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THE INTEGRATION OF THE ADA AND THE PROBLEM OF DE-INSTITUTIONALIZATION

*Melinda Bird**

Thank you for being here. I'm going to talk about Title II of the ADA¹ and as I was getting ready yesterday for this talk, I dug out of my files some materials from a seminar Loyola did ten years ago on disability law. There was a great article by Michael Perlin and a wonderful article by Jim Preis and Jan Costello on the constitutional right to treatment for mentally disabled persons in our community. In fact, they should probably be the ones giving this talk.

I am going to talk about state statutes as a way to get around the problem of de-institutionalization that occurred in the 1980s, and the problem of de-institutionalization as it manifests itself in the 1990s. It is both the problem of people in institutions who want to be in the community and cannot because there are not enough community mental health services to support them, and also the problem of de-institutionalization. To some extent, what we saw in the 1970s and 1980s was big state hospitals and institutions closing down, but our problem is the revolving door. People are continually re-institutionalized and then discharged with basically nothing. One of the paradigms that we're looking at—and I'm going to talk about it at the end when I talk about the litigation that's ongoing right now—is a phenomenon that I've seen for ten years. Most people who are involuntarily committed because they are a danger to self or others, or gravely disabled, are held in a state hospital in an acute psychiatric ward. Some people are kept for days or weeks and then are discharged with a week's worth of psychotropic meds, the phone number for the county mental health agency, and sometimes the number for a shelter. When they call the shelter, it is full. And, when

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1. Americans with Disabilities Act of 1990, Pub. L. No. 101-336, 104 Stat. 327.

they call the counselor, mental health agency, or the center, the first appointment they can get is weeks after their medication runs out. We have seen that for so many years, we don't even flinch. It just happens all the time. We call it discharge to the streets. It happens to people that are housed as well as homeless. And it's so foolish that there's got to be a way to tackle it.

What Jim and Jan were struggling for in their article in 1987 were some theories that would help us tackle it, but what we didn't have then was the Americans with Disabilities Act. And the ADA has given us, in Title II, a wonderful federal statutory claim that is markedly different from the constitutional due process and statutory claims that we were wrestling with in the 1980s.² The provision that I am going to talk about is what we call the "integration mandate."³ It is part of the regulations that the ADA requires and I will read it to you. Let me first back up and say that the ADA itself says, in Title II, that no qualified person with a disability—"shall, by reason of such disability, be excluded from participation or be denied the benefits of the services, programs, or activities of a public entity, or be subjected to discrimination by such an institute."⁴ So that's what the statute says.

The regulations are great. The regulations recognize that discrimination can be manifested by segregation, by excluding people and not integrating them into the community.⁵ So the regulations go further and say, "a public entity shall administer services, programs and activities in the most integrated setting appropriate to the individual needs of qualified handicapped persons."⁶ We call that the integration mandate. If you're going to provide services, you have to do it in the most integrated setting appropriate. When I think about it conceptually, I think of it like an adverb. It's not a substantive right. Rather, it attaches to a right and tells the entity how it is going to do what it is doing anyway. So, many of the cases say, and I think it's correct, that this integration mandate doesn't create a right to services or treatment, but it attaches to benefit programs that are already there and that the states are already doing. Like an adverb—it tells them how they have to do this program.

The lead case interpreting the integration mandate appears in

2. 42 U.S.C. §§ 12131-34 (1997).

3. Integration Mandate, 28 C.F.R. § 41.51(d).

4. 42 U.S.C. § 12132.

5. See 28 C.F.R. § 41.51(b)(4)(i).

6. *Id.* § 41.51(d).

your materials. It is called *Helen L. v. DiDario*.⁷ The cite is there; it is a Third Circuit decision from 1994. What happened in *Helen L.*? The plaintiff was a woman in a nursing home who was ready for discharge but who could not go home because there were no home-care, attendant-care services for her. Her state, Pennsylvania, like many other states, didn't have a home-care or attendant-care program that was available to everybody. Attendant-care programs are funded through the Medicaid statute under the federal Medicaid program. I am going to talk about Medicaid as one of the most important state/federal programs that we're working with now for people with mental disabilities.

Pennsylvania did not want to spend the money to provide attendant-care to everybody who needed it. Instead, they had what's called a "waiver" where they could provide some attendant-care, but they could cap their expenses, so they could have a waiting list for people to get attendant care. Idell—the person who ended up being the actual plaintiff who is discussed in the Third Circuit case—couldn't get attendant-care services. Instead, she was getting Medicaid funding to stay in the nursing home. The bottom line is if the states can spend money—Medicaid dollars—to keep her in the nursing home, it has to spend those Medicaid dollars "in the most integrated setting appropriate" to Idell S.'s needs. The state had stipulated that she could live in a community with attendant-care. Now the state's protest was sort of feeble. They said, "We're not set up to do this and we don't have a statute." The court said: "Forget it! You are spending more money on the nursing home services than you would on the attendant-care services. Retool your program to deliver the services that Idell needs."

Even more fundamentally, there is language in *Helen L.* that talks about that linkage between segregation and discrimination and integration. I will read it to you: "In enacting the ADA, Congress found that, '[h]istorically, society has tended to isolate and segregate individuals with disabilities, and . . . such forms of discrimination . . . continue to be a serious and pervasive social problem.' Congress concluded that '[i]ndividuals with disabilities continually encounter various forms of discrimination, including . . . segregation.'"⁸ Again, this is back to Michael's keynote at the very beginning, that segregation of people with disabilities keeps them locked away in an institu-

7. 46 F.3d 325 (3d Cir. 1995).

8. *Id.* at 332 (quoting 42 U.S.C. § 12101(a)(5)).

tion. It is part of the pervasive discrimination that the ADA was intended to address.

Many people are currently using the integration mandate in litigation. Basically, what we are trying to do is look at situations where people are either in locked institutions and not given the option for services in the community, or they're in the community with nothing. The only place they can get care is when they get into an acute episode. There are relatively few reported decisions on this, but there is a group of a couple dozen people doing a lot of these integration mandate cases. I brought a notebook of pleadings from the Disability Law Project in Pennsylvania as an example of how people across the country are trying to network. Elaine Shane and Mark Murphy of the Disability Law Project put this great packet together, and they even included a disk with all of their pleadings. And so, there is case after case that they've been bringing to get people out of locked facilities and into the communities with services that will support them. In most of these cases, the community services are rationed for whatever reason. It's usually budgetary, but the courts have been wonderful about rejecting budgetary justifications, if you can get over the procedural hurdles to actually get a ruling on the merits.

There is another good research tool that I rely on a lot, and that is a docket that is issued every couple of months by a group called NAPAS, the National Association of the Protection and Advocacy Systems. They do a docket of significant integration and institutional conditions cases. It's a compendium of what people are litigating all over the country and there are probably thirty integration mandate cases going in various parts of the nation. And I'll just back up and say here that every state has a protection and advocacy program. Some of them are more aggressive than others. Some of them are located in the Governor's office. My program, the California Protection and Advocacy Program, is independent and actually a strong program as they go nationwide.

Before I start talking about what we're actually doing right now, let me say that both in *Helen L.* and in another case I wanted to mention, the court has carefully distinguished what it was doing from de-institutionalization cases. And they did it in a way that's slightly defensive. It's okay with me because the de-institutionalization case law tended to be so disastrous for us. So in *Helen L.*, for example, the court said this is not de-institutionalization. The court said that de-institutionalization involves massive changes in the state's program. It is not required absent a clear statutory command. They are

saying, instead, these are services the state already chose to provide, and we're just telling you if you're going to spend this money you have to spend it in an integrated setting so we are not requiring you to create whole new programs.

The other case I wanted to mention to you is also illustrative of how the courts are saying, "We're not doing de-institutionalization stuff; we're doing integration mandate stuff that's okay." This is a case called *Martin v. Voinovich*.⁹ It's a case which takes place in Ohio in 1993. *Martin* is very interesting because like *Helen L.* it deals with the Medicaid program.¹⁰ The plaintiffs brought due process de-institutionalization claims saying there's a right to treatment in a less restrictive setting, as well as integration mandate claims. They lost the due process claims but they won under the integration mandate claims.¹¹ So, *Martin* analyzes in a very traditional, non-progressive way, the constitutional due process claims but then rules for plaintiffs strongly on the ADA integration mandate claims.¹²

Let me talk about how we're taking this wonderful opportunity in the integration mandate and using it in California. There are actually five cases I'm going to talk about. One is a case that we filed in March 1996 called *Hale v. Belshé*. *Hale* was brought on behalf of a class of people in locked psychiatric nursing homes. We've got 5000 people in this state in these settings. Our contention was that the state illegally limits community mental health services, the rehabilitative mental health services available to people in the community and funded through the Medicaid program. Because these are arbitrarily limited, people have to stay in these locked psychiatric nursing homes who are ready to go into the community. We argued *Helen L.* We presented strong claims that this is a violation of the ADA denying the state's motion to dismiss. We got a very good decision from the federal district court in San Francisco on the state's motion to dismiss finding, yes, there is a revolving door.

At that point, the state raised a procedural challenge that we're seeing all over the country in response to the Americans with Disabilities Act. Advocates are raising these ADA Title II claims against state entities and we're doing them in federal court. The Eleventh Amendment says the states are immune from suit in federal

9. 840 F. Supp. 1175 (S.D. Ohio 1993).

10. See *id.* at 1180.

11. See *id.* at 1192.

12. See *id.*

court unless there is an abrogation of state immunity.¹³ Congress specifically abrogated state immunity from suit in federal court under the Americans with Disabilities Act, but the states are taking a pretty steep position that Congress's abrogation of state immunity in the ADA is unconstitutional. Why? Because the integration mandate, among other things, requires affirmative acts that go beyond the power of the Fourteenth Amendment, and Congress can't authorize suits for relief that exceed what is directly available in the Fourteenth Amendment. The good news is that after the state appealed, we won on this issue in the Ninth Circuit. But by the time we got back to the district court, we'd gotten everybody who was our named plaintiff out of the locked nursing homes because we couldn't just leave them there while we're off in the Ninth Circuit. So we were effectively mooted.

Even though the *Hale* case is over, I think we focused on the right group of folks—residents of psychiatric nursing homes. They were folks who were the most in need. These psychiatric nursing homes, they're horrible. They're commercial enterprises; they actually recruit patients. They replaced the big state mental hospitals, and they're a little bit better, but not much. The problem is that when we came in with our experts to do psychological assessments, they said this person really needs to be in the community. The first impulse of the nursing home is, "Fine! We'll discharge her!" So our representation triggered a discharge, and it was very hard to hold the class together with the focus on the people in the locked nursing facilities.

We dismissed the *Hale* case voluntarily without prejudice in October. We've actually now asked the Ninth Circuit to publish its good decision on the Eleventh Amendment and the ADA. We argued *Hale* with two companion cases on the application of the ADA to state prisons, *Clark*¹⁴ and *Armstrong*.¹⁵ There are petitions for certiorari on those two cases. And I think eventually this question of the Eleventh Amendment immunity of states under the ADA will finally become a moot point; but for a while, at least, it's really time that is impeding federal litigation. After we dismissed the federal case, we're continuing with one of our main plaintiffs, Mr. Hale, actually, in a state court action in San Francisco. It's an individual action trying to get

13. See U.S. CONST. amend. XI.

14. See *Clark v. California*, No. C96-1486, 1996 WL 628221 (N.D. Cal. Oct. 1, 1996).

15. See *Armstrong v. Wilson*, 124 F.3d 1019 (9th Cir. 1997).

him the community mental health services that he needs. So, in a small context we're still working on that.

The issues in Mr. Hale's individual case are also interesting because it illustrates another subtle level of discrimination that people of psychiatric disabilities experience, and that is the idea that you have to be cured, as opposed to making accommodations to your behavior. For people with developmental disabilities, the idea of behavior and behavior management is very common. We don't expect people with developmental disabilities to "get better" and become able to do things just fine on their own. With people with psychiatric disabilities, there's an expectation they should get better. In institutions, the attitude is that we're not going to let them out until they get better. With Mr. Hale, because he's been institutionalized so long, he has a lot of difficult behaviors. We want a behaviorist to come in and work with him and create a structure that will support him the way you would support someone with developmental disabilities. What you do is work with his impairments as opposed to expecting him to overcome them on his own. And it is amazing how, in the psychiatric disability community, there's resistance to behaviorists coming in and working with people like Mr. Hale about a home plan that would enable him to deal with things like inappropriate urination or poor eating habits. It's literally those two things that are keeping this man in a psychiatric nursing facility. If he were developmentally disabled, people would work with him around that, as opposed to saying, "You're going to be locked up until you stop peeing in public." Because he's been institutionalized for twenty-five years and can't help these behaviors, the way they're approaching it is simply punitive. So that's a second case that we're doing for an individual client.

There are two other integration mandate cases that we're working on. One is what we call "the discharge to the streets" case. Instead of focusing on, as I said before, people in a locked facility, we're working with people who have been involuntarily committed and then discharged with nothing. Many of these are people who are homeless in the community. The only way they're going to get services is when they have another crisis and they are recommitted. Their prospects of getting services that are even vaguely equal in terms of cost, if they're in the community, is nil. In other words, we'll spend \$1000 a day or \$1000 a week to keep them in a locked facility, but we won't spend one cent when they're in the community.

So, the integration mandate and the Medicaid statute are the sort of engines that will drive this case. Most all of the people that

we're working with are, in fact, eligible for the Medicaid program and covered under our state Medicaid plan. We have an excellent package of rehabilitative mental health services that includes case management—what we call “brokerage services”—that can link you up with housing and job training, but very few people get it because it's rationed. There is a series of really strong claims to these benefits based on the Medicaid Act. One of them is that services have to be provided with reasonable promptness. In many of the county mental health clinics, there are waiting lists. So, if you have a crisis, that's fine. We'll give you an appointment in two weeks. You're running out of medication, the next appointment for medication management is December. Failing to provide services with reasonable promptness for someone for whom this treatment is medically necessary, and necessary now, is a violation of federal law. Budget limitations are not availing, both when you're looking at Medicaid law and when you're looking at the integration mandate, because the truth is, if you have a breakdown or a psychotic episode, they'll put you in a psych unit in an acute care hospital and give you your meds then. So, they will provide services but not in an integrated setting as an option.

One of the things that makes the new approach that we're taking easier, I believe, is that we're working with people who the state will agree, at this point, don't need to be institutionalized. So we won't have a factual dispute as we did in the first case about whether people are able to be in the community. They've been discharged. Somebody's already said they can be in the community. They just won't give them the services to remain there.

There are two other cases that we're working on that involve children. A part of the Medicaid program is called EPSDT, Early Periodic Screening Detection and Treatment. For some of you, your eyes may glaze like they did when I was talking about the Eleventh Amendment, but I'll just tell you a bit about the Medicaid program. Under the Medicaid program, each state has the ability to pick and choose the package of services and optional benefits that it provides to adults. Benefits that you think are pretty basic, like medication, are optional. They certainly don't have to provide rehabilitative mental health services or home attendant-care—those are all optional. So states can pick and choose for grown-ups. But for children, who are defined as people under age twenty-one, the state *must* provide all services that are medically necessary, if these services

could be covered under Medicaid any place in this country.¹⁶ So my reading of it is if, in any place in the United States or its territories, there is a service that is reimbursed by Medicaid, then it's mine. When we request services for children, we attach copies of the Medicaid plans from states that have good benefit packages and say, "Look! In Pennsylvania you're funding crisis intervention where you have a one-on-one para-professional aid who comes in with a child and stays in the home as a one-on-one. You won't do that here, but you have to because that's what's medically necessary for this child." EPSDT is a very, very powerful mandate for treatment.

Advocates in California filed an EPSDT case several years ago, and have gotten a lot of services implemented, but the part that the state has never really implemented is mental health services. Their whole delivery system—who you ask for benefits and how you know what you can get—is all extremely vague. But for children with mental health needs, the EPSDT program says you get whatever the child needs if it's medically necessary. Think of this in conjunction with the integration mandate. What you have is—for a child in an institution or a child locked up in a state hospital—the creation of the right to any service which will enable that child to be in the community. If you spend one dollar of Medicaid money on this child, then you've got to provide all the services that the child needs in the most integrated setting, which is going to be in the community.

The state has had a number of units at the state hospitals for children. These are about as restrictive as placements can get for a kid. The state has been consolidating these hospital units to the point where shortly, as of January 1, 1998, there will be only one state hospital placement for children with psychiatric disabilities—at Metropolitan State Hospital here in Norwalk. Metropolitan subjects these children to terrible conditions. Those of you from L.A. may have seen last week in the *Los Angeles Times* a good article that they did. Metro hospital—I have no idea why they were so stupid—but they let the *Los Angeles Times* reporter come in and take a black and white photo of the bare tables with the leather straps where they strap these children down when they impose restraint and seclusion. It looks like something out of the middle ages. So there are eighty children on those units at Metropolitan and the conditions are really terrible.

We believe that through the EPSDT program and the integra-

16. See 42 U.S.C. § 1396(d)(r) (1997).

tion mandate there is no reason on God's earth that any child should be on that unit. If you think about it with reference to a child with physical disabilities such as a child who is a complete quadriplegic, we think nothing of giving that child one-on-one aid in school and at home, and we'll pay for it through Medicaid without flinching because that child can't carry out his or her activities of daily living without assistance. These children with psychiatric disabilities are similar in some ways in that they also cannot do activities of daily living on their own. And when they do, they have crises, or they decompensate, or they don't know how to modify their behavior. They aren't successful on their own in the community. But our response—rather than to say let's give them the one-on-one aid who can model behavior and be a mentor for them and help them calm down in a crisis and then help them understand it—is to lock them up. In the past we also locked up children who were quadriplegic, but we stopped doing that. Part of this change in thinking is saying that if we're willing to deliver enough services to the children in the community, there's no reason to keep them locked up.

There are now thirteen children at the other remaining state hospital, Napa State Hospital in Northern California, who are going to be transferred down to Metropolitan State Hospital. Nine of these children are children from Northern California. So just before Thanksgiving and Christmas they're going to be transferred five hundred miles away from their families down to Metropolitan State Hospital, where there are as many as six incidents of restraint and seclusion per day on the children's wards. It's really horrible that they're trying to move the children that far away. What we've told the state is, "You cannot move these children." Under the EPSDT program, you have to put these children in the most integrated setting, and that's someplace in the community. Many of these kids have left group homes. They bombed out of group homes because they had behaviors that couldn't be managed. But the question is, if you went to the group home and said "I'll give you a one-on-one to stay with little Susan," or whoever, would the group home have kept the child? And I'll bet you the answer would be yes. If you offered the placements that they failed in more services and support, they probably could have been successful. We will have the opportunity, I suspect, next week to see how these theories work in action when we seek a temporary restraining order to stop the transfer of these children from Napa to Metropolitan.

Another issue we are looking at is the fact that, as horrible as

Metropolitan Hospital is, there's a waiting list to get in. There are children who are in temporary holding facilities with the dependency or the juvenile court. So the other suit we'll be working on is to remedy the situation, and the class will be the children on the waiting list to go to Metropolitan. Our standard is before you spend \$100,000 a year to lock this child up in a state hospital, look at what else you can buy with that money in the community. And until you can show us that you negated every possibility—and my standard is up to \$100,000 per year—you can't put that kid in the facility. We have other kinds of claims about discharge planning, pre-admission, screening, and other sorts of planning claims that are involved when you institutionalize somebody. But the guts of the case will be the integration mandate and EPSDT and the idea that if you're going to spend one dollar of Medicaid money you have to spend it in the most integrated setting, which is in the community.

I was very excited at the Colloquium because we're obviously up to our eyeballs in these lawsuits. So, it's exciting. Thank you.

