

**REMARKS BY DEPUTY ASSISTANT ATTORNEY GENERAL SAMUEL R.
BAGENSTOS OF THE CIVIL RIGHTS DIVISION AT THE ANNUAL CONVENTION
OF THE ARC OF THE UNITED STATES
NOVEMBER 13, 2009**

Thank you for that warm introduction. I'm very pleased to be here to discuss the efforts of the Department of Justice to protect the rights of Americans with disabilities. It's a very special pleasure to speak on the same panel as Governor Thornburgh. When I was in private life, I had the honor of serving as cocounsel with Governor Thornburgh in a case in which we represented the family of a boy with cerebral palsy, who successfully sought asylum based on the persecution of children with developmental disabilities in their home country. Governor Thornburgh's example of rectitude and public service is one to which I certainly aspire. His strong support of the Americans with Disabilities Act is a salient demonstration that disability rights know no party—they are the fundamental human rights to which all Americans are entitled.

The great disability rights leader and thinker, Jacobus tenBroek, said that the most fundamental right for people with disabilities was “the right to live in the world.” The right to live in the world means that people with disabilities—all disabilities—have the right to be full members of our Nation's civic and economic life. It means the right to live, work, shop, and move about in the community. It means making good on our Constitution's promise of equal citizenship. The right to live in the world was the basis for the Rehabilitation Act, the Individuals with Disabilities Education Act, and the ADA. It was the basis for the litigation that successfully moved people with intellectual disabilities out of inappropriate congregate institutions like this state's own Pennhurst State School and into life in the community. And it is a guarantee our Nation has made to Americans with disabilities.

At the Civil Rights Division of the Department of Justice, we are working every day to make this right a reality. Our Attorney General, Eric Holder, has described the Civil Rights Division as the “crown jewel” of the Justice Department, and we often are called upon to serve as the conscience of the government. Under the leadership of Assistant Attorney General Tom Perez, who was confirmed last month, we are open for business. With a committed, energized career staff, and a political leadership dedicated to the goals of restoration and transformation—restoring the traditional tools of civil rights enforcement, while transforming our focus and approach to meet the problems of the Twenty-first Century—the Civil Rights Division is working with renewed vigor to enforce the civil rights of all Americans.

I want to talk today about two important components of the right to live in the world. These aren't the only components of the right to live in the world by any stretch—and they're far from the only ones we focus on in our enforcement work—but they are of exceptional importance to people with intellectual and developmental disabilities.

First, the right to live in the world necessarily implies the right to move about in public places free from violence and crime. The Fourteenth Amendment guarantees the “equal protection of the laws.” In its original, core sense, this guarantee promises that the laws will

protect all persons against infringements on their person or property, regardless of their status or group membership. But reality has too often failed to measure up to this promise for people with disabilities. According to a report issued by the Bureau of Justice Statistics last month, people with disabilities of a given age are more likely than their nondisabled counterparts to be the victims of violent crime, including rapes, robberies, and assaults. “For rape or sexual assault,” the report concluded, “the age-adjusted rate for persons with disabilities was more than twice the rate for persons without disabilities.” And people with cognitive disabilities experienced violent crimes at a higher rate than people with any other type of disability. In about a fifth of cases, violent crime victims with disabilities believed that they were targeted precisely because of their disability.

Hate crimes committed against individuals with disabilities are vastly underreported, and prosecutions have been rare and difficult even in the cases that are reported to authorities. There’s a big gap in our knowledge on this issue. But there are some important things we do know. We know that people with intellectual and developmental disabilities—both inside and outside of institutions—are among the most susceptible to bias-motivated violence. In one notable case—rare only because it was criminally prosecuted—eight men and women in New Jersey lured a man with cognitive disabilities to a party. A newspaper article described the treatment he received next:

When he walked in, still wearing his work uniform, one man put a choke hold on him and someone else cut his tie in half. Next they seized a small stuffed whale that he always carried and tore it apart as he watched.

They stripped him to his underwear, slapped him, kicked him and forced him into a plastic garden chair. They taped him to the chair and dragged it around the room[—something they copied from a horror film].

[One woman] tried to shave [the victim’s] head and eyebrows with a razor. Someone else completed the job with electric hair clippers.

They whipped him with a rope knotted with plastic beads across his naked chest, back and face, creating a grid of cuts and bruises.

They cut him from the chair and forced him to put on a bra and a woman's green suit. They put a pillow case over his head and dragged him downstairs into a van[.].

They drove to a marshy area [, where] the group marched [the victim] into the woods, punching him and slamming him to the ground. After about an hour, he got away and staggered to the guard booth on a nearby property.

Too often, violent attacks against people with intellectual and developmental disabilities are written off as some sort of “abuse” to be addressed by the social services system rather than as the crimes they are. That is especially true when the attacks occur in institutions, but it is true all over.

At the Department of Justice, we take these acts of violence extremely seriously. And just two weeks ago, President Obama signed a bill that gave us an important new tool to combat them. The Matthew Shepard and James Byrd, Jr., Hate Crimes Prevention Act creates the first general federal criminal prohibition of violence undertaken because of the actual or perceived disability of the victim. This new statute represents a major step forward in truly guaranteeing people with disabilities the equal protection of the laws, and we intend to enforce it vigorously.

So the right to live in the world means the right to go about one's life free from violent attacks. But many people with intellectual and psychiatric disabilities are being denied the right to live in the world in an even more basic sense—to receive services, they must submit to confinement in inappropriate institutional settings. America no longer has its Pennhursts—behemoth institutions that housed 3,000 or more people with intellectual disabilities at a time—but smaller institutions, nursing homes, and other care facilities continue to unnecessarily segregate people with intellectual disabilities from the community and deny them the right to live in the world.

Avoiding unnecessary institutionalization is a matter of foundational civil rights for people with disabilities. Throughout history, people with disabilities have been pushed aside, shut out, and ignored. Whether because of fear or because of misplaced paternalism, people with disabilities were been forced to live in out-of-the-way facilities where basic, day-to-day decisions were made by others. People with disabilities became effectively invisible in the public square, and unfamiliarity combined with fear to encourage prejudice.

The Twentieth Century phenomenon of institutionalization of people with disabilities, which peaked in the mid-1950s, was but a later chapter in the same story. People with intellectual and developmental disabilities were confined to institutions for their care and protection, but institutionalization massively restrained their freedom. And as more and more people moved out of institutions in the 1970s and 1980s, we learned that institutionalization was often unnecessary for their care and treatment. This was true even for individuals who all observers had previously thought to need to live in institutions.

Consider Nicholas Romeo, a Pennhurst resident whose case went to the Supreme Court. He had what the Court characterized as a “profound[]” intellectual disability, “with an I.Q. between 8 and 10.” His own counsel had conceded, in light of what he called “the severe character of his [disability],” that Romeo could never live outside of an institution. Yet “ten months after the Court’s decision,” as the late Timothy Cook told us, “Nicholas Romeo moved to a community residence in Philadelphia,” where he lived successfully. That experience was typical of the residents released from Pennhurst.

The Americans with Disabilities Act, which Governor Thornburgh played such a key role in getting adopted, requires states and local governments to serve people with disabilities in the most integrated setting appropriate to their individual needs. In the landmark 1999 decision in *Olmstead v. L.C.*, the Supreme Court held that the ADA therefore prohibits the unnecessary institutionalization of individuals with disabilities. As Justice Ginsburg explained in her opinion

for the Court, that holding flowed from the statute's basic prohibition of discrimination against individuals with disabilities. She said:

Recognition that unjustified institutional isolation of persons with disabilities is a form of discrimination reflects two evident judgments. First, institutional placement of persons who can handle and benefit from community settings perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life. [S]econd, confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment. [D]issimilar treatment correspondingly exists in this key respect: In order to receive needed medical services, persons with mental disabilities must, because of those disabilities, relinquish participation in community life they could enjoy given reasonable accommodations, while persons without mental disabilities can receive the medical services they need without similar sacrifice.

The *Olmstead* decision has often been called the *Brown v. Board of Education* of the disability rights movement, and this passage shows why. There, in that part of her opinion for the Court in *Olmstead*, Justice Ginsburg perfectly encapsulated the basic principles of disability rights—of Jacobus tenBroek's right to live in the world—and showed that they are core civil rights principles.

Olmstead celebrated its tenth birthday this year, and it's fair to say that it has been a bittersweet one. In the first year or so following the *Olmstead* decision, many states worked to develop effectively working plans to move people with disabilities out of inappropriate institutional placements and into homes in the community. But the state budget crises of the early 2000s, and the economic difficulties that began last year, have stalled those efforts if not stopped them in their tracks. Today, *Olmstead* stands as an important, even historic, promise, but one that remains unfulfilled.

Tom Perez and I are committed to making good on that promise. As you probably know, President Obama has issued a proclamation declaring this year the "Year of Community Living," and he has directed his Administration to redouble our efforts to enforce *Olmstead*. It's not an exaggeration to say that I get up every morning and ask myself, "How can I enforce *Olmstead* today?" Although the Civil Rights Division has many important priorities in the disability rights area, *Olmstead* is at the top of the list. We have no more important challenge than the challenge of ensuring that states end inappropriate institutionalization and instead provide services in integrated, appropriate, community settings.

Let me tell you a little bit about what we are doing to invigorate our enforcement of *Olmstead*. Our lawyers are now looking systematically at identifying potential *Olmstead* cases—whether they are lawsuits that private plaintiffs have already filed, in which we could participate, or they are fact settings that seem ripe for an *Olmstead* investigation initiated by the federal government. Growing out of this process, we have moved to intervene in *Disability Advocates, Inc. v. Paterson*, a case involving people with psychiatric disabilities that is likely to

be the most significant *Olmstead* case in the ten years of that decision. We are also moving aggressively to file amicus briefs—at all levels of the federal judiciary—to push the law forward in the unsettled areas that remained after the Supreme Court’s decision. We filed such a brief in a case currently under submission in the Eleventh Circuit, *Long v. Benson*, and we are actively considering amicus participation in a number of *Olmstead* cases pending in federal district courts. Over the next year, you will see us begin to open our own investigations of state systems on *Olmstead* grounds as well.

We are also transforming the way in which we carry out our responsibilities under the Civil Rights of Institutionalized Persons Act (CRIPA). Traditionally, our investigations and litigation under CRIPA have focused on institutional conditions. We have asked, essentially, what it would take to turn the institution we are investigating into the best institution it could possibly be. But Tom Perez and I believe that we cannot intelligently address a concern about inappropriate *conditions* at an institution without asking the logically prior question whether the institution is the appropriate *setting* for its residents. In our investigations of facilities for individuals with intellectual, developmental, and psychiatric disabilities, we often find that substandard conditions at those facilities are caused or exacerbated by having too many people in those facilities—and too many who do not belong there. In our findings letters and our filings in court over the last few months, we have made clear that *Olmstead* issues are deeply intertwined with problems of inadequate conditions, and we have resisted any effort to try to solve the conditions problem without looking at whether the people in the facility belong there. Over the next year, you will see our CRIPA lawyers investigating possible *Olmstead*-only cases, in which we sue a state for violating *Olmstead* but do not at the same time challenge the conditions at its facility.

In resolving *Olmstead* matters in this administration, we have sought to get states to take a two-pronged approach. The first prong is discharge planning. We have told states that they have to have a process in place, for each resident, that determines that resident’s appropriate placement according to professional standards. If that process determines that the resident should be placed in a less segregated setting, the state should follow that determination. And the state should provide extensive means of educating residents and their parents or guardians about the benefits of community placement.

The second prong is community capacity. *Olmstead* cannot work unless individuals who are discharged from institutions have somewhere to go. That somewhere has to be safe, it has to provide adequate and appropriate services, and it has to be the most integrated setting appropriate to the individual resident. We have been seeking enhancements to community capacity in a number of our open *Olmstead* matters. We are working closely with our partners at HHS, HUD, and elsewhere to seize opportunities to use available federal funding in a way that enhances community capacity and promotes integration.

These are not easy tasks, and we have a long way to go. But the ADA has been on the books for almost 20 years and *Olmstead* has been on the books for 10. The time for delay has past. The time for compliance has come, and it is long overdue. To guarantee people with disabilities the right to live in the world, we must—and will—be aggressive in enforcing the

ADA and the Matthew Shepard hate crimes bill. We have no illusions about the significance of the challenges ahead. But we will make progress, inexorably, toward fully enforcing those guarantees. Dr. King said that “[t]he arc of the moral universe is long, but it bends toward justice.” The right to live in the world is a matter of fundamental justice for people with disabilities. If we all work together—the Department of Justice, the advocacy community, and the protection and advocacy network—we can make that right real. Thank you.