accessible medical equipment in its proposed revisions to Titles II and III of the ADA, *see* *Nondiscrimination on the Basis of Disability in State and Local Government Services and Places of Public Accommodation; Equipment and Furniture*, 75 Fed. Reg. 43452 (proposed July 26, 2010) (to be codified at 28 C.F.R. pt. 35 and 36).

<sup>46</sup> PPACA, Pub. L. No. 111-148, 124 Stat. 119, sec. 4203, § 510(a)-(b) (2010).

<sup>47</sup> *Id.* § 510(a) (“Not later than 24 months after the date of enactment . . . the [Access Board] shall, in consultation with [the FDA], promulgate regulatory standards . . . setting forth the minimum technical criteria for medical diagnostic equipment used in (or in conjunction with) physician’s offices, clinics, emergency rooms, hospitals, and other medical settings”).

play an important role in the development of guidelines which are then proposed for public comment.<sup>48</sup> The two-year timeline suggests to me that the Access Board will not only develop standards for a table or a chair, but they are also going to consider what we call “scoping” which determines how much of this equipment should be required in a given office or facility, as well as the factors that go into making those kinds of decisions.<sup>49</sup>

The second important set of provisions in PPACA is aimed at collecting data. People with disabilities have not been studied as a federally recognized health disparities population. Although PPACA does not specifically identify them as such, it does require the collection of data based on disability status, which will provide some information to inform the development standards.<sup>50</sup> Also, there is some specific data collection related to accessibility of health care spaces and how much training providers have on disability related issues.<sup>51</sup>

The third aspect is provider training and education. The continuing problem and invisibility of inaccessible medical equipment suggests deeper issues, such as stereotypes and assumptions, and a lack of training and education in disability related issues for providers. Despite requests from some providers, few professional health care training programs address disability issues in their curricula. Now, there are financial incentives to develop such training and education programs, as PPACA provides support for grants and incentives to institutions for additional training in caring for “vulnerable populations” and in cultural competency, which could include people with disabilities.<sup>52</sup>

## V. A PROMISING DIALOGUE

Although the right to nondiscriminatory access to health care can, and should, be protected through civil rights law, health care reform offers a new and complementary approach. The two differ significantly in terms of standing, the definition of disability,<sup>53</sup> and en-

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<sup>48</sup> *Board Holds Forum on Medical Diagnostic Equipment*, U.S. ACCESS BOARD (July 30, 2010), <http://www.access-board.gov/news/mde-meeting.htm>. The Board develops guidelines, which do not directly affect the public but instead serve as the basis for standards issued by other agencies.

<sup>49</sup> *Reducing Disparities*, *supra* note 4, at 1074-75.

<sup>50</sup> PPACA, Pub. L. No. 111-148, sec. 4302, § 3101, 124 Stat. 119, 578 (2010) (to be codified at 42 U.S.C. § 300kk).

<sup>51</sup> *Id.* § 3101(a)(2)(D)(i-iii).

<sup>52</sup> *Reducing Disparities*, *supra* note 4, at 1080; *see generally* PPACA, Pub. L. No. 111-148, sec. 5307, 124 Stat. 119, 628-29 (2010).

<sup>53</sup> In contrast to the detailed definition of disability under the ADA, PPACA generally leaves the definition of disability up to the Secretary of Health and Human Services. For exam-

forcement mechanisms, just to name a few examples. So I think of this as an ongoing dialogue between two different ways we might think about or address inequities and disparities experienced by people with disabilities, rather than a transition from one model to another.

An example that illustrates the complementary nature of these two approaches is the concurrent, but independent, rule making processes by the DOJ and the Access Board. Currently, both the DOJ and Access Board are involved in developing standards for accessible medical equipment. The Access Board conducted a public information meeting on the new medical equipment accessibility standards on July 29, 2010<sup>54</sup> while the DOJ issued an Advance Notice of Proposed Rulemaking on July 26, 2010.<sup>55</sup>

PPACA was a significant factor that caused both the DOJ and Access Board to begin promulgating regulations. As stated above, PPACA amended the Rehabilitation Act and required that the Access Board promulgate regulations establishing “minimum technical criteria for medical diagnostic equipment used in (or in conjunction with) physician’s offices, clinics, emergency rooms, hospitals, and other medical settings.”<sup>56</sup> The DOJ’s Advance Notice for Rulemaking cites to this requirement of PPACA and states that “[a]s an Access Board member, the Department will work closely with the [Access] Board in the development of [accessible medical equipment] design standards.”<sup>57</sup> While the DOJ is not required to adopt the Access Board standards, it has stated that it “will not issue a final rule on medical equipment until the Access Board has completed its medical diagnostic equipment standards.”<sup>58</sup> Waiting until the Access Board has completed its process suggests that the DOJ is likely to adopt the

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ple, PPACA Data Collection provisions do not define disability but instead states that in collecting the data described, including disability status, the Secretary or a designee should develop standards for the measurement of disability status. Similarly, the evaluation of disparity data collection provides that the Secretary of HHS shall submit a report on the evaluation that identifies approaches for identifying, collecting and evaluating data on health care disparities on the basis of disability status. PPACA, Pub. L. No. 111-148, §1946(b)(1), 124 Stat. 119 (2010), amended by The Health Care and Education Reconciliation Act of 2010, Pub. L. No. 111-152, 124 Stat. 1029.

<sup>54</sup> *Board Holds Forum on Medical Diagnostic Equipment*, U.S. ACCESS BOARD (July 31, 2010), <http://www.access-board.gov/news/mde-meeting.htm>.

<sup>55</sup> See *Nondiscrimination on the Basis of Disability by State and Local Governments and Places of Public Accommodation; Equipment and Furniture*, 75 Fed. Reg. 43,452 (July 26, 2010).

<sup>56</sup> PPACA, sec. 4203, §510(a); OFFICE OF THE LEGISLATIVE COUNSEL, COMPILATION OF PATIENT PROTECTION AND AFFORDABLE CARE ACT 496 (June 9, 2010), available at <http://docs.house.gov/energycommerce/ppacacon.pdf>.

<sup>57</sup> *Nondiscrimination on the Basis of Disability by State and Local Governments and Places of Public Accommodation; Equipment and Furniture*, 75 Fed. Reg. 43,455 (July 26, 2010).

<sup>58</sup> *Id.*

Access Board standards, as it has done with other standards developed by the Access Board.<sup>59</sup> Lastly, the DOJ goes on to state that if it does adopt the Access Board standards that it will then develop specific scoping requirements.<sup>60</sup>

Addressing the health and health care experiences of people with disabilities as part of the larger project of health care reform creates the possibility of a more systemic approach than civil rights litigation alone. I am interested in exploring other aspects of PPACA that impact people with disabilities in this context, as well. As I have written previously, addressing the inequalities and disparities experienced by people with disabilities through these complementary approaches could also provide an opportunity to think about disability issues more broadly, and to connect any solution to a deeper and more informed understanding of disability rights and health care reform, generally.

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<sup>59</sup> The standards for buildings and facilities subject to Title II and Title III contained in the ADAAG is an example of the process. For the full text of the 2004 ADAAG, see Americans with Disabilities Act (ADA): Accessibility Guidelines for Buildings and Facilities, 36 C.F.R. pt. 1191 app. A (2004), available at <http://www.access-board.gov/adaag/ADAAG.pdf>.

<sup>60</sup> *Id.*