

Panel Presented By Judith Heumann and Eve Hill

Building Coalitions and the Disability Rights Movement

Judith Heumann and Eve Hill*

JUDITH HEUMANN: Eve and I, what we want to do is enter into a discussion. She has done some fantastic work, which we will get into discussing in a little bit. But also, Eve has taken her personal experience, which has evolved over the years, and her commitments to social justice and equality, and really honed in beyond the surface. To be able to implement pieces of the law like the *Olmstead* court case, we need to understand why the law is important, what implications it has for people's lives, why situations like this have been able to evolve for more than a century, and also what people think about when they look at those of us with visible and invisible disabilities. I think it ultimately means that we do not believe that disabled people are necessarily equal to others. And if you don't believe someone is equal to others then it isn't difficult for you to take people's rights away.

EVE HILL: I'm so excited to be here beside an advocate who has literally been the North Star for disability rights. I just want to talk about what *Olmstead v. L.C.* did. *Olmstead* is a Supreme Court case that was decided ten years after the ADA was passed. The ADA recognized that we built our society with barriers to people with disabilities, because we assumed people with disabilities would not be out here with the rest of us.

So, the ADA recognized that we as a society have an obligation to unbuild those things that turn out to be unnecessary barriers to people with disabilities. There's nothing inherent about using a wheelchair that means you can't be a lawyer. The only thing that gets in the way is the stairs. It's not about the disability; we just assumed you would not be here. That's the underlying point of the ADA; it says, "Let's take those barriers out." We don't need them. Almost everybody can use the ramp; everybody can use the elevator. That's the idea of the ADA. We will take down those barriers, because those barriers are unnecessary for our programs and they keep people with disabilities out unnecessarily.

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But *Olmstead* goes further. What the ADA did not explicitly talk about was the other reason people with disabilities haven't been out here with people without disabilities: We are putting them over there in that institution, in that sheltered workshop, in that nursing home. So, *Olmstead* said, people with disabilities have a right to be out of that institution. That's another assumption we had—that people with disabilities were so special that they could not just be in the world. We could not provide them the extra services that they need in the regular world. We had to have special places for them. This is not a thirty-year fight since the ADA. This is a 400-year fight; a 500-year fight almost. So, it's not enough to open the doors to our employment, to our businesses, to our state and local services and say, "You can come in now." We have to get people with disabilities out of the places we have been keeping them.

Olmstead said, "The ADA applies not just to the services and programs and work that we give to nondisabled people, it applies to the services that we give to people with disabilities." You can't assume that there is anything special about healthcare services for people with disabilities. And the original argument had been "Well, these are services that we don't give to anybody else; you only get these because you have a disability. There is no equality question here because these services don't go to people without disabilities." And what the Court said was "No, these are healthcare services and vocational services. And even though there are certain types of healthcare services and vocational services for people with disabilities, we provide healthcare and vocational services to people without disabilities in the community. And there is nothing magical about the institution. The same services you provide there can be provided anywhere else, including in people's own homes." So, the Court said it is discrimination to keep people in those institutions unnecessarily. This was a big change. The Supreme Court said the civil rights laws apply to the "special" stuff we do for people with disabilities as well. Not just the things that we do for people without disabilities. And the Court said you have to serve people in the most integrated setting.

I emphasize that a lot, because the opinion doesn't just say you have to get people *out* of institutions. It says you have to serve them in the most integrated setting. Those services that you provide in the institution, you have to provide them in the community. So, we at the Department of Justice (DOJ) and other advocates don't say, "Close the institution"; we say, "Move the services into the community, and people will come out and have equal rights to access all the other things." But until you can get out of the institution, you can't access all the other programs and services, and the life that everyone has a right to.

Olmstead does not stop there either. In every *Olmstead* case I've ever worked on or even heard about, they had to talk about how they are providing these services. And they had to change their regulations, laws, or policies about how they provide the services. So, it does not stop with the civil rights law that says you have to move people out and serve them in the community. It goes into how we fund services for people with disabilities. How we deploy healthcare professionals. How we deploy DME (durable medical equipment). How we deploy medical devices. All these things were thought of as a whole different system than the civil

rights system, but the civil rights system says you have to make these things work so that people with disabilities can be out in the community.

So, looking at how Medicaid works, long-term services and supports, and the employment vocational rehabilitation (VR) services -- all that has to comply with the ADA integration mandate. And the ADA integration mandate says to jurisdictions: change those policies, procedures, and laws. And that is where we are now. Too many jurisdictions have not changed those policies, procedures and laws. They just try doing a workaround when a lawyer comes and yells at them that they are not changing as systemically as they need to.

JUDITH HEUMANN: When we talk about where we are today with *Olmstead*, in the cases you worked on in Rhode Island, Virginia, and Oregon, what was the common thread between the three and where was government?

EVE HILL: So, *Olmstead* started out with healthcare services for people with disabilities which were provided in nursing homes, psychiatric hospitals and ICF (intermediate care facilities). So, at first people looked at *Olmstead* and thought, it's just about medical institutions. But as we implemented the ADA's employment nondiscrimination requirements, employers would say "we can't find anyone with a disability." And I never believed that.

I asked, "Where did you look?" And they responded, "I expected them to show up at my door." So, where are they? It turns out they are in sheltered workshops, and that looks like a segregated setting. It is a place where people with disabilities work, but only people with disabilities and their support staff work there. And they tend to make widgets, or they are cleaning or landscaping. The shorthand for this is: "food, filth, and flowers." They assemble things, shred things, and package things. These are low-paying jobs and for people with disabilities at sheltered workshops, they tend to be even lower paying because so many of those workshops have 14 C certificates under the Fair Labor Standards Act.¹ They don't even have to pay the minimum wage; they pay less than minimum wage.

Sheltered workshops were intended, they say, to help people with disabilities transition into work by learning basic skills that would then make them prepared to go to work in more integrated employment. That was a huge failure if that was the intention, because people did not leave. Less than five percent of people with disabilities left their sheltered workshop in any given year. So, people stayed there

1. Section 14(c) of the Fair Labor Standards Act authorizes employers, after receiving a certificate from the Wages and Hours Division, to pay wages that are less than the Federal minimum wage to workers with disabilities for the work they perform. *Subminimum Wage Employment for Workers with Disabilities*, U.S. DEP'T OF LAB., <https://www.dol.gov/agencies/whd/workers-with-disabilities/overview> (last visited Feb. 22, 2020). In 2010, there were approximately 3,300 entities in the United States which held 14(c) subminimum wage certificates, but the actual number of individuals being paid subminimum wage is not tracked by the Department of Labor. *Section 14(c) Subminimum Wage Certificate Program*, U.S. DEP'T OF LAB., <https://www.dol.gov/odep/pdf/ChapterTwo14cProgram.pdf> (last visited Feb. 22, 2020). On February 12, 2014, the President signed Executive Order 13658, which raised the minimum wage to \$10.10 for workers on Federal contracts, including workers with disabilities. *Subminimum Wage Employment for Workers with Disabilities*, U.S. DEP'T OF LAB., <https://www.dol.gov/agencies/whd/workers-with-disabilities/overview> (last visited Feb. 22, 2020).

for decades. Why didn't people leave? Because the workplace of today does not shred paper by hand, like the employees in the workshops do. Most workplaces are mechanized and use technology, but the workshops aren't. So, people with disabilities are really not learning a useful skill in the competitive labor market by hand shredding paper or by putting things together without the machinery that is used now in the real world. The expectations were low and people in sheltered workshops tend not to be accommodated even with the kind of accommodations they would get in a mainstream integrated workplace. So, we said that is segregation, and there are government systems and school systems pushing people into those sheltered workshops. The systems need to be reformed so that they serve people in competitive integrated employment. Their goal can't just be a job, however defined. It has to be a regular job. A job like any person without a disability would seek. It ought to be based on what the market availability is and what the person is good at. Everybody is good at something. What the person wants to do tends to be what they are good at. And then we can help people get those jobs.

Sheltered workshops were also based on the idea that you would train and then place people with disabilities. You would spend years learning to do a job and then we could put you in that job, it will be like magic. And that never worked. In fact, in mainstream integrated employers now, they know it doesn't work either. On-the-job training works for everybody. It works for people with disabilities as well. It's not magic. And we can support people in integrated competitive employment settings.

So how do you change from a government-funded system that sends people to segregated settings and then forgets about them to one that is integrated? You need to shift government funding and services from those segregated settings into integrated settings.

So we did that in Rhode Island, and Rhode Island, to its credit, worked with us to do it. Their key problem was that the Providence schools and others had sheltered workshops on premises. So, kids would enter high school and go to the disability wing of the high school. Picture this: it's somewhat Dickensian, with a disability wing and a non-disability wing, where the students were only integrated during lunch, and then the students with disabilities were cleaning and doing things for the students without disabilities. They spent their days in this wing. And they worked there instead of learning. They worked on a contract for an adult sheltered workshop, doing the same things the adult sheltered workshop did. Guess what they were prepared for when they left school? They were prepared to work in a sheltered workshop. So that's where they all went. In fact, that's where they were told to go. It formed a school-to-sheltered-workshop pipeline.

Rhode Island closed that and, it turns out, the amazing thing was, the assumptions they had about people with disabilities were so stunningly wrong. We had one kid who was pretty non-verbal. So, they just had him shredding and packaging and so forth for five years after he left high school. Then, he got a job in a hospital, in their payroll division, and it turns out he was a whiz at Excel. But because he couldn't communicate with us the way we expected him to, we assumed he couldn't do much. But he can. At one time, he made almost as much as his

lawyer, and he was in the union and got full employment benefits. So, it was not a bad transition.

Rhode Island did not fight it and went with it and got out of the consent decree, and now does not have court oversight anymore. Oregon, however, fought it. It was the same thing there: The students with disabilities were doing the laundry for the students without disabilities. They were serving their meals. They were cleaning up in the cafeteria. At least they didn't have so many sheltered workshops in the schools, but they were preparing—pipelining—students with disabilities from schools into sheltered work. So, Oregon is in the middle of a transition away from that, taking the *Olmstead* mandate and not just looking at healthcare services.

We are not looking just at particular types of institutions, because anything that looks like an institution is an institution. What is sending people there? There is nothing off the table in terms of the services we need to lead to integration. No kind of services are off the table in terms of having to comply with the civil rights laws. So now we are moving into criminal justice. Jails were not intended as institutions for people with disabilities. But, as we hear frequently, they are becoming those. More and more people with disabilities are ending up in jail. And I know a lot of people with disabilities, and they are no more criminal than anybody else. So why is that? What are we doing? Is it our law enforcement or our societal supports for people that leaves them with no options but jail?

JUDITH HEUMANN: So, I think what you can get from this discussion is to look at things like an onion. And you have to peel an onion. And that is not just in the area of disability, but typically things are very complex. And when we're looking at the causes of people going into institutions. I'd like to deviate for a second to ask what you consider an institution? Nursing homes?

How many of you would consider a nursing home an institution? Do you believe people are going into nursing homes freely and willingly? Or do you think there may be other obstacles in their lives that are causing them to go either into a nursing home or what we call a long-term adult living situation? Do you think when people have choices in their homes and their communities, they would choose a nursing home or to live in their homes?

I presume some of you have parents and grandparents who are getting older. Think about their lives, think about what they may need now or in the future, and look at what is available in the community, not only what is available, but how you access it. Are there means-tested programs that would preclude some people from getting into them? Are there programs that are in place that might be easily accessed? Say you know someone is going to need personal assistance. Personal assistance is there to help you go to the bathroom and help you get dressed. Not all people know that, but it is part of what personal assistance is and it's relevant to this discussion in *Olmstead* in so many ways.

I had polio in 1949. When you are five years old in the 1950s, if you can't walk, you can't go to school. My mother pushed my wheelchair to school in 1953.

My parents were immigrants, and there were no laws in place. So, she [my mother] was not thinking about an IEP or some kind of a plan; she was not thinking about asking the school district to provide transportation or to help me get in and

out of the school or go to the bathroom. She only wanted them to take me in the classroom and teach me what they were teaching my brothers. But the answer was no.

You may think that is something that no longer happens today. For any of you who have any interest in international issues or come from another country, it's always interesting to look at what is going on in these countries. The reason why I think it's important is because of the path that we have gone down in the United States as far as the creation of institutions, stigma of disabled people, lack of employment and education opportunities, basically not allowing people to believe they have the same rights as other people. And even for those who do believe they have the same rights, having to legitimize the disabilities. And one of the acts that is so important to recognize, is that members of Congress did not believe that discrimination was systemic. They did not believe there was a need to end unjust discrimination against disabled people. We don't see it as discrimination. I think in the area of disability, this is a really important issue.

Discrimination as it pertains to disabled people is still a relatively new term. In the civil rights movement, discrimination is something that has been around for a long time. People used the word. They used it more and more. They thought about the importance of the word. They were looking at what discrimination is. In *Brown v. Board of Education*, they looked at the discrimination that existed if you were a black child versus white child, including what the children thought about themselves and relationship to the overall society. In the area of disability, I think many people don't want to believe that someone is discriminating and so we say, "Oh, well, they did not mean it. They did not understand it." Well, that may be true. But what does that mean when I am being discriminated against?

AUDIENCE QUESTION: Can you please address the issue of the additional cost of all these services fostering independence and integration? How do we pay for them?

JUDITH HEUMANN: I think one of the issues that people frequently will raise is, "it will cost too much money." I will give you an example. When Section 504 came out in the 1970s, that law says you can't discriminate based on disability in any program or area receiving money from the federal government. One of the areas is accessible transportation, because all transportation systems in the U.S.—buses, transit systems, etc.—receive money from the federal government. And people argued that it would cost too much money to make buses accessible. So, if you take this little "onion" example: We buy buses every fifteen to twenty years; that is the life expectancy of a bus. The issue for accessibility of the buses was that there are stairs, and they had to address the stairs. For those people who were really knowledgeable about transportation, ultimately what we found was that it cost as much money to make a bus accessible as it did to install air conditioning and heating. And when we were not making buses and trains accessible, it was not only having an adverse effect on disabled people, but also an adverse effect on people with minor disabilities and people who did not pay attention.

So, one of the points we need to look at when we talk about costs is: what are the real costs? You put people in the institutions, and I think the costs are equal or even more expensive. We look at some of the situations that are going on in institutions, for example, violence against people in the institutions, the inability of people to be able to get into the community and be able to work, to be able to participate in society. I don't believe any cost-benefit analysis as far as it pertains to civil rights. But I believe the bottom line is that we can see it is no more expensive for people to be in the community than it is for people to be in institutions. Because in the community you can contribute in so many ways that you can't in an institution. One of the points we need to look at when we discuss costs is what do we take into consideration when looking at cost. Placing people in institutions is costly both from the pure dollar amount and then the adverse effect segregation has on the individual and the society overall. Assault and sexual violence that occurs in institutions is frequently not reported, making victims of disabled people. Disabled people are unable to get into the community for employment and the false view of society that disabled people cannot contribute continues to be perpetuated. Actual costs for institutionalization are more expensive [but] cost benefit analysis should not be looked at when we are discussing civil rights. Most importantly, segregation in these institutions is because of bias and historic discrimination.

EVE HILL: Following up on that, in all litigation we have to look at the cost question, and in each case, we have shown it is not more expensive to provide these services outside an institution. And shockingly, as I mentioned earlier, it's the same services. The additional costs tend to be transportation, because now you have to move those staff people around to different locations, and housing. But you reduce costs on buildings. So, the cost argument is not true. Just as the cost defense in *Brown v. Board of Education* was not true. I would say I'm not sure cost is supposed to be a defense to civil rights.

The cost issue exists because we set the system up this way. And now we have to dismantle it. That's when there is extra cost. The only time there is extra cost is when you are running two systems. You have a community-based system and an institutional system. When you have the money follow the person out of the institution and into the community, the cost doesn't go up. It's just while you have two systems going on. So that's a short-term cost, and I would say worth it. But when we look at civil rights for other groups we *don't* say: "Oh, it will cost us too much to do that. We will have to educate all of these minority children. Oh, women will come, and we will have to educate them, and then they will want to work, and who will take care of the kids?! We are all going to die." We don't accept that argument for racial minorities and women. We don't accept them for people with disabilities either.

JUDITH HEUMANN: I want to say this discussion is looking at *Olmstead*, which is where we talk about individuals who have significant disabilities. But, when we're having this discussion, we're talking about the full range of disabled individuals. It's important for this conversation to understand that discrimination can be anything

from someone having a limp to someone knowing that you had HIV in your family, to discrimination against being overweight. Whatever it may be.

And I think it's important to understand that the Americans With Disabilities Act and the results of *Olmstead* are intended to go beyond people with the most significant disabilities. For those of you who are studying law or looking at other forms of employment in the social service system, we really are talking about a very broad group of people.

I want to give a little bit more information following up on the story of my mother taking me to school. So, then I had the privilege of having a teacher come to my house for two-and-a-half hours a week. One day for an hour, one day for an hour-and-a-half. And when I was really good, they sent an occupational therapist to my house. So, I could say it was three-and-a-half hours, but I never counted that as part of the educational program. But nevertheless, I would say it is important for people to realize that in many ways these situations still exist for certain populations of children. When I finally did get to go to school, I was in a regular public school, but in a basement classroom that was for the disabled to learn. This issue of separate schools for disabled kids, or separate classrooms for disabled kids, remains. We were on the same floor as the dining area and we were not allowed to eat with the non-disabled kids. We used to share the bathrooms, but then they built bathrooms in the special ed classes. The only time we were being “integrated” was once a week for the assembly.

And you can go visit schools today, not just the special ed schools where everything is segregated, but you can go to a school where they have special ed classes for kids with disabilities and look at what kinds of integration are really happening. Now, why is the issue of integration important? I don't think that we should be saying that integration for disabled children is different than for non-disabled children. So, if we believe in *Brown v. Board of Education* and other cases, and we recognize the fact that segregation is not good, then segregation for disabled children is not good. It does not mean that children with certain types of disabilities may need additional support and may need to come out of classes to get certain kinds of supports.

There was a really great film called “Educating Peter.”² It was about a mother and her son—I think he had down syndrome—and how when he was in kindergarten, the school said, “No, not yet. We want him to get used to school.” So, he was in a segregated environment. Then she wanted to integrate him into first grade, and it was the same thing. So, he was going into third grade, and the mother said, “I want him in the third grade, period. You need support in the classroom.” And they did it. As I was looking at the documentary, I thought “I don't know that I really want to show this to anybody,” because for the first six months in the classroom, Peter was having real difficulty. He was being disruptive. But what was really important about this film is that it showed that as he was becoming more integrated and accepted in the classroom, both himself and his peers, his behavior dramatically changed.

² EDUCATING PETER (HBO 1992).

On the issue of preparing disabled kids to move forward: I visited a school when I was the assistant secretary where—and they told me this with a straight face—they were preparing these kids to be able to have lunch with non-disabled kids. Their classes were totally segregated. When I asked why they weren't eating lunch together, one of the teachers said, "They need to be prepared." So, I think when you leave here today, if this is an issue you really are interested in, you need to be in the community, you need to talk to people who have disabilities themselves. You need to look at some of the better organizations and get a better understanding of the problems that people are facing and what is it that you need to know and what is it that you need to be demanding that you are learning in your classes. Because I think another very big issue that is still going on is that disability, as an issue of discrimination, is still not frequently taught in law classes, for example. Or social work classes. Or education classes. Or medical school. Pick any area. And so you are not learning what you need to learn. But the fact that you are here today shows that you have an interest, whether a minor interest or a major interest, that I think really needs to be nurtured.