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2005

The Definition of Disability in the Americans with Disabilities Act: Its Successes and Shortcomings: Proceedings of the 2005 Annual Meeting, Association of American Law Schools Sections on Employment Discrimination Law; Labor Relations and Employment Law; and Law, Medicine and Health Care

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## **Repository Citation**

Hoffman, Sharona; Miller, Paul Steven; Feldblum, Chai R.; and Stein, Michael Ashley, "The Definition of Disability in the Americans with Disabilities Act: Its Successes and Shortcomings: Proceedings of the 2005 Annual Meeting, Association of American Law Schools Sections on Employment Discrimination Law; Labor Relations and Employment Law; and Law, Medicine and Health Care" (2005). Faculty Publications. 1575.

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THE DEFINITION OF DISABILITY IN THE AMERICANS WITH DISABILITIES ACT: ITS SUCCESSES AND SHORTCOMINGS: PROCEEDINGS OF THE 2005 ANNUAL MEETING, ASSOCIATION OF AMERICAN LAW SCHOOLS SECTIONS ON EMPLOYMENT DISCRIMINATION LAW; LABOR RELATIONS AND EMPLOYMENT LAW; AND LAW, MEDICINE AND HEALTH CARE

**Professor Sharona Hoffman**: Welcome to our program on the definition of disability. We have three terrific speakers today. This should be a very interesting program. This program is being recorded and will be published by the *Employee Rights and Employment Policy Journal*. I am Sharona Hoffman. I am going to be moderating this program. The format is going to be approximately twenty-five minutes for each speaker, and then we will take questions at the end.

Our three speakers are, first, Paul Miller, who as of August 2004 is teaching at the University of Washington School of Law. Before that he was one of the longest serving presidentially-appointed commissioners of the Equal Employment Opportunity Commission (EEOC). That is no small feat. I actually worked at the EEOC for part of that time, so he is my former boss. Paul has also held several other high-level federal government positions and serves on several important national boards. His talk is entitled "Let the Wild Rumpus Begin: the Definition of Disability Under the ADA."

Our second speaker will be Chai Feldblum, who is a professor of law and founder and director of the Federal Legislation Clinic at Georgetown University Law Center. She has been very active in drafting and promoting legislation that affects the disability community, and she is one of the authors of the Americans with Disabilities Act of 1990 (ADA). Chai's talk is about the tale of two cities: yes, perhaps one marginal neighborhood and one that's experienced some development.

Finally, we have Mike Stein, who is a professor at William and

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<sup>1.</sup> Americans with Disabilities Act, 42 U.S.C. §§ 12101-12213 (2000).

Mary School of Law and, for the last year, has been a visiting scholar at Harvard Law School, with additional fellowships in Harvard's Human Rights and East Asian Legal Studies programs. Mike also serves on several advisory boards of disability organizations, and he is currently working on a draft of the United Nations (UN) Convention on the Rights of Disabled Persons. He is going to be presenting a comparative international study of the definition of disability.

Professor Paul Steven Miller\*: Thank you very much, Sharona. I am pleased and honored to be here at this meeting, to be with all of you this week, and to be here as a member of this Association rather than as an interloper. As we approach the fifteenth anniversary of the passage of the ADA, one could say that the statute is smack in the middle of its adolescence. Now, I do not believe that the ADA is, in fact, the unruly teenager that some courts and business associations would want you to think it is. Rather, I think the ADA is a repressed child, one who is not allowed to become the person we expect or envision it to be.

As Sharona mentioned, I originally titled this talk, "Let the Wild Rumpus Begin," because, as the father of a five year-old daughter, my frame of reference revolves around her reading list. However, as I began thinking about this paper I realized that the title and the theme were all wrong. I was thinking "children" when I should have been thinking "teenagers." So, I toyed with calling my talk "The ADA and The Chamber of Secrets," or "The ADA and The Prisoner of Ashcroft," but those titles didn't seem right either. At the end of the day, I decided to call this paper, "Yossarian's Law, Addressing the Catch-22 of the Americans with Disabilities Act." The Catch-22 that many federal courts have read into this Act is, I think, one of the greatest impediments to the ADA becoming the civil rights law that its parents envisioned it to be.

Catch-22 is that mysterious military regulation from Joseph Heller's novel of the same name that keeps Joseph Yossarian engaged in the front line of war:

There was only one catch and that was Catch-22, which specified that a concern for one's own safety in the face of dangers that were real and immediate was the process of a rational mind. Orr was crazy and could be grounded. All he had to do was ask; and as soon as he did, he would no longer be crazy and would have to fly more

<sup>\*</sup> Professor of Law, University of Washington School of Law.

missions. Orr would be crazy to fly more missions and sane if he didn't, but if he was sane he had to fly them. If he flew them he was crazy and didn't have to; but if he didn't want to he was sane and had to.<sup>2</sup>

The Catch-22 of the novel was used by military superiors to retain their authority and preserve the status quo. It created a situation where you think that everything is perfect, but then Catch-22 applies, making everything impossible.

Catch-22 aptly applies to the problem with the way the courts are interpreting the ADA. To prevail in a disability discrimination lawsuit, plaintiffs must prove that they are covered by the ADA as a person with a disability.3 Unlike other federal civil rights laws, courts have defined disability so narrowly and stringently that once plaintiffs demonstrate that they are disabled enough to be covered by the statute, the courts find that they cannot possibly do the job: Catch-22. In addition, even if one lost a job, or was not hired, because of a disability, if the plaintiff demonstrates that he or she is able enough to function regardless of that disability, he or she is not protected by the ADA even though the disability was the reason for the discrimination: Catch-22. The court never gets to test the disability pretext for the adverse action because the plaintiff is not disabled; again: Catch-22. A great majority of ADA employment litigation and federal court opinions involve this issue of the definition of disability that is, who is impaired enough to qualify for protection from disability discrimination?

There are two reasons for the tremendous amount of litigation over the definition of disability. First, it is easier to prevail against an ADA claim by arguing that the person is not disabled than by arguing that the accommodation is not reasonable; that the accommodation presents an undue hardship; or that the person is, in fact, not qualified. Second, courts seek certainty. Coverage under the statute is determined by applying a contextual, flexible, individualized definition of disability, and our judicial system abhors vagueness. Standing under the statute is open to wide interpretation by a bench that does not generally understand the social and historical context of the disability experience. On the other hand, Title VII<sup>4</sup> employment discrimination cases are different because judges have a better

JOSEPH HELLER, CATCH-22, at 56-57. (1994) (1961).

See Sutton v. United Air Lines, Inc., 527 U.S. 471, 475 (1999).

<sup>4.</sup> Title VII of the Civil Rights Act of 1964, 42 U.S.C. §§ 2000e to 2000e-17 (2000).

understanding of the cultural and historical legacy of discrimination that Title VII seeks to redress. Thus, while Title VII litigation glosses over the prima facie requirement that the plaintiff belonged to a protected class, 5 ADA litigation rarely gets beyond this battlefield.

There are several rational and substantive reasons why the ADA's definition of disability is structured using this individualized analysis of who has standing. The disability experience, especially as it relates to employment discrimination, exists in a social context, and not simply within a medical framework. It involves the relationship between the individual and others; a relationship between the individual and the environment and the culture. By acknowledging this social context of disability through the individualized analysis of coverage, the ADA responds to disability myths and stereotypes and seeks to achieve economic integration in a way similar to the means used under every other civil rights law. Notwithstanding these very valid rationales, the definition is not working. The courts are excluding disabled victims of discrimination from the ADA's protection.

In its rulings in the *Sutton* trilogy,<sup>6</sup> the Supreme Court heightened the likelihood that, by successfully demonstrating disability under the statute, plaintiffs will be forced to prove themselves out of the ADA's protection. The Court held that if an otherwise substantially limiting impairment is corrected by a mitigating measure, that impairment does not presently substantially limit a major life activity and thus may not be a covered disability under the ADA.<sup>7</sup> Under these standards, impairments that were previously routinely considered disabling, like diabetes and epilepsy, were cast into a limbo of doubt because mitigating measures might render these conditions not substantially limiting. As a result, courts have been denying people with significant medical conditions protection from employment discrimination arising from those conditions.

For example, in Orr v. Wal-Mart,<sup>8</sup> the court found that an insulin-dependent diabetic pharmacist was not disabled under the ADA. The underlying issue was whether the pharmacist should be

<sup>5.</sup> See McDonnell Douglas Corp. v. Green, 411 U.S. 792 (1973).

Sutton v. United Air Lines, Inc., 527 U.S. 471 (1999), Murphy v. United Parcel Serv.,
 527 U.S. 516 (1999); Albertson's, Inc. v. Kirkenberg, 527 (U.S. 555 (1999).

<sup>7.</sup> See Sutton, 527 U.S. at 475.

<sup>8.</sup> Orr v. Wal-Mart Stores, Inc., 297 F.3d 720, 725 (8th Cir. 2002).

allowed to take an uninterrupted thirty minute lunch break to eat during his ten-hour shift as a pharmacist at Wal-Mart. Now, just think about that for all sorts of non-ADA reasons. Wal-Mart was arguing that the pharmacist couldn't take a thirty minute break during his ten-hour shift as a pharmacist. Think about that the next time you get your prescription filled. The uninterrupted lunch was necessary for this insulin-dependent, diabetic pharmacist to regulate his blood sugar and control his diabetes. Because the pharmacist was able to control his diabetes through medication and diet, the court found that he did not suffer any limitation of a major life activity and thus was not disabled.9 Since the pharmacist was not covered by the ADA as being disabled, the court never had to rule on the reasonableness of the accommodation sought.10

Similarly, in Fraser v. Goodale<sup>11</sup> another insulin-dependent diabetic worked in a bank that had a policy of not allowing people to eat at their desks. Because of this rule, Ms. Frasier was unable to eat immediately following a drop in her blood sugar. She became disorientated, passed out, and subsequently was terminated. The district court granted summary judgment concluding that Ms. Fraser was not disabled as she could control her diabetes by eating. 12 Ultimately, the Ninth Circuit found that there was a genuine issue of fact regarding whether she was limited in a major life activity and remanded the case.13

And, finally Gillen v. Fallon Ambulance Service14 provides a striking illustration of how the Sutton rulings have caused courts to deny ADA protection to those individuals who have successfully integrated themselves into the workplace. Though ultimately the decision was reversed by the First Circuit, the district court in that case found that a genetic amputee, born with only one functioning arm and with the other arm ending a few inches below the elbow, was not disabled and not covered by the ADA.15 The district court's conclusion was based largely on the plaintiff's testimony that there was nothing that she was not able to do because of missing a hand and that the plaintiff demonstrated an ability to lift and move patients

<sup>9.</sup> Id. at 724.

<sup>10.</sup> Id. at 725.

<sup>11. 342</sup> F.3d 1032 (9th Cir. 2003).

<sup>12.</sup> Id. at 1034.

<sup>13.</sup> Id. at 1045.

<sup>14. 283</sup> F.3d 11(1st Cir. 2002).

<sup>15.</sup> Id. at 17.

required for the job, albeit in a different and arguably more awkward manner than an emergency medical technician with two functioning arms. Since the plaintiff was able to perform the job functions and was upbeat about her prowess at challenging physical tasks, she had shown that she was not disabled.<sup>16</sup>

Each of these individuals experienced adverse employment actions based upon discriminatory stereotypes arising solely from their medical conditions. Yet, because they found ways to manage and accommodate their conditions, they were denied the protection of the ADA: Catch-22.

Oftentimes, courts confuse two separate and distinct issues in their analysis of the ADA. They collapse the question of whether an individual is disabled under the law with the very different question of whether the individual is qualified for the job. Several federal circuits have recognized the problem of the ADA Catch-22 and, at a minimum, I think that the First and Ninth Circuits discussed this paradox with consternation. They each seemingly invite the Supreme Court to reassess the ADA jurisprudence of the last decade. Particularly, they invite the Court to take another look at the *Sutton* trilogy to opt for a broader definition of a qualifying disability.

For example, in *Sullivan v. Neiman Marcus*, <sup>18</sup> the First Circuit explicitly stated that "by demonstrating that his ability to work is substantially impaired, he may demonstrate that he is unqualified for the job and therefore excluded from ADA protection. If he does not introduce that evidence, however, he may fail to show that he was substantially impaired." Similarly, in a different First Circuit case, the court noted the law required the individual to be both substantially limited and reasonably functional. <sup>20</sup> Now, in a Ninth Circuit case, concerning a plaintiff with a learning disability, *Wong v. Regents of the University of California*, <sup>21</sup> which was a Title II case, not an employment case, the dissent insightfully acknowledged that, "a history of academic success alone cannot justify the conclusion that as a matter of law a plaintiff is not disabled. To do so places the ADA

<sup>16.</sup> Id. at 20.

<sup>17.</sup> See Fraser, 342 F.3d at 1042; Gillen, 283 F.3d at 24.

<sup>18. 358</sup> F.3d 110 (1st Cir. 2004).

<sup>19.</sup> Id. at 114.

<sup>20.</sup> Calef v. Gillette, 322 F.3d 75, 83 (1st Cir. 2004) (Plaintiff diagnosed with attention deficit hyperactivity disorder and a history of verbal outbursts failed to show that he was disabled or qualified for the job of mechanic).

<sup>21. 379</sup> F.3d 1097 (9th Cir. 2004).

plaintiff in the 'untenable situation where success negates the existence of the disability, whereas failure justifies dismissal for incompetency.'"22

One way of addressing some of the most egregious manifestations of this ADA Catch-22 dilemma is to take a look at modifying the ADA to establish a per se category of presumptively covered disabilities for certain impairments. This concept of establishing presumptive disabilities under the ADA was first suggested in the scholarly literature by my good friend, Professor Mark Rothstein, two years ago, in a Washington University Law Quarterly article, 23 and few if any other scholars have continued to develop this idea. As Mark said, that article was met with deafening silence. With a category of presumptively covered individuals under the ADA, a prospective plaintiff in an ADA lawsuit would be presumed to be covered by the statute if the diagnosed impairment was defined to be a per se disability. If the impairment was not a per se disability, the individual would need to demonstrate ADA coverage through the existing, individualized, case-by-case analysis.

I believe that a category of per se covered disabilities would accomplish several goals. First, doing so would focus ADA litigation on some of the underlying discrimination at issue in the case. Second, it would avoid some of the vagueness and uncertainty of current statutory coverage. Third, such a measure may, in fact, reduce litigation and promote settlement of cases because employers do not have the incentive to roll the dice to get the case knocked out on summary judgment. Fourth, it would implement the ADA in a manner closer to Congress' legislative intent. The resulting change in the definition of disability would diminish some of the effect of the Catch-22 dilemma.

Justice Souter, writing for the majority in *Kirkingburg*, alluded to the theory that there may be disabilities which are presumptively covered by the ADA.<sup>24</sup> He wrote, "While some impairments may invariably cause a substantial limitation to a major life activity, we cannot say that monocularity does."<sup>25</sup> A presumptive disability designation would be ill-suited for conditions that vary in degree or in

<sup>22.</sup> Id. at 1110. (Thomas, J. dissenting)(quoting Andrew Weiss, Jumping to Conclusions in "Jumping the Queue," 51 STAN. L. REV. 183, 205 (1998).).

<sup>23.</sup> Mark A. Rothstein et al., Using Established Medical Criteria to Define Disability: A Proposal to Amend the Americans with Disabilities Act, 80 WASH. U. L. Q. 243 (2002).

<sup>24.</sup> Albertson's, Inc. v. Kirkingburg, 527 U.S. 555 (1999).

<sup>25.</sup> Id. at 566.

extent from person to person. Rather, per se disabilities would include a limited list of conditions that are static and variable in impact and whose symptoms are easily definable from person to person.

Per se disabilities could be established through regulations developed by the EEOC. The EEOC may look to other agencies and other standards, like Social Security, workers compensation schedules, or the *Diagnostic and Statistical Manual of Mental Disorders*, even though the purposes of these frameworks are different from the ADA. Disabling conditions such as paraplegia and quadriplegia, insulin dependent diabetes, epilepsy, loss of limb, clinical depression, schizophrenia, and bi-polar disorder might be good candidates for per se disability.

The Catch-22 dilemma that has been read into the ADA by many courts needs to be addressed and resolved if the statute is going to mature and develop into adulthood and fulfill the promise of responding to disability discrimination. A potentially politically viable first step might be to look at adding categories of presumptive per se disabilities in the ADA's definition. Thank you very much.

Professor Chai R. Feldblum\*: I am glad Paul started with trying to figure out how to describe the ADA as an adolescent. I often say in my talks that I do not have kids, I have laws. One of them is this adolescent who had his bar mitzvah last year and the other one is in utero, which is the Employment Nondiscrimination Act. That's the thing about having laws not kids: they hang around inside your womb. The other thing with kids is that I can imagine parents saying, "If only it was just us influencing the kids... none of those peers, just us." Well, we have courts instead of peers and it has been a problem. There is no doubt that there has been a problem in terms of the definition of disability under the ADA.

This concept of the tale of two cities is from something that I first wrote and gave as a talk four years ago. It was really after the Sutton trilogy in 1999<sup>26</sup> that, legally, the major change happened in terms of reducing the scope of coverage under disability. I think the question for us as academics is to think about what there is to say, what there is to think about, other than simply noting the next case and the case

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Sutton v. United Airlines, 527 U.S. 471 (1999); Murphy v. United Parcel Serv., 527 U.S. 516 (1999); Albertson's, Inc. v. Kirkingburg, 527 U.S. 555 (1999).

after that in which it is so obvious that there is a problem with coverage under the ADA.

Now, what the Supreme Court would say, what it has said any number of times when it engages in statutory interpretation, is: "if this isn't what Congress intended, let Congress tell us what it did intend. If this is a Catch-22, fine, let Congress fix it. That's the point of statutory interpretation."

Of course, anyone who has worked in any legislative setting knows that drafting legislation is a lot harder to do than statutory interpretation. That is one of the reasons that, in terms of statutory interpretation, I am generally more of a legal process person – interpret the words in light of the purpose underlying the law – and not a strict textualist. My concept of the role of courts is as a partner with the legislature in implementing the law, as opposed to a third grade teacher with a ruler going, "You bad girl, you should have used better words then that," which is the way I sometimes think of the textualists when they admonish Congress.

So, the new stuff that I am going to say in this talk is in the spirit of encouraging some new developments in the law. First, the metaphor of a tale of two cities that I will go through here will simply be a reinforcement of what you just heard from Paul, but with a bunch of additional visuals to make the points clear.<sup>27</sup> The marginal neighborhood I will reference is based on the "Mike Gottesman theory" as to why we've had some of these problems with the Court and the ADA.<sup>28</sup> And then the new development I will focus on the most is: What are possible ways of addressing this problem of judicial interpretation of the ADA? In light of how difficult it is to change the ADA itself through the legislative process, what are other creative ways to approach the problem?

Those of us who worked on passing the ADA had two overarching goals. I think it is fair to say that one goal has come to fruition and the other has crashed and burned.

The first goal had three elements. We wanted to change the physical landscape for people with mobility impairments; we wanted to change access to society for people with vision and hearing

<sup>27.</sup> There is a PowerPoint that accompanied this talk. The PowerPoint, with the visuals referenced in this talk, is available by emailing Professor Feldblum at feldblum@law.georgetown.edu.

<sup>28.</sup> Professor Mike Gottesman has never written this theory down in an article, but I heard him present it on a panel we were on together.

impairments; and we wanted to change the social landscape for people with "traditional disabilities" – so that employers and businesses would focus on "ability" and not on "disability.

First, with regard to the physical landscape. We wanted there to be no more restaurants that just had one step in front of the entrance. There are still some that do, but we wanted to develop the concept that businesses have to retrofit if it is readily achievable. And we wanted to establish the principle that if a business is making renovations, then it has to ensure accessibility so long as it is not disproportionately expensive.

Our main goal was to draw a line in the sand and say: "With respect to new construction, from here on, if you build a structure you have to be aware that society is made up of people who have mobility impairments. You can't just build something with stairs and think that you've made it open to society."

So, we wanted to change the physical landscape for people with mobility impairments and we wanted to change the access to society for people with visual and hearing impairments, and indeed, to change the overall social landscape for the range of people with "traditional" disabilities.

In an article I wrote called "Rectifying the Tilt: Equality Lessons from Religion, Disability, Sexual Orientation, and Transgender,"29 I made the point that we are brought up in a society that has made certain background decisions. For example, our society has decided that most of our materials will be in writing. Our society has decided we will grow up learning a spoken language (English) and not also sign language. These are decisions we have made as a society. Reasonable accommodations - having interpreters or having materials available in brail and on audiotapes - are measures that create access to society for people who are also part of society. These measures create access to the basic social landscape for those individuals with traditional disabilities. Most people in society have the idea that there is an "us," without any disabilities, and a "them," people with disabilities. They focus on the person's disability and not on the person's ability. Goal number one was focused on people with "traditional disabilities" and on opening up for them a range of social access.

At the time, we were drafting the ADA, we explained that we

<sup>29.</sup> Chai R. Feldblum, Rectifying the Tilt: Equality Lessons from Religion, Disability, Sexual Orientation, and Transgender, 54 ME. L. REV. 166 (2002).

had an additional goal – what I call, goal or city number two. We wanted to extend protection in employment and public accommodations to people with a range of health conditions, even those not traditionally considered "disabilities." And we wanted to change the public's cognitive understanding of "disability" by bringing into the category of "disability" people with a range of medical conditions.

That is, we wanted the law to establish that "us" is a spectrum and that all people have health conditions that might, at some point, cause them to be unable to participate in society because of prejudice, stereotype, an actual physical barrier, whatever. We wanted to show that people in this group were also people with disabilities and, in that way, to change the cognitive understanding of disability.

Just imagine which one of our goals crashed and burned: clearly goal number two. We now have a situation of shrinking coverage, the "Honey, they shrunk our law" reality. And that's what creates the "tale of two cities."

As you all know, the ADA prohibits discrimination against someone who has a physical or mental impairment that substantially limits one or more major life activities of such an individual, <sup>30</sup> or who is regarded as having such an impairment. <sup>31</sup> What we meant to convey by this definition was that you have coverage (this is the smaller circle) of people who have "traditional disabilities" (such as being paralyzed, blind, deaf, or mentally retarded) and then, in the larger circle, you have coverage for people with serious health conditions: for example, a heart condition, a lung condition, epilepsy, diabetes, or cancer. While these conditions are not generally ones that the public thinks of as "disabilities," those of us drafting the ADA certainly believed they were part of the definition of disability under the law.

I still remember one district court judge dealing with someone who had a heart attack, didn't get his same job back after returning to work, and sued under the ADA. The judge basically said, "Well, I've had a heart attack and I am not disabled." So, there are people with

<sup>30. 42</sup> U.S.C. § 12102(A) (2000).

<sup>31.</sup> Id. § 12102(C).

<sup>32.</sup> See Katz v. City Metal Co., 87 F.3d 26, 30 (1st Cir. 1996)(quoting the district court judge who wrote, "The only evidence is that he has a blocked artery that was opened up by balloon angioplasty. That does not show that he has a permanent disability or heart disease. I know. I've been there. I had a heart attack." The First Circuit reversed and remanded the district court's decision.).

serious health conditions that we know are serious, but other people do not necessarily think of as disabilities. And then, there are those in this last outer circle – people with mild health conditions, arthritis, or a limp, or whatever – that we also considered to be covered as people with disabilities under the ADA.

So, how did we get from this ADA text to this picture of three circles?

You've already heard some of this from Paul, so I'm just going to emphasize one point. The mitigating measures that individuals with impairments often take in order to function were never meant to be taken into account when deciding whether a person is disabled. Obviously, we were building off of Section 504 of the Rehabilitation Act of 1973. We used the same language for the definition of disability that the Rehabilitation Act used for the definition of handicap: a "physical or mental impairment which substantially limits one or more of such person's major life activities." Obviously, for the Catch-22 reasons, the court should not take into account that a plaintiff has taken medication that brings her diabetes under control. We felt that individual assessments would be largely irrelevant at this stage of the analysis of whether someone has a disability. Just like there is not a lot of effort expended in a Title VII case in deciding whether a person is really black or really Jewish.

Of course, we recognized there would be a question if a person had an impairment that wasn't really limiting her in any significant fashion. Then she would not fall easily under prong one of the definition without some individualized analysis. But that was really okay. You'd tarry there but a moment because a different type of individualized assessment would be available under the reasoning of the *Arline* case. Under the *Arline* case, even someone with a minor impairment would be covered if she was discriminated against because of that impairment.

I was clerking for Justice Blackmun when the Court decided the *Arline* case. I was very active in working on the opinion in that case. The next year I was working for the ACLU on the ADA. It was like I knew *Arline* in my bones. In *Arline*, the Court noted that Congress was as concerned about the effect of the impairment on others as about the effect of the impairment on the individual. With the clause

<sup>33. 29</sup> U.S.C. § 794 (2000).

<sup>34. 29</sup> U.S.C. § 706(7)(B) (2000).

<sup>35.</sup> Sch. Bd. of Nassau County v. Arline, 480 U.S. 273 (1987).

"regarded as," an impairment that might not really diminish someone's capabilities could nevertheless substantially limit that person's ability to work as a result of the negative reactions of others to the impairment.

Jean Arline, a school teacher with tuberculosis, ends up not being reinstated to her job as a teacher. One job. The job of teacher. Not a range of jobs. One job. The court said Arline was covered under Section 504 of the Rehabilitation Act because she was regarded as having an impairment that limited her in the life activity of working.<sup>36</sup> It was only being denied work in that one job – that was enough for the Court to establish coverage under Section 504.

So, under the reasoning of the *Arline* case, the simple act of being denied one job, or of being denied one instance of access to some goods or services, was sufficient to create coverage under the law. What more could we want? Everyone was potentially covered under the ADA under that reasoning, just like everyone is covered under Title VII of the Civil Rights Act of 1964.

How many people in this room are covered by Title VII? All of you. You are all covered. You all have a race. Most of you may not be discriminated against because of your race. You may not need Title VII. But if for some reason you were discriminated against because you were white, you would have Title VII to protect you. To, for us, the ADA was just like every other civil rights law. Once we had prong three in the definition (the "regarded as" prong), we assumed that if you could show that you didn't get a job or if you are fired from a job because of your diabetes or because you didn't have two arms, you would qualify for ADA coverage under either prong one or under prong three. It was even better. We were giving people two options for coverage.

Then, the Supreme Court began shrinking the city of coverage. The minute you take into account mitigating measures, what you then have is the current picture. This is basically the situation that Paul was describing. Now, not all serious health conditions are covered – only those serious health conditions which, despite medication or devices or self-compensation, still make it hard for the person to function. These are the conditions that are still covered – the ones that are not effectively medicated, or controlled using devices, or whatever. But this little triangle of people are also the ones most likely not to be

<sup>36.</sup> Id. at 279 & n.4.

<sup>37.</sup> McDonald v. Santa Fe Trail Transp. Co., 427 U.S. 273 (1976).

qualified for jobs because their conditions are not under control.

And in one of the true ironies of legal reasoning, Justice O'Connor's opinion in Sutton cites the transcript in the Arline case in the part of the Sutton opinion where she shrinks the coverage of individuals under the "regarded as" prong.38 It makes you think, "Honey, have you read that Arline opinion?" Justice O'Connor cites the Arline transcript to note that imagining that coverage could be created simply because one was fired from one job would seem quite circular.39 But what's remarkable about that reasoning is that the Arline court concluded that being fired from just one job was sufficient to establish coverage, while the Sutton court decided the opposite!40 You have to show that you are regarded as limited in a whole range of jobs.41 You have to show that lots of people would have discriminated against you. With mild health conditions, it is not enough that you cannot perform just one job without an accommodation, you must show that you would be limited in a range of jobs. You have to show that the employer regarded you as not being able to get lots of positions.

So, it is fair to say that goal two crashed and burned. I think the reason for that has a lot to do with the power of the image of people with disabilities as "not us," as opposed to people with health conditions, that are "all of us." I also think that it has been hard for the courts to adjust to applying the ADA definition of disability when they are so used to applying the Social Security definition of disability. Under that definition, a plaintiff definitely has to demonstrate that he or she is unable to work. It is as if the courts have done so many of those Social Security cases that I felt we need to say to them: "You should take a brain shower from your last Social Security Disability Insurance case; now you are doing an ADA civil

<sup>38.</sup> Sutton, 527 U.S. at 489.

<sup>39.</sup> Sutton, 527 U.S. at 492. "We note, however, that there may be some conceptual difficulty in defining "major life activities" to include work, for it seems "to argue in a circle to say that if one is excluded, for instance, by reason of [an impairment, from working with others] . . . then that exclusion constitutes an impairment, when the question you're asking is, whether the exclusion itself is by reason of handicap." Transcript of Oral Argument at 15, Sch. Bd. of Nassau County v. Arline, 480 U.S. 273 (1987) (No. 85-1277) (argument of Solicitor General.).

<sup>40.</sup> The Court in *Arline* quoted the same statement from the Solicitor General quoted by Justice O'Connor, but then expressly rejected the government's concern by ruling that being fired from even one job was sufficient to establish coverage under Section 504. *See Arline*, 480 U.S. at 283 n.10 ("The argument is not circular, however, but direct. Congress plainly intended the Act to cover persons with a physical or mental impairment (whether actual, past, or perceived) that substantially limited one's ability to work.)

<sup>41.</sup> Sutton, 527 U.S. at 479.

rights case."

But let's not lose sight of the important fact that there is continuing viability of goal number one, or what I call city number one. If you are covered under the ADA (or your coverage is not contested), then under PGA v. Martin, 42 you can demand a modification of rules and policies so long as it does not fundamentally alter the nature of the service. That's a key disability rights principle. The Olmstead holding: that you can receive the services in the most integrated settings possible also remains viable. 43 The truth is there is lots of good stuff left. Yesterday I received an e-mail about a case won by a plaintiff that was about an emergency evacuation - where a business has to have a plan when evacuating to make sure that someone who has a mobility impairment does not get stuck.44 The facts in that case were horrible. I think that there is some good movement. It has been slow on the Olmstead Medicaid front, but there is a more of a general sense of the significance of disability in the public. I think the ADA has done that. The ADA has made the public aware that civil rights includes people with disabilities.

I will now briefly address what I call "the Mike Gottesman theory" – which is that the Court simply does not like employment cases. Mike's theory – not written down anywhere, but articulated on a panel he and I were on together – is that the Court feels that it has become much too difficult for employers to deal with all of the employment laws imposed on them. So, according to Gottesman, it is very relevant that the trio of cases in which the Court cut back on ADA coverage of disability dealt with seemingly semi-trivial conditions in an employment setting: in *Sutton*, the twin sisters with the eyeglasses; Murphy with the high blood pressure, and Kirkingburg with the one blind eye. Then there are the other subsequent cases where people with disabilities have lost: Toyota v. Williams; Barnett; Chevron. These were all employment cases as opposed to the Olmstead case or PGA v. Martin. So, the "marginal"

<sup>42.</sup> PGA Tour, Inc. v. Martin, 532 U.S. 661 (2001).

<sup>43.</sup> Olmstead v. L. C. by Zimring, 527 U.S. 581, 607 (1999).

<sup>44.</sup> Savage v. City Place Ltd. Partnership, No. 240306 (Montgomery County, Md. Cir. Ct. Dec. 28, 2004), available at <a href="http://www.evacuationplans.org/opinion\_12\_28\_04.pdf">http://www.evacuationplans.org/opinion\_12\_28\_04.pdf</a>.

<sup>45.</sup> Sutton, 527 U.S. 471.

<sup>46.</sup> Murphy v. United Parcel Serv., 527 U.S. 516 (1999).

<sup>47.</sup> Kirkingburg, 527 U.S. 555.

<sup>48.</sup> Toyota Motor Mfg., Ky., Inc. v. Williams, 534 U.S. 184 (2002).

<sup>49.</sup> U.S. Airways, Inc. v. Barnett, 535 U,S. 391 (2002).

<sup>50.</sup> Chevron U.S.A., Inc. v. Echazabal, 536 U.S. 73 (2002).

neighborhood," according to Gottesman, would be the neighborhood of employment cases.

So, here's a recap of the twin cities. Under goal/city number one, we have people with traditional disabilities that are still covered under the ADA and receiving important rights. Under goal/city number two, there are people with a range of health conditions not being covered under the ADA and, therefore, whose rights are not protected in the same way. But (and I find this a fascinating sociological point) lots of employers still act as if people with diabetes, epilepsy, heart conditions and breast cancer are covered under the ADA. And that's a good thing, from my perspective.

Actually, the importance of having a law say "disability" is covered (even if the courts have shrunk what that word means) came home to me very forcefully when I and my colleagues were debating whether the Employment Non-Discrimination Act should be reintroduced with "gender identity" added as a protected category, and not just "sexual orientation" which the bill currently covers. One of my colleagues argued strongly that the bill had to be inclusive of transgender people. This lawyer said, "Let's stop thinking like lawyers, let's start thinking like employers." For employers, having a word in the statute makes all the difference. If you have protection for transgendered people in the law that's going to make a difference. If the word gets on the flyer about employee rights that is posted in the coffee room, you get gender identity on people's minds.

It's the same with disability rights. We have an inclusive definition in the ADA. The courts have totally decimated it, but the employers are still operating as if the definition is broad. The word "disability" is still on the poster of employee rights. So, whenever I get a call about an accommodation that an employer should make for a person with a health condition, I walk through the whole analysis. Of course, I know that if the employer actually went to court, the person with the health condition might not win because of lack of coverage, but why bring that up if that does not seem to be the conversation at hand?

Finally, let me turn to three possible affirmative ways to deal with the shrinking coverage created by the Supreme Court. Obviously, one possibility is to amend the ADA. Paul's suggestion picks up and develops a slightly different way from Mark Rothstein's suggestion of actually having a list. Obviously you would not want to have a list if one of your goals is to expand the cognitive

understanding of disability. But if you've lost on that point anyway, you could at least get some of the advantages that Paul was talking about by amending the law in that manner.

With regard to amending the ADA, there was an editorial in the New York Times<sup>51</sup> and then an op-ed by Steny Hoyer in the Washington Post<sup>52</sup> shortly after the Toyota case<sup>53</sup> came out, that both called for updating the ADA to restore its intended coverage. The National Council on Disability report on amending the ADA also recently came out.<sup>54</sup> And I've written elsewhere that I think the definition of the ADA should be amended to better reflect Congress' original intent.<sup>55</sup> So, I definitely think that amending the ADA is one possibility that's high on the list.

But now I am going to talk about two additional possibilities that I have either worked on or am working on now. Both these approaches start with the assumption that there will not be a broadened definition of disability under the ADA – partly because there are health conditions that the general public will simply not admit are disabilities because of all the negative stereotyping that comes with being disabled. Even so, we know that people do not think that employers should know all about their health conditions. The level of public support for medical privacy protection is actually quite high.

I worked for over ten years trying to get a medical privacy bill passed in Congress. While public support for such protection is quite high, the politics of getting that bill passed have been remarkable. It has been remarkably difficult. One of the things my client, Janlori Goldman, and I managed to do in 1996 was to convince Congress to insert a provision in the Health Insurance Portability and Accountability Act that said that if Congress failed to pass a law establishing medical privacy protection by a certain date, the Secretary of the Department of Health and Human Services had to

<sup>51.</sup> Editorial, Revisiting the Disabilities Act, N.Y. TIMES, Jan. 10, 2002, at A10.

<sup>52.</sup> Steny H. Hoyer, Op-Ed., Not Exactly What We Intended, Justice O'Connor, WASH. Post, Jan. 20, 2002, at B1.

<sup>53.</sup> Toyota Motor Mfg., Ky., Inc. v, Williams, 534 U.S. 184 (2002).

<sup>54.</sup> NATIONAL COUNCIL ON DISABILITY, RIGHTING THE ADA (Dec. 1, 2004), available at <a href="http://www.ncd.gov/newsroom/publications/2004/pdf/righting\_ada.pdf">http://www.ncd.gov/newsroom/publications/2004/pdf/righting\_ada.pdf</a>.

<sup>55.</sup> Chai R. Feldblum, The Definition of Disability Under the Americans with Disabilities Act: What Happened, Why, and What Can We Do About It?, 21 BERKELEY J. EMP. & LAB. L. 91 (2000).

issue regulations establishing such protection.56

Those regulations have now been issued.<sup>57</sup> But they don't directly regulate employers. So, I think one could still try to get a medical privacy bill that prohibited the misuse of medical information by employers. That is, an employer could not disclose the fact that someone has diabetes. An employer couldn't publicize the information about an employee's health condition on an employee website or misuse that information to fire the person, for example.

Such a law would not, however, get you accommodations. All it would do is get you the non-discrimination part. So, a medical privacy law would have to be coupled with what I call a workplace flexibility bill.

A workplace flexibility bill would deal with a situation in which an employee with diabetes needs thirty minutes to sit and have her lunch. It would allow an employee to go to a doctor's appointment, to go pick up a kid, or to go home and wait for the plumber. A workplace flexibility law would not just address health conditions. The point of the law would be to change the workplace more generally.

I know it's not the topic of this talk, but I have spent the last four months reading every case about serious health conditions under the Family Medical Leave Act. 58 And the law can be a mess for employers because an employee can get a certification that he or she has a serious health condition and then the employee must be permitted to take intermittent leave which can be in chunks of basically fifteen or twenty minutes without an undue hardship limitation. 59 So, even if it would be really problematic for the employer, the employer has to give employees who have such certifications on file intermittent leave.

To deal with these issues, and other types of problems that employees have, I have a new project that I started on workplace flexibility. Right now we have a real stalemate generally on labor issues in Washington. What my project, Workplace Flexibility 2010, wants is to have a workplace that takes into account and accommodates life's emergencies as well as regular life, whether you

<sup>56.</sup> See Pub. L. No. 104-91 § 264, available at <a href="http://aspe.hhs.gov/admnsimp/pl104191">httml>.</a>

<sup>57. 45</sup> C.F.R. Parts 160 and 164. See <a href="http://www.hhs.gov/ocr/hipaa/finalreg.html">http://www.healthprivacy.org</a> 2005.

<sup>58. 29</sup> U.S.C. §§ 2601-54 (2000).

<sup>59. 29</sup> C.F.R. §§ 825.100-800 (2005).

are taking care of your kid, taking care of your diabetes, or dealing with the plumber. You are working full-time, but since you do not have a wife at home anymore, we need the workplace to change. We also need a norm that allows people to have satisfying and secure careers that might be part-time or part-year and that can change over a career. A person might be in one field for ten years and then in another field after that.<sup>60</sup>

The challenge of my Workplace Flexibility 2010 project is that I want to achieve these goals in a way that works for employers and employees. And that's why I'm working with the lawyers from the different communities. This is part of breaking the stalemate; to imagine, for example, how the current law that is the FMLA could work better. To figure out what's the problem when you have these medical certifications on file and there is no defense for employers. And then to work with the advocates to get this law, as well as others that affect the workplace, to work better.

The reason my project is called Workplace Flexibility 2010 is that by the year 2010 we would like to come forward with a comprehensive national policy that would advance workplace flexibility because the stalemate right now is extreme. Workplace Flexibility 2010 signifies that we have a period of time in which to try to imagine the new approach. I am not guaranteeing any changes by 2010. The idea is to work with the advocates to think about how various laws that affect the workplace might be modified and think about the type of public policies that will advance flexible careers over our lifespan. That way, for people who have, for example, a health condition that makes it necessary for them to permanently work part-time, we will be better able to deal with some of the benefits, health insurance, and pension issues that are currently a problem.

We've got a tale of two cities, and maybe a marginal neighborhood. My hope is that we're also ready for some new development. Thank you.

**Professor Michael Stein**\*: Sharona, thank you so much for putting the panel together. Thank you, everyone, for attending, both because it is Saturday afternoon and because, looking around, there are quite a few of you who I think would be better suited then myself

<sup>60.</sup> See <a href="http://www.workplaceflexibility2010.org">http://www.workplaceflexibility2010.org</a>.

<sup>\*</sup> Professor of Law, College of William & Mary School of Law; Visiting Professor, Harvard Law School.

to be up here. I wish that we could sit around a circle and talk. Hopefully we can provoke some thoughts and questions and get a real, interactive discussion going afterwards.

The topic of discussion is the ADA's successes, failures, and some comparative thoughts about it. I thought I would just sketch out what I think some of the successes of the ADA are and some of the difficulties with it. I suggest to you that both those successes and failures often are related to factors outside the ADA rather than to the ADA itself. Specifically, these factors are not directly connected to the definition of disability, but are contingent to and hooked on to the definition of disability. Afterwards, I would like to ask your thoughts on how you would define disability if you were, for example, drafting a UN Convention or European Union (EU) framework directive. Hypothetically, how would you define disability to avoid some of these problems and learn from the successes and failures of the ADA?

I think the best thing the ADA has done so far in the disability project is through Title III public accommodations. Instead of being excluded from the mainstream, where the disabled should neither be seen nor heard, nor out and about in the world, people with disabilities are now out and about and seen to a larger extent than before. I believe that this has a very positive effect on social consciousness raising or if you wanted to be technical, norm changes. There are economic and social theories about this, but in plain language, the idea is that once an employer might have never seen a disabled person or rarely seen disabled people. Now she sees the disabled every day on public transportation. Lo and behold there are people with disabilities on that bus or train with her. Perhaps when the employer has an applicant with a disability before her, she'll start to think of that person a little bit differently because the disabled applicant is now a member of her community.

The second effect is one that has to do with more broadly international instruments. At last count there were forty-six countries who had adopted either verbatim or near verbatim versions of the ADA or at least words and phrases from the ADA – especially the notion of reasonable accommodation. The EU and the UN, hopefully rather soon, might be adopting some of this ADA language as well.

Third, there is a visibility effect internationally, Anecdotally, when I go to conferences or when I speak to disability nongovernmental organizations or international organizations where

there are people from countries that do not have disability rights legislation, a glint comes into their eyes and a smile crosses their faces. They say, "Oh, but for an ADA! Oh, if we had an ADA!" I wish that for them. But one should also be very careful for what one wishes for because the gift comes with certain difficulties as well. These last two effects really are not related to the definition of disability, however. These are effects that are outside the actual technical definition of who is disabled and who is not disabled.

Among the failures most would point to are the post-ADA employment rates and the win/lose rates of Title I plaintiffs in federal courts. Some of that is related to the actual ADA language. My splendid co-author Anita Silvers and I have talked about the definition of disability being lifted from the Rehabilitation Act. The regulations from the Department of Health and Human Services would give form, at least, to what a disability is or is not. Judges would then not be left to discover a brave new world all on their own.

Professor Hoffman has also written on the benefits of a vague definition of disability in the ADA. There is something to both arguments. There are, as well, many factors beyond what's actually in the ADA and what's actually in the definition of disability that have affected how the ADA has – or has not – worked. You can see some of those factors if you read through the 2003 book edited by Richard Burkhauser and David Stapleton assessing employment provisions of the ADA. More recently, you could also read Samuel Bagenstos's article, hot off the Yale press, about the lack of a social network and a lack of health care and transportation for the disabled. Bagenstos explores how its very American, existential, that to believe that we have civil rights that we can enforce to make the world level and even, but that we haven't given people the ability by which to actually and practically enforce these rights.

Many people actually connect the failures of the ADA to the open-ended definition of disability in the ADA. One of those people is Justice Sandra Day O'Connor (referred to just recently by this

<sup>61.</sup> Anita Silvers & Michael Ashley Stein, Equality Paradigm for Preventing Genetic Discrimination, 55 VAND. L. REV. 1341 (2002).

Sharona Hoffman, Corrective Justice and Title I of the ADA, 52 Am. U. L. REV. 1213 (2003).

<sup>63.</sup> THE DECLINE IN EMPLOYMENT OF PEOPLE WITH DISABILITIES: A POLICY PUZZLE (David C. Stapleton & Richard V. Burkhauser eds., 2003).

<sup>64.</sup> Samuel R Bagenstos, The Future of Disability Law, 114 YALE L. J. 1 (2004).

<sup>65.</sup> Id.

panel as "Honey") who stated extra-judicially that the ADA language reflects the uncertainties about what Congress had in mind and creates the problem with the scope of the coverage. 66 According to Justice O'Connor, because the legislative sponsors were so eager to get something passed what passed was not as carefully written as what a group of law professors might put together. 67 Well, you just heard from one of those law professors who put the ADA together. The question I'd like to throw out to you - this is not a rhetorical question, it is a genuine question that I hope you'll respond to afterwards and give me some ideas - is whether the issue is really the definition of disability in the ADA? Is the issue this technical problem of who is and is not included or is it a broader question? Is it a larger issue of whether judges, employers, owners and operators of public accommodations, and other members of society are just not accepting the disabled and/or the notion that the ADA is about rights and equality? This is what Chai just referred to as the "not us" syndrome. To be even more provocative and turn this around the other way, in a disability-sensitive, accepting, utopian kind of world, would it even matter how we define disability?

The ADA is now in its teens. The number of Supreme Court cases on the ADA is now rapidly approaching twenty. The Court has yet to actually explain in any kind of useful detail what disability is or what a reasonable accommodation is. What is very clear to me (Chai touched on this point as well) is that the Court seems more receptive to the notions of Title III and Title II coverage than it is to Title I coverage. There is a downward ramp of less acceptance starting at Olmstead, Bragdon, and Martin. The Court seemed quite inclined, or at least receptive, in those cases to the idea of the most integrated environment, the idea of individuals receiving treatment from dentists, the idea of golf carts on golf courses.

Then, the Court slid down towards Lane<sup>71</sup> where yes, we know that courthouses ought to be accessible. Query: must accessibility also extend to interpreters and something else beyond steps for wheelchair users? We believe that the Lane case extends to voting

See Charles Lane. O'Connor Criticizes Disabilities Law as Too Vague, WASH. POST, Mar. 15, 2002, at A2.

<sup>67.</sup> Id.

<sup>68.</sup> Olmstead v. L.C. by Zimring, 527 U.S. 581 (1999).

<sup>69.</sup> Bragdon v. Abbott, 524 U.S. 624 (1998).

<sup>70.</sup> PGA Tour, Inc., v. Martin, 532 U.S. 661 (2001).

<sup>71.</sup> Tennessee v. Lane, 541 U.S. 509 (2004).

rights. Does it include other social services under Title II? I am not sure. Also, *Lane* was an extraordinarily narrow decision with, to my mind, a narrow majority, with Justice Souter writing a separate concurring opinion discussing sterilization, eugenics, and other things that states have done that may not be so very equality-orientated.<sup>72</sup>

Finally, as we continue to slide down towards Title I we have the employment cases, (Chai, I think got this exactly right) where the Court seems extraordinarily reluctant not only to define disability and to define reasonable accommodations, but also to accept the idea that changing the workplace and challenging the role of employers and the exclusion of disabled folks from the workplace as a different notion from equality arguments. These cases are not really about rights but are about something more than rights. We have gone from kind of equal to more equality plus.

Look at *University of Alabama v. Garrett*,<sup>73</sup> one of my favorites, with Patricia Garrett suing the university after being demoted to a poorer job. This happened after Ms. Garrett underwent treatment for breast cancer, a treatment that Justice O'Connor and her sister have had. The Supreme Court, of course, did not reach the merits of her case because *Garrett* was decided on Eleventh Amendment grounds.<sup>74</sup> The Chief Justice stated in the opinion that it would be entirely rational for state employers to conserve scarce financial resources by hiring employees who are able to use existing facilities.<sup>75</sup> State actors could quite hard-heartedly, maybe even hard-headedly, hold to job qualifications which do not make allowance for the disabled.<sup>76</sup>

Chief Justice Rehnquist also characterized Ms. Garrett's claim as one for special accommodations. Query: I wish him only good health, but is the Chief Justice not working at home and not attending oral arguments, but only every now and then writing into the Court? Is this an accommodation? Is there a possibility that a Supreme Court Justice with having life tenure would not be reinstated after an illness? Again, I wish Chief Justice Rehnquist good health. I am only poking fun at his inconsistency.

Justice Kennedy, of course, emphasized the idea in his concurrence that this case was not about rights. He chimed in with a

<sup>72.</sup> Id. at 534 (Souter, J., concurring).

<sup>73.</sup> Board of Trustees of Univ. of Ala. v. Garrett, 531 U.S. 356 (2001).

<sup>74.</sup> Id. at 364.

<sup>75.</sup> Id. at 367.

<sup>76.</sup> Id. at 368.

<sup>77.</sup> Id. at 374.

concurrence that got us all excited to read about how society has both overt and more inferential forms of discrimination and how we have to guard against both kinds. When you read Justice Kennedy's concurrence for the first time your heart starts to flutter and you get all excited. However, in a paraphrase that would have Abraham Lincoln turning in his grave, Justice Kennedy referred to the great internal struggle between our own human instincts, which causes us to ostracize unfamiliar folks, and the better angels of our nature that sympathize with those disadvantaged by mental or physical impairment. It is not about rights, but about something other than rights.

This is when we turn to the international dimension. I am really asking for your thoughts. This is not a rhetorical flourish. It may be a pompous flourish, but it is not a rhetorical one because I really do want your thoughts. I've been fortunate enough to participate in a very small way in the UN Convention on the Rights of Disabled People. One of the things we are working on is trying to figure out what the definition of disability is or should be. Briefly speaking, the fifth session is coming up at the end of January 2005.

I will read you the Convention's interim definition of disability in the Article III definitions. It is even broader and more inclusive then the ADA. The third and the fourth working sessions have not even addressed the definition of disability because it is considered too touchy and too politically volatile.

Disability in the Convention means a process rather than something which individuals possess. The process of dissemblance occurs when people with impairments experience barriers to their full participation in society and their recognition, enjoyment or exercise of human rights and fundamental freedoms in civil, political, economic, social, cultural, or any other field. The definition of impairment shall encompass full and diverse range of functional impairments including physical sensory, neurological, psychiatric, and intellectual, all of which may be permanent, intermittent, temporary or perceived as impairment by society, but not necessarily by individuals. <sup>80</sup>

What do you think the Supreme Court would say about that? This definition has been out there for six months. Interestingly,

<sup>78.</sup> Id. at 374-75 (Kennedy, J. concurring).

<sup>79.</sup> Id. at 375.

<sup>80.</sup> Working draft on file with author.

during the drafting there were several delegations, notably in this case Canada and the European Union (you would not have guessed that it was Canada and the European Union), who questioned the utility of including an article on definitions. Also, Canada and EU, joined by the Russian Federation and Japan, questioned the appropriateness of including a definition of disability at all within the Convention. There was quite a lot of feeling and political energy spent on the idea that the definition should be open-handed to allow states, parties, or signatories to the Convention, to take the Convention back and in their domestic courts apply their own, culturally-sensitive, appropriate definition of disability. The counterpart to that was that there ought to be at least a floor beneath which these culturally-sensitive, independent, local definitions of disability ought not to exist. There are many places where, because they've never had any form of disability rights, there is no definition of disability at all.

Interestingly, at the next session, disability non-governmental organizations will not be able to intervene. If they are allowed to intervene, if there is a change in that, it will be very briefly at the end of each article. This is the Convention, by the way, whose password is "Nothing about us without us," so the next session will be "Everything about us without us." The definition of disability has been no less controversial among the disability community and the disability caucuses than it has been among the nation states.

Without identifying the sources, I will read you a couple of comments representative of the email among the working group that was looking at this. This is from one individual who is heading up an NGO. Responding to the issue of whether we want to talk about impairment or organize any concept related to disability around impairments, the writer asks, why, then, are all the main organizations classified by impairment? The organizations not only use impairments as titles but are also congregated by impairment. Isn't impairment part of our identity? This is a question that has been asked by disability studies and others for a long, long time. I haven't seen a proper answer to that yet.

Another comment from within the disability caucus agrees that we need to keep disability as a social concept, e.g., the processes in society, the way that they affect physical and administrative environment, that affects impairments and not get drawn to diagnosis of impairments. At the same time the writer says that we have to insist on the plurality of disability groups because there have been

different historical developments. Then she goes on to talk about how blind people are different from wheelchair users who are different from psychiatric users. The writer says that this difference is neither right nor wrong, but there is certainly a tension here between the groups.

If you were starting with a blank paper, as some hypothetically are, what kind of definition of disability, learning from the ADA, would be a better definition to use? That's an open question and I hope for answers.

Another issue is that UN treaty monitoring bodies have been criticized, and correctly so, for enforcement that has been largely ineffective. With this Convention, the participation of disabled individuals would be required as part of the process. This would occur not only at the treaty monitoring body, but also on the individual state levels of creating policies and enforcements. Ultimately, however, isn't compliance more about the will to obey? Isn't what's important the idea of inclusion and the role that disabled people have in society rather than technical provisions or enforcement? Put another way, regardless of the definition of disability, whether here, domestically under the ADA, or internationally under the Convention or in the EU under a framework directive, how can we create an environment, best practices, or a scenario in which the technical basis of who is disabled and who is not is less important because we have better practices in place that include disabled folks from the beginning?