



Transcript of Conference Call Presentation

The Olmstead Decision and Services for Youth with Disabilities in Community Settings

presented by:

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MS. LEUCHOVIUS: I want to welcome everybody to the phone call today. Our topic is The Olmstead Decision and Services for Youth with Disabilities in Community Settings. Here is what you can expect today. We will have formal presentations by Bobby and myself. After our presentations, we will open it up to questions and answers. Individuals are asked to announce their name and the state they are calling from when they ask questions or before speaking.

I am Deborah Leuchovius. I work on technical assistance projects with parent centers funded by the Rehabilitation Services Administration (RSA) as well as the Office of Special Education Programs (OSEP) here at PACER Center. I also am involved with NCSET on their Parent and Family Network. I have presented this topic to folks at NCSET because I felt that I was hearing a lot of information about Olmstead from Washington, DC policymakers, and a relatively small but influential group of analysts, ADA specialists and advocates, in the disability community.

These individuals have been immersed in planning for Olmstead for some time. However, the parent advocates and educators that I spoke to were less familiar with Olmstead and some of them were only vaguely aware of it and its implications. Those who were familiar with it thought primarily in the context of health care and housing issues. These are huge issues and central to Olmstead. I am speaking

as a parent of a 17 year old who really requires an institutional level of care at home, so I recognize the importance of health care and housing, but I think parent trainers, families, advocates, and educators need to begin to develop a broader understanding of the central impact of Olmstead, especially now that federal implementation efforts are beginning to move forward. I think this is especially important for families of transition age youth with significant disabilities who are preparing to leave special education settings, access adult services, and participate more fully in the community.

We are very lucky today to have Bobby Silverstein, the director of the Center for the Study and Advancement of Disability Policy, with us to provide us with a foundation for our discussion, which is sure to be a continuing discussion, on Olmstead and its significance for transition age youth with disabilities. Bobby, I am going to turn it over to you.

MR. SILVERSTEIN: Thanks a lot. Before I became director of the center, I spent 13 years on Capitol Hill. I was the staff director and chief counsel of the Senate Subcommittee on Disability Policy chaired by Tom Harkin for 11 years, and for two years served as the counsel to the House Subcommittee on Select Education chaired by Pat Williams from Montana. During my tenure on the Hill I worked on the early intervention program, the IDEA including the 1997 amendment, the

Americans with Disabilities Act (ADA), the Tech Act, the Developmental Disabilities Act, et cetera.

In terms of the presentation I am going to explain in a nutshell what the Olmsted case said and didn't say. Then, I am going to describe briefly a document that is on the web (www.PACER.org), which is entitled "Using the Emerging Disability Policy Framework to Craft a Comprehensive Effectively Working Olmstead Plan." This is the document I prepared for this presentation. The document provides a lens, guidepost, or an outline for advocates who are interested in getting involved in Olmstead planning. It's a kind of checklist that advocates can use to hold state systems accountable for complying with the ADA's most integrated setting mandate.

Then I am going to briefly describe some of the actions taken by the Clinton administration, some of the efforts done by Senators Harkin and Specter to provide funding, some of the actions undertaken by the Bush administration in general, and with respect to transition in particular.

Let's start with Olmstead. Its official title is Olmstead versus Lois Curtis and Elaine Wilson. The Supreme Court decision was handed down on Dec. 22, 1999. In a nutshell, Lois Curtis and Elaine Wilson are woman with mental retardation. Lois Curtis had a diagnosis of schizophrenia, and Elaine Wilson had a diagnosis of having a personality disorder. They were both basically put in institutions, Lois Curtis in a psychiatric unit; Elaine Wilson was voluntarily admitted to a hospital in Georgia. In both cases, the treating professionals believed that they did not require institutionalization that they could function with community-based services and supports.

The question before the Supreme Court was basically whether the ADA or the prohibitions against discrimination in the ADA, require placement of persons with mental disabilities in community settings rather than in institutional settings. Basically, the Supreme Court answered with a qualified "yes" to that question. It found first the state's treatment professionals must have determined that community placement is appropriate. Second, the individual does not oppose

the transfer from institutional care to a less restrictive setting and the placement can reasonably be accommodated, taking into account available resources to the state and the needs of others with disabilities. And the case was sent down to the lower court to determining what was appropriate.

And the key thing here is the Court also said is that it expects that the state will maintain a range of facilities for care and treatment of persons with diverse mental disabilities. And its overall program must be administered in an "evenhanded way." So, in a nutshell, what the court did is recognize that unjustified, unnecessary, inappropriate isolation and segregation is unacceptable under the ADA, that people should not give up their right to interact with nondisabled persons in order to recoup services, in this case, health care services. They shouldn't give up their right to interact with non-disabled persons, to be able to go to church with friends and neighbors. They shouldn't give up those rights in order to receive a service, in this case, health care and long-term services and supports.

Now, at the end of the decision, one of the points made by Court that in maintaining a range of facilities and administering services in an "evenhanded way," one of the strategies that a state could do is develop a comprehensive, effectively working plan for placing qualified persons in less restrictive settings. And it also recognized that waiting lists that move at a reasonable pace, not controlled by the state, endeavor to keep its institutions fully populated, are okay to repeat. Waiting lists that move at a reasonable pace which are not controlled by the state's endeavors to keep its institutions fully populated may be an acceptable administrative mechanism for carrying out its comprehensive effective working plan.

Now, in reference to the materials that we put on the web called, "Using the Emerging Disabilities Policy Framework to Craft the Comprehensive Effectively Working Olmstead Plan," what I tried to do here is to say, okay, we know what the Supreme Court said specifically in Olmsted. Now, a lot of states are heeding the direction of the Court and are developing a comprehensive, effective working plan. But the advocates need some sort of a lens or

checklist or audit for seeing how well states are doing.

And that's what the intent of this document is, and again, in five minutes I am not going to be able to do anything other than to highlight what's in it. But you know, I ask you all to look at it and see if it's helpful for you. But the essence of this is, again, a checklist to make sure that your plan is accomplishing the four goals of disability policy articulated in the Americans with Disabilities Act.

And those four goals are: equality of opportunity, which means that you treat people as individuals based on facts and objective evidence and best practices, not fear, ignorance, and prejudice. You come up with an individualized plan. You treat people in the most integrated setting appropriate, and the presumption is that that's where services will be provided, and that you provide effective and meaningful opportunity for people.

The second goal is full participation in the decision-making processes. That means that people with disabilities and the families must be involved in decisions affecting their lives at the individual level as well as at the systems level. And that's what we mean by empowerment and self-determination and real choice and person-centered planning and budgeting.

The third goal is that independent living is the legitimate outcome of public policy, that we provide independent living skills that are necessary, and that we provide the long-term services and support that enable folks to live independently.

And the fourth goal is economic self-sufficiency, recognizing that a job may be a legitimate outcome of public policy, that some people may need cash assistance but there must be work incentives.

Now, the second part of this framework is to say, okay, those are all good goals but what about implementation? Implementation—how do we maximize that these goals are achieved? And we have to look at the methods of administration that a state uses. What kind of financing system does it have? Does the financing system have an institutional bias? What kind of personnel preparation do we have? Are we teaching folks to

understand best practices so that the professionals know that individuals with disabilities can, in fact, live in the community or are they stuck in an old medical model which looks at people with disabilities as defective instead of as people. We need to look at disability as a natural part of the human experience.

Do we have a comprehensive approach that puts the person at the center of the public policy rather than having silos based on different departments or agencies or committees in the state legislature or do we have action plans that are set up that really have goals and objectives and action steps and performance measures and budgets to make things happen? What about the design elements of the plan?

What about employment? What about transition services? What about education? What about prevention? What about transportation? What about the finance of the reimbursement schemes for providers? Do they provide a capitation where you get a certain amount resulting in providers not willing to work with and meet the needs of those with significant disabilities? In other words, does creaming occur? Do we have an adequate network of qualified providers? Is there monitoring in force? These are just things to list in terms of a checklist to consider if you are participating in an Olmstead planning effort.

Now, the Clinton administration set out in guidance a number of things to explain what was meant or what the expectations were with great specificity as to what constitutes compliance. The Department of Health and Human Services, Office of Civil rights, wrote a series of guidelines. They are on the web. They are very important to review. And then when President Bush came in, in his New Freedom initiative, one of the key things that he said is that he was going to sign an Executive Order supporting swift implementation of Olmstead.

And in fact, very shortly after he was inaugurated, he did in fact, issue an Executive Order. And one of the things that the executive order required — and the order was issued on June 18, 2001 — was that there be a report submitted to the President by various folks in the various

agencies. And that report was to be submitted to the President by Friday, December 21, 2001. And you have specific steps that the various departments are going to do to try to implement. And in this report there are at least nine or ten specific references to what the Department of Labor and the Department of Education will do with respect to transition services.

So, transition is specifically identified in the report to the President on at least nine or ten occasions. So, for example, it says that the new Office of Disability and Employment Policy (ODEP) in the Department of Labor, with the Department of Education and other agencies, will promote the transition of young people with disabilities from schools' to postsecondary opportunities and their employment including research, demonstrations, and disseminating acceptable strategies for transitioning young folks.

Another one is it will establish a study group to look at the issue of transition. As I said, there are seven or eight other specific references so that when you all go back and work with other advocates, there are what I call "handles" in this report to the President to say transition must be a component of an Olmstead plan.

Now, one last point and then I will stop my initial presentation, and that is Senators Harkin and Specter introduced the Micassa legislation, which was designed to eliminate the institutional bias in Medicaid and require as a mandatory service community-based services, supports, and personal assistance. That part of the legislation did not get passed, but another part was to fund what was called Real Choice systems change grants. This was money that went to states to help them design and implement Olmstead plans. And about \$50 million was actually appropriated for that purpose and about three-fifths of the states actually got funds. So, they are ranging from \$500,000 to over \$1 million.

So, there is actual money in many states to help them implement Olmstead. And again, connecting with those folks in your state is a strategy that, I think, makes a whole lot of sense. And again, to emphasize transition as part of it is now fully supported by the report submitted to the President

by the various agencies pursuant to the executive order. Deborah?

MS. LEUCHOVIUS: Thanks, Bobby. I just want to reassure folks that we have posted information—the information and reports that Bobby mentioned are on the PACER Web site. If you go to www.PACER.org, you will reach PACER's homepage. On the homepage there is a button for "Transition Issues", and if you click on that button, you will be directed to a number of links to online documents including the information that Bobby prepared for this presentation. It is "Using the Emerging Disability Policy Framework, etc." Also, there is a link to the December 2001 report from HHS that Bobby also mentioned and a number of other resources. I am going to refer you to these two documents, because we have such a brief amount of time. I am hoping that people will investigate some of these issues in more depth on their own. The two papers that I found, I think, most helpful in linking Olmstead specifically to transition issues for youth were that HHS report and a working paper from the Center for Health Care Strategies, which is called an *"Analysis of Olmstead Complaints."* That is also from December 2001.

What I would like to achieve in my next remarks is to draw some concrete connections to transition. Looking first at that working paper analyzing Olmstead complaints, the authors looked at 334 complaints (they call them "most integrated service complaints") filed with Health and Human Services Office of Civil Rights between 1996 and mid-2001.

So, some of this was actually prior to the Olmstead decision, but they were all complaints filed under ADA Title II or Four Section 504 of the Rehabilitation Act and what they found is evidence of the impact that Olmstead will have for youth and families. Thirty percent of the complaints were from individuals at risk of institutionalization but not currently in institutional settings. Many of these "at-risk" individuals were living with family but they considered themselves to be in danger of medically unjustified institutionalization in the absence of assistance.

One in seven of the complaints were made on behalf of a child or adolescent with a disability in institutional settings. Complaints were filed for individuals in skilled nursing facilities, psychiatric facilities, and hospital settings. The complaints also demonstrated a wide range of disabilities that are leading to unjustified institutionalization. It's just not mental retardation or developmental disabilities or mental illness or psychiatric disabilities. One-third of the children and youth had physical disabilities.

An interesting difference between the adults and children was that more of the complaints filed on behalf of youth were for youth who had dual or triple diagnoses, not just single diagnoses. It was more common for adults to have a single disability. The complaints—again, these were complaints filed with HHS—were dominated by requests for health care and affordable appropriate housing, regardless of age. However, complainants also mentioned education, training, equipment, and transportation.

So, problems were both qualitative and quantitative with current services. The office concluded that these complaints indicated that a policy of long-term care reform must also encompass education, job training, income supplementation, and other types of intervention. Again, that goes to the broad scope of the impact of Olmstead that Bobby was talking about in his remarks.

I also wanted to look at a few things from the December 2000 report from Health and Human Services to the President that Bobby referred to. One of the interesting things is that the report is organized under several categories. Those categories include transportation, housing, personal assistance services and healthcare, community living, employment, assisted technology, education, and interagency collaboration. And I don't know about you, but that all sounded pretty familiar to me, and I began to think of this report as the 'mother of all transition plans'.

And of course, it is a transition plan for individuals with disabilities of all ages. But its relevance for youth with disabilities in transition is not hard to see. Another thing that struck me is

that it's very clear that what we regard as best practice in transition is considered best practices for delivering services to all individuals with disabilities, for example, person-centered planning, self-determination, and Real Choice. Those topics were mentioned as well.

And then there are the areas that Bobby referred to where the report specifically addresses transition planning and services for youth with disabilities. Bobby picked a few out. I encourage people to go to the report and they will find much more depth than what we are able to present here. A lot of the activities that federal agencies have reported that they are engaging in are technical assistance activities. Many of these activities are to reach individuals with disabilities and their families as well as outreach to service providers, employers, and states.

Some of the technical assistance activities referred to are to reach individuals with disabilities and the parents of youth with disabilities regarding the Olmstead decision, community living options, community-based resources. It's interesting that parent training and information centers are specifically cited here as an avenue for providing information to families.

There are several places where ODEP, the new office within the Department of Labor, has indicated that they will be developing and disseminating new strategies to increase the participation of youth in work force development activities and one-stop shops, for example, and other youth programs authorized by the Work Force Investment Act. ODEP also plans to provide information and technical assistance to employers as a benefit of hiring young people with disabilities as employees.

There are also several points where the report refers to outreach activities to involve stakeholders in the development of federal policy. There is a Disability Advisory Committee established by Health and Human Services and a Youth Advisory Committee to advise the Secretary of Labor on related issues for the Presidential Task Force on the Employment of adults with Disabilities. In some cases, the federal agencies just reported that they are

continuing their existing activities. For example, OSEP reports that it will continue to enforce IDEA requirements, transition planning, and OSEP and the Rehabilitation Services Administration indicate that they will jointly be monitoring the state VR agencies and state education agencies regarding transition from school to work.

So, those are a few of the examples that caught my eye and I felt were of significance. Now, we have some time to devote to questions and answers from listeners.

MS. PETERSON: This is Colleen from Nebraska, the PTI in Nebraska. We are a subcontractor on a Real Choice grant for the state. Bobby, I was very intrigued with your comment about how the Real Choice money became available because there has never been one word from anyone anywhere in this state that that money was a result of the Olmstead decision. Our grant doesn't mention it. That's another issue, the grant.

My second question is I want to know from someone knows more than me, because I just came on this last six months, there was a HCFA letter sent out to the state departments of health and human services in January. What was that?

MR. SILVERSTEIN: There was a July 29, 1998, letter to the Medicaid directors. There is Olmstead update Number Two, July 25, 2000; update Number Three, July 25, also 2000. There was an update Number Four January 10, 2000, and there may have been some additional letters that went out describing the availability of funding under these systems change grants. But I am not aware of any additional interpretations.

MS. PETERSON: Okay. That answered my question. Thank you.

MS. LEUCHOVIUS: Next question?

MR. PORTER: Yes, this is Doran Porter from Hawaii. Bobby, you mentioned the state grants that went out, and, I think, three-fifths of the states accessed those. Is there a listing of those amounts and which states got them?

MR. SILVERSTEIN: I believe that's on the HHS.gov Web site. And actually, more than three-fifths applied. And they didn't fund everyone, which was, in my opinion, a mistake. I would have

preferred to have everybody who applied get less because it's just one more angle for advocates to use because the funds are there. The interest is there, and now there are funds to help people do stuff. And I would have put money in everybody's hands that expressed interest. But I think there may be a second round, and that I will find out more about next week.

MS. LEUCHOVIUS: Next question?

MS. ROMANO: This is Sheila Romano from the Illinois DD Council. Bobby and Deborah, both of you talked about the December report that was issued, and I was very excited as I read through it. But I also was disappointed that I didn't feel there was a lot of stuff in there and I didn't see timeframes for completion. I was wondering if you could comment on that.

MR. SILVERSTEIN: Well, my comment is I certainly agree with what you are saying. But as a person who has been working in this field for 20 years, I look at everything that is done as another opportunity, another possible angle for action. Yes, it would have been much better to have more specificity, actual actions already taken, et cetera, but to the extent that you don't have that, at least you have an action step that theoretically should be taken and provides an opportunity for advocates to say, okay, you promised it, where is it?

So, yeah, it's not what many would have liked, but it's also more than nothing. And this is on the radar screen, and people are saying things that need to be done. And now, it's all of our responsibility to hold people accountable for what's in here. And yes, it's another delay of six or eight months or whatever it is, but you know, I am just by nature an optimist. Here's another opportunity.

MS. LEUCHOVIUS: Well, Bobby, I think I share your optimistic nature, and at the same time I do recognize that most of the activities outlined in the report are initial or preliminary steps and anticipate that more significant programs and policy changes will be the result. I think what they have really done is outline the areas where they need to be focusing. Again, I felt the emphasis in the report was on technical assistance activities and less on policy, program, and practice.

MR. SILVERSTEIN: Right. I agree on the one hand, but on the other hand what a terrific outline for state-comprehensive, effective, working Olmstead plans. I mean, if this is the concept of Olmstead from the federal government, well, this should be the concept in the states. And that means Olmstead plans include transition and employment and technology and not just health care and housing. I mean, again, it's another handle. It's another conceptual framework for helping ensure that state stuff is done in a comprehensive, person-centered way.

And the most important thing to me in a state plan is a comprehensive — listen to the words again — comprehensive, effectively working plan. This is not some notion of maybe this is what we might do at some point in time. For it to be a comprehensive, effective working plan, you need goals. You need measurable benchmarks, objectives. You need specific action steps. You need outcome performance measures. You need budgets to see how you implement this stuff. Any plan that doesn't have those components is not a comprehensive, effective working plan, in my opinion.

MS. LEUCHOVIUS: Next question?

MS. MAXWELL: This is Susan Maxwell from the Texas DD Council. I was curious if you all happen to know if the President's Commission on Excellence in Special Education is addressing this issue in their charges?

MR. SILVERSTEIN: Let me answer the question this way: IDEA was amended in 1997, and this is one of the revolutions of the 1997 amendments, and I don't know how many people realize this. But prior to 1997, IDEA had one purpose basically, and that was to ensure equality of opportunities for children with disabilities. In other words, it was an access statute, a civil rights statute ensuring access for a free appropriate public education.

But in 1997, it was amended to say that the purpose of IDEA is not only equal access but it also includes two outcomes: independent living and economic self-sufficiency/employment. And so, should the commission be addressing independent living and economic self-sufficiency as well as

access? Yes, it should. And in broad terms, they recognize outcomes as a key component of what they are doing. And whether or not they specifically are mentioning Olmstead, I don't know.

MS. MAXWELL: Thank you.

MS. LEUCHOVIUS: Next question?

MR. SILVERSTEIN: But do you all want to take some time to talk about what Texas is doing if you have been involved? Take a couple of minutes. Texas is one of the states that is doing a lot of great stuff in terms of Olmstead. And at least from a national perspective, that's what we are hearing, as is Missouri.

UNIDENTIFIED: Well, in Texas we are getting great planning started, but it's slow going and we have still got lots of rough areas.

MR. SILVERSTEIN: Got you. Next question then?

MS. LEUCHOVIUS: Bobby, this is Deborah, and I just would like you to address the issue of employment - how Olmstead affects employment opportunities in community settings. I know that was an issue that several individuals had expressed an interest in hearing more about.

MR. SILVERSTEIN: Okay. Let me comment on that by looking at this issue in a number of different ways. Many of you may know that the RSA has put some funds out for systems change. The Department of Labor has put some money out for systems change and employment. Medicaid infrastructure grants are out there to look at Medicaid buy-ins dealing with issues of employment for people with significant disabilities, particularly those on SSI and SSDI. And then you have these Real Choice systems change grants out there.

Are the Medicaid infrastructure folks talking to the folks responsible for the SSA, DOL, RSA, Real Choice grants, and the Social Security Administration? They are different people, different organizations. That's crazy. And yet I'm afraid that that's what's happening in too many states. What Congress did, in my opinion, when it passed the Ticket to Work and Work Incentives Improvement Act, is it recognized the multiplicity of barriers that people with significant disabilities face. And those

barriers include issues dealing with lack of skills, the issues of work incentives and cash assistance programs, health care issues, transportation, housing issues.

This is all recognized. And when Congress wrote the legislation, it tried to make changes in terms of the training component by having the Ticket to provide more choice for people with disabilities. Whether it accomplishes that or not is a question for another audio conference. But they did it with that goal, and we have things about Medicaid buy-ins, and we have some changes to the cash assistance programs, and we have funding for benefit counseling. So, Congress recognized the need for a comprehensive, integrated, person-centered approach.

But the question is are the states recognizing this message, which is comprehensive, person-centered systems? Person-centered in the sense that the individual with a disability is the center of the public policy and the system, and comprehensive in the sense that it meets the multiplicity of needs of folks. We can't have separate silos with the Department of Labor and the Department of Health and the Department of Education all taking their infrastructure grants or the systems change grants and going down their own roads.

The whole essence of this — and advocates need to make this happen — is we are talking about one comprehensive, person-centered system again with the individual in the middle. And this is not just me speaking. It's not just Congress speaking. If you look at this report that Deborah and I have made reference to, there is a section on collaboration between agencies. And you know what this report to the President identifies as the major problem? It's not Medicaid bias. It's not issues by dealing with the Social Security Administration.

The major problem identified in this report is the lack of collaboration and coordination and integration of the various federal programs. And that's certainly also the issue at the state level. And one of the things that's perfectly appropriate at the state level in terms of Olmstead planning is to identify federal barriers to comprehensive, person-

centered approaches. I don't know if I answered your question or not. Would you like a follow-up or did I address the question?

MS. LEUCHOVIUS: This is Deborah, and I found that a helpful answer. And I just think it's very interesting how the lack of interagency collaboration and cooperation is a major barrier at both the national systems level and also at the individual, transition-plan student level as well. Rachel from Minnesota has a question.

MS. PARKER: This is Rachel Parker from Minnesota. It's a perfect segue into my question. I know that there are centers for independent living that are working on practical levels of getting people into the community and out of nursing homes. I don't know to what extent CILs are being included in this. Are there connections being made in various states?

MR. SILVERSTEIN: I think that NCIL and the SILCs are certainly coordinating and talking to each other, and I know ILRU down in Texas just got a lot of money to help anybody, including those in terms of the advocacy community, who is interested in implementing Olmstead and systems change. That's Lex Freden's shop.

I'll give a telephone number. You don't need to talk to Lex, but you can find out about all kind of resources — and these people would come into states and help find experts and put things together. That's what they are getting paid to do. It's kind of a backup center for the systems change grants. The telephone number is 713.797.5283.

MS. PARKER: It's great to be in cooperation with them. We are natural allies.

MR. SILVERSTEIN: Yeah, absolutely.

MS. LEUCHOVIUS: We will definitely get a link to their Olmstead project on our Web site. Next question?

MR. PHEAL: Yes. Ernie Pheal, Hattiesburg, Mississippi, Institute for Disability Studies. What role is recreation playing or what is the part of recreation in these support services for youth with disabilities?

MR. SILVERSTEIN: Again, to me, recreation is part of independent living, and that could certainly be a component of any plan. The question

is if somebody doesn't raise the issue, it won't be addressed.

MS. LEUCHOVIUS: I think I had really hoped Dixie Jordan would be able to join us today to talk about how to participate in a state's implementation plan because there are opportunities to influence the way states are developing their plans at this point. So, I think that's a good point— to encourage individuals who are interested in finding out how to become involved in their states.

MR. PHEAL: So, would there have to be, I guess, more interest expressed in that area for funding to be available to promote inclusive recreation programs for youth with disabilities or how would that work?

MS. LEUCHOVIUS: I have not seen recreation addressed on a systems level. From a parent advocacy level, I know it's addressed within individual student plans as part the category of independent living and community participation. Much of the focus of ADA is access to programs that are not disability specific for people with disabilities. The National Center on Accessibility in Indiana, for example, has focused a lot of attention on recreation issues and accessible recreation opportunities, again, the focus being on making non-disability programs that are not disability focused accessible to people with disabilities. I do not know how people are addressing that within the context of Olmstead.

MS. SCHOELLER: Deborah, it's Kris Schoeller, from Minnesota, and I just wanted to add a little piece to that as you look at a lot of people who are out of school — I don't know if this person's question is related to transition in school or adults in the community. But if their service plan through HHS addresses the social needs, then recreation is definitely a part of the funding for their waiver and their housing and their whole service plan as persons using those dollars. So, it can be addressed that way also.

MS. LEUCHOVIUS: Thanks, Kris.

MS. LUFT: We have a question in Texas. This is Janet Luft. Do you have a good definition for community-based options for placement?

MR. SILVERSTEIN: I have a good definition for community-based personal assistance services, and that would be in the MICASSA legislation, which is S-1298, and it was dropped in on the Senate floor on August 1, 2001. And in the legislation, there are a number of definitions including a definition for community-based attendant services and support.

MS. LUFT: Thank you.

MS. LEUCHOVIUS: Next question?

MR. SMITH: Yeah, this is Mike from North Dakota. We are struggling with a definition for institution. It keeps coming up in quite a few discussions that we have, and our Olmstead commission is also struggling with that definition of what is an institution.

MS. LEUCHOVIUS: That sounds like a question for a lawyer.

MR. SILVERSTEIN: Well, this lawyer is not going to try to do that over the phone. But have you talked to Bob Kafka at ADAPT who was very instrumental in bringing the Olmstead cases before the courts? Bob's telephone number is 512.442.0252.

MS. LEUCHOVIUS: In terms of the definition of institution, I think that one policy change that's pointed out in the HHS report that I found especially interesting (because PACER Center has applied for funding through our state Perkins Act program) is that in the WIA legislation which incorporated the Perkins Act, the sort of "set aside" for serving students with disabilities was changed significantly from the way it had been addressed in the past. It now merely mentions that addressing the needs of students with disabilities in *institutionalized settings* was an appropriate use of Perkins Act funding. And one of the things in the report that came up was that the Office of Vocational and Adult Education would be looking at that particular definition and requirement of the Perkins Act and perhaps recommending changes in the next reauthorization. We have time for a few more questions.

MS. SEYBOLD: This is Pat Seybold in Kentucky with the DD Council. Could someone clarify for me what is unjustified and unnecessary?

It seems that different states have different theories on what that means as far as what is appropriate for a person to be institutionalized and what is appropriate. We have some issues here especially with folks who are medically fragile, indicating that those folks need to be in an institution because they need all this care. And having come from Michigan, that is a totally different philosophy. How do you address that?

MR. SILVERSTEIN: That's a terrific question because if you look at what Olmstead said, the first thing it says is that the professionals must believe that this placement in the community is appropriate. So, if you have got a professional who is — I apologize for age discrimination — who is 80 years old, who was educated and is still functioning in the old paradigm of disability policy, which is that people with disabilities are defective and in need of fixing and if you can't fix them, then we put them in an institution. That person may be not using promising practices, have the most current knowledge of assistant technology, or different strategies that are available that have been developed in the last decade or more.

To me, when they are talking about professionals, they are talking about qualified professionals who are up to date in terms of state-of-the-art policies, practices, and techniques, and knowledgeable about technology and other devices and services that are available. So, from my point of view, the answer to your question is, if in your state they may not be focusing on most promising practices and therefore, what they are saying is that's why it's different from what's being said in another state. And so, to me, the advocates and the plan must have components to make sure that not only is there training, but folks are making decisions based on the most current state-of-the-art policies, practices, procedures, and based on knowledge of existing and available technology and other support services.

MS. SEYBOLD: Thank you.

MS. LEUCHOVIUS: Thanks, Bobby. I think we have run out of time. We have many of these resources available on the Web site of PACER Center. And again, our web address is

www.PACER.org. Click on Transition Issues, and you will be directed to the Olmstead resources. Again, Bobby, I want to thank you for helping us to understand the significance of this decision and how it applies to young people with disabilities, and I want to thank all of you for joining us this afternoon.

MR. SILVERSTEIN: My pleasure.

(End of Teleconference)

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