

"The Olmstead Decision Five Years Later" 6/21/2004

Transcript of panelist Bob Williams' Presentation

[Bob Williams]:

Thanks. It is good to be on the panel with Michael, who I have not had the pleasure of meeting before, and my other colleagues who I've worked with over the years in one capacity or another. It will be 5 years ago, tomorrow, when Donna Shalala, who I worked for at the time, called me and Tom, Perez, who was then, the new head of the Office of Civil Rights, into her office to discuss the decision that the Supreme Court had just handed down in Olmstead. The thing to say in these situations is that I remember that day like it was yesterday. I don't. Often it seems like it was a light year ago.

But, what stays with me is how the Secretary stressed the need for the Department, and the Administration, to provide positive and balanced leadership on achieving both the letter and intent of the decision, and the ADA that under girds it. This meant 3 things. That the federal government needed to examine our own house and steadily, make damn sure, we got rid of policies, practices and yes, prejudices, that get in way of people with disabilities being able to live in our own homes and communities. Second, it meant offering, steadily, increasing levels of resources and support to states that would enable them to meet the letter and intent of the law, and then, holding them accountable for doing so. And, it meant making certain that the lines of communication, between the Federal government states and the disability and aging communities remained open.

As others on the panel will no doubt touch on in more detail, it seems fair to say that when taken together, the requirements of the ADA itself, the Olmstead decision and Medicaid, require that a similar, 3-point balance be struck as well. Balancing the needs and liberty interest of the individual with a disability, with those of the federal government and the states, as well. There is no question, that tremendous progress and individual successes, such as that highlighted in the video have been achieved in the last 5 years. All of which is something, I think, we should all celebrate, and hopefully, build upon. But, it is also something that, I do not think that any of us, should take great comfort in. Or, allow to eclipse, two large realities. First, that that far more work remains to be done. And, the second, far more serious, reality that I believe we need to confront is, that the balance I have alluded to, not only has yet to be struck. But, remains, badly out of kilter.

Some may find the way I will illustrate what I mean by this to be offensive. And, frankly, I hope you do. Because many of us are offended by just how much the following analogies, ring true. That said, I want you to all imagine, for a second, that a federal, state or local governmental entity, took the following actions, in regard to the scenarios I am about to outline, all under the guise, whether valid, or not, that doing so was necessary to ensure national security or homeland security.

Scenario 1. Imagine that prisoners were being detained throughout the U.S. for indefinite periods of time, long after wardens, certified that they were free to go, without any due

process what so ever. Scenario 2. Imagine that say, for example, Muslim American parents were, suddenly, being presented with the following, ultimatum. They can either let the government send their sons away to a remote facility, where they would be expected to no more than subsist. Or, they can keep them at home, provided, of course, they agreed that their sons would be tethered to them wherever they went for the rest of their lives. And, finally consider scenario 3. Imagine that federal contractors were authorized, to place certain Americans under permanent, house, arrest, not for any crimes, but because they were 6 feet, 5 inches, and would remain 6'5" for the rest of their lives. What would be the reaction be to the fact that such policies and practices exist? Shock, out rage, hearings, investigations, decisive action by the Executive, the Congress and Judiciary to put an end to such policies and practices that thwart the very meaning of what it is to be an American citizen. One should hope and expect all of the above should occur in short order.

What's the point I am trying to make? There are several, actually. As I said, each of the scenarios I've just spun out has an analog with regard to people with disabilities of all ages. The dilemma of scenario one, is the same dilemma that forced Lois Curtis, and Elaine Wilson, to go all the way to the Supreme Court to free themselves, and bring about what has come to be known as the Olmstead decision. And, 5 years after Olmstead, it is a scenario that all too many find themselves living out. The second scenario, is fortunately not one being visited upon Muslim American families, per say. But, it is one that parents and young people with disabilities, of every creed, face the day they turn 21, and are no longer eligible for EPSDT, and often made to go without vital Medicaid services. The third scenario is one, that the Medicare homebound rule imposes on those who have permanent disabilities, combined with serious health needs, that will require them to receive skilled home health care for the rest of their lives.

When we talk about Olmstead, we often discuss it in terms of protecting civil rights, improving Medicaid, and opportunities for independence. It is, in fact, as my fellow panelists will amply point out, about all these things. I would simply say it is likewise about some additional things just as fundamental. The scenarios and analogies I've tried to, highlight are very real. They raise, enormous, issues of both civil liberty and personal autonomy that especially in the post 9/11 eras need to, number one. Should pose deep concerns for average Americans and policy makers from all across the political spectrum. And, consequently, should be debated and addressed in a far wider, national context, than has ever been the case, up until this point.

In fact, the issues I've laid out, and many more like them, involve such core questions of American citizenship, that Congress and the Executive, not the states, must be the ones that take primary responsibility for addressing this set of challenges.

States certainly have a vital role to play in helping to frame and carry out whatever strategies get developed. But, the budget crises that they have faced in recent years, and will likely recur at some future point, to me underscore, 2 things. That rather than capping or otherwise reducing federal Medicaid payments to states, we need to look for ways to not only increase but better target their use over time.

The money follows the person initiative and family opportunities act represent excellent first steps in this direction that, in my view, warrant immediate action, but then must lead to other more comprehensive reforms. Affording states added flexibility is not the sole solution, in my view. And, affording states, added flexibility, minus, increased federal resources, which is a policy option, under consideration, would likewise, I believe, undercut much of the progress made. These, in my view, are some of the lessons that must be learned and applied in the coming 5 years. Thank you.