Statement of Robert Bernstein,

President and Director of the

Judge David L. Bazelon Center for Mental Health Law

Before the

Committee on Health, Education, Labor and Pensions

United States Senate

Hearing on

The ADA and *Olmstead* Enforcement: Ensuring Community Opportunities for Individuals with Disabilities

Presented On

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Mr. Chairman and Members of the Committee, I am pleased to testify before you today about the Americans with Disabilities Act (ADA), legislation that is crucially important to people who have mental illness. My name is Robert Bernstein and I am the president and director of the Bazelon Center for Mental Health Law, which has advocated for the rights and social inclusion of people with mental disabilities for almost four decades. I began my work as a psychologist in public mental health, where I learned first-hand how law and policy define—or foreclose— opportunities for people with mental illness, particularly those who must rely on public systems.

From the ADA's inception, the Bazelon Center has worked to make sure that its protections include people with mental disabilities, and we continue to advocate in the courts, with legislative bodies, and with federal and local agencies to ensure that it has its intended impact. No group of disabled Americans has been subjected to more harmful and enduring discrimination than people with serious mental illness. Hundreds of thousands of these Americans were once physically segregated behind the locked doors of huge abusive state hospitals, based on fear, disdain or the perception that there were no viable alternatives. In many ways, that history remains alive— in nursing homes, board-and-care facilities and jails across the nation.

The ADA represents a very ordinary vision, but one that dramatically departs from this history: A vision that people with serious mental illness have homes they can call their own and participate in society as neighbors, friends and co-workers, and that they are judged as individuals, untarnished by shaming stereotypes. Recognizing the harmful effects of ingrained discrimination and inaction—or even resistance—by states to the reforms demanded by the ADA, the Bazelon Center played an important role in defending the law's "integration mandate" when *Olmstead* came before

the Supreme Court. Gleaning the essence of the ADA and the larger civil rights movement for people with mental illness, the Supreme Court found in *Olmstead* that "Unjustified isolation…is properly regarded as discrimination based on disability."[1] Without question, the marginal social status of many individuals who have serious mental illness is the product of such discrimination. Further, the Supreme Court affirmed that public systems' unnecessary consignment of people with mental illness to institutional living, "perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participation in community life."[2]

Of course, a bold act of Congress—even when bolstered by a landmark Supreme Court decision—does not instantly reverse discrimination that is embedded in society and reflected in its institutions. But on this 20th anniversary of the ADA's enactment, I am happy to report that we have at last begun to think in very different ways about mental disability and the proper role of public systems. Recovery and hope have replaced containment as the new focus of public mental health services.[3] And nationwide, we see many examples of programs demonstrating that people with serious mental illness can recover, live in their own homes outside of psychiatric ghettos and not be regarded as "ex-mental patients." Scattered-site supportive housing is a powerful model that the Bazelon Center is promoting to support successful community membership among people with serious mental illness.[4] Through local programs providing flexible, individualized services and supports to people in their own homes, individuals who were once relegated to isolated custodial settings now fulfill the vision of the ADA. These individuals not only realize their personal dreams but, by example, demonstrate that the ambitious goals of the ADA are achievable, even among a group as derided as people with serious mental illness. And as we have seen in New York, where the Department of Justice has joined the Bazelon Center and local advocates in litigation to allow residents of archaic adult homes to live in scattered-site supportive housing, the very individuals who were once confined in these settings are reaching back to assist their peers in re-entering community life.[5]

Ironically, these positive outcomes in supportive housing can be achieved at costs that are lower than, or at most equal to, institutional care. The cost of serving a person in supportive housing

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[1] Olmstead v LC, No 98-536 (US Sup Ct, June 22, 1999).
[2] Ibid.
[3] New Freedom Commission on Mental Health, *Achieving the Promise: Transforming Mental Health Care in America. Final Report*. DHHS Pub. No. SMA-03-3832. Rockville, MD: 2003.
[4] See http://bazelon.org.gravitatehosting.com/LinkClick.aspx?fileticket=q6FsuL6o_Jw%3d&tabid=241
[5] See http://bazelon.org.gravitatehosting.com/In-Court/Current-Cases/Disability-Advocates-Inc.-v.-Paterson.aspx

is half the cost of a shelter, a quarter the cost of being in prison and a tenth the cost of a state psychiatric hospital bed.[6] And supportive housing is not unique in this regard. For instance:

- Investments in treatment and parole services could save states $4.1 billion. For example, every dollar spent on community-based drug treatment avoids $18 in state spending.[7]

- An in-home crisis intervention program for psychiatric patients found that nearly 81 percent could be treated at home and that patients who received home care were less likely to be readmitted to the hospital. Considering that the average 2007 Medicare payment was $137 for a home health day versus $1,447 for a hospital day and $325 in a skilled nursing facility, the home-care option can produce significant savings.[8]

- Systems of care for children reduce inpatient hospital days, saving an average $2,777 per child, and arrest rates, for average per-child savings of $784. Multi-systemic therapy for high-risk youth saves more than $31,661 in subsequent costs to the criminal justice system, while multidimensional treatment foster care for troubled youth saves $43.70 in residential treatment costs for every dollar spent.[9]

Our challenge today is not so much demonstrating that we know how to assist people with serious mental illness in realizing their rights under the ADA, or even in demonstrating that the outcomes we seek are fiscally sound. Much more at the forefront of our advocacy in pursuit of community integration for people with serious mental illness is the task of deconstructing the systemic barriers and challenging the vested interests that sustain segregation and low expectations. Large state hospitals may be relics of the past, but many people with serious mental illness remain on the margins of society because supportive housing and other good programs are in short supply. Often, access to these programs is targeted to groups that have been visibly failed by human service systems—people with frequent hospitalizations, or those who are homeless or incarcerated, for instance. However, many more people with serious mental illness languish in archaic facilities, such

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[6] Houghton, The New York/New York Agreement Cost Study: The Impact of Supportive Housing on Services Use for Homeless Mentally Ill Individuals, May 2001, 6-7. http://www.csh.org/index.cfm/?fuseaction=Page.viewPage&pageID=3251.
[7] Justice Policy Institute, *Pruning Prisons: How Cutting Corrections Can Save Money and ProtectPublic Safety*, http://www.justicepolicy.org/content-hmID=1811&smID=1581&ssmID=84.htm
[8] Agency for Healthcare Research and Quality, H*ome Health's Ability to Control National HealthCare Costs*, http://www.ahhqi.org/download/File/databook/ControlCosts.pdf
[9] Daly, R. Mentally Ill Youth Do Best In Community Care Settings, *Psychiatric News*, June 2, 2006; Washington State Institute for Public Policy, The Comparative Costs and Benefits to Reduce Crime, 2001, http://www.wsipp.wa.gov/rptfiles/costbenefit.pdf

as nursing homes, group homes and the infamous "adult homes" in New York City that a federal court recently declared in violation the ADA.[10]

Such facilities may be physically located in communities—and some even have the physical appearance of houses—but they are not at all what one would consider homes. The residents remain isolated from community life and they have no privacy, no meaningful personal choice, and no hope for something better. They often live with assigned roommates and may receive visitors only at defined times and in defined areas of the facility. The rights of these individuals under the ADA notwithstanding, people living in these settings have been mischaracterized by public systems as "successfully placed" because they are no longer in hospitals. Ironically, even as they face dire budgetary cuts, states continue to waste money by consigning people with mental illnesses to such institutional settings, often pressured by profit-making providers. While the annual cost of housing someone in these places may range $60,000 or more, it costs only $22,500 a year to provide independent housing with a full range of supportive services for a person with a serious mental illness—and this in New York City, one of the nation's highest housing markets.[11] As documented by the media nearly every day, public mental health systems, instead of shifting to such cost-effective (and *Olmstead*-compliant) approaches, continue to struggle.

This is not to suggest that public mental health is adequately resourced—in part reflecting public attitudes about people with serious mental illness, state mental health systems were never adequately funded to achieve the basic ambitions of deinstitutionalization, let alone the goal of recovery. And growth in states' mental health spending (even during times when state coffers were flush) has lagged far behind that for other state agencies, representing about half of the growth in spending within their corrections systems.[12] But even in today's difficult times, a more rational use of available dollars could very dramatically increase the availability of housing and supportive services that allow people with serious mental illness to realize their rights under the ADA.

Shortly after *Olmstead* was decided, the Bazelon Center issued a report entitled *Disintegrating Systems: The State of States' Public Mental Health Systems.*[13] In that report, we anonymously quoted

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[10] See http://bazelon.org.gravitatehosting.com/In-Court/Current-Cases/Disability-Advocates-Inc.-v.-Paterson.aspx

[11] Bazelon Center for Mental Health Law, *Still Waiting...The Unfulfilled Promise of Olmstead. A Call to Action on the 10th Anniversary of the Supreme Court's Decision,* 2009, http://bazelon.org.gravitatehosting.com/LinkClick.aspx?fileticket=S5nUuNhJSoM%3d&tabid=104

[12] Ibid.

[13] Bazelon Center for Mental Health Law, *Disintegrating Systems: The State of States' Public Mental Health Systems,* 2001.

the mental health commissioner from a large state who was frustrated at the daunting systemic and political barriers (and, notably, *not* clinical barriers) that would need to be overcome if people with serious mental illness are to realize their rights under *Olmstead.* That state commissioner told the Bazelon Center: "Someone should sue us."

Three years later, the Bazelon Center issued a statement on the impact of the ADA and the *Olmstead* decision to people with serious mental illness:

> Where real progress has occurred, it is largely because states have been sued. Five years after *Olmstead* and 14 years after enactment of the Americans with Disabilities Act, litigation should be unnecessary. Yet it remains the single most effective way to combat the persistent segregation of people with mental illnesses.
>
> It's past time for *Olmstead* implementation to move out of the courtroom and into America's communities.[14]

Although the Bazelon Center has a vibrant, longstanding and nationally recognized litigation agenda, it is a sad commentary that, in the face of obvious social, moral and fiscal arguments, we still need to turn to the courts to enforce the basic rights of these Americans. Yet, in the absence of litigation, people with serious mental illness are no one's priority—particularly those who live quiet lives, robbed of hope and isolated in archaic congregate facilities.

For this reason, the Bazelon Center is working closely with the U.S. Department of Justice toward vigorous enforcement of *Olmstead* and to ensure that its benefits extend to all people with serious mental illness, including those who remain hidden on the sidelines. We are also working closely with the Centers for Medicare and Medicaid Services to extend to people with serious mental illness initiatives, such as Money Follows the Person, that have promoted *Olmstead* outcomes for other disability groups. We are grateful for support from the Substance Abuse and Mental Health Services Administration (SAMHSA) that allows us to provide technical assistance to states around *Olmstead* implementation. And one potential source of funding for the services we seek is the SAMHSA Mental Health Block Grant, which needs to be restructured to be more targeted and to focus more directly on the ADA as a priority.

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[14] Ibid.

Last year, on the 10th anniversary of the Supreme Court's decision, the Bazelon Center issued a call to action titled *Still Waiting —The Unfulfilled Promise of Olmstead*, in which we decried the slow progress toward integration and listed many opportunities for federal, state and local action.[15] My testimony today reflects many of the findings from our report. Our recommendations for federal actions call for Congress and the federal agencies to carefully consider what we have learned in the twenty years since enactment of the ADA, including our successes, missed opportunities, and understanding of the system dynamics that have stalled progress for people who have serious mental illness.

The recent healthcare reforms enacted by Congress move us significantly forward in expanding access to coverage and addressing mental health as an aspect of overall health, on par with medical and surgical care. The impact of this legislation for people who have mental illness, particularly with regard to their rights under the ADA and *Olmstead,* will be defined in the law's implementation. Among our recommendations for federal actions, which may be of particular interest to the Committee, we urge Congress and the federal agencies to:

- Include in healthcare reform incentives that adequately address the needs of people with serious mental illnesses. The law requires that the essential benefit include rehabilitation services, but these are not defined. It will be critical for the Department of Health and Human Services (HHS) to define this term so as to include coverage of psychiatric rehabilitation, peer support and case management services.

- Establish linkages between private plans and the public mental health systems. Comprehensive systems that address a person's total health care needs, such as medical homes, need to address mental health issues and specialized medical homes that serve individuals with serious mental illness (such as are authorized as a demonstration of SAMHSA) need to be expanded.

- Pass the Community Choice Act, which would make a package of home- and community-based services a mandatory Medicaid service for individuals who would otherwise be served in institutional settings.

[15] Ibid.

- Amend Medicaid to give states the option to provide home- and community-based services to children with serious mental disorders who are at risk of placement in residential treatment facilities (at this time, these facilities do not qualify as "institutions" under the section 1915(c) authority).

We recommend that CMS, as the agency administering the Medicaid program, should:

- Issue letters to state Medicaid directors highlighting both ways for states to facilitate integration and options for financing services in integrated settings for people with mental illness.

- Clarify that while Medicaid permits states to limit the number of individuals served in waivers, *Olmstead* may require that limits on waiver participation be lifted. CMS should streamline and accelerate the waiver process and condition renewal on a state's expanding the waiver to cover more people.

- Revamp the federal rules on rehabilitation services to encourage states to furnish the evidence-based services that have proven effective in helping people with serious disorders to live in the community.

- Encourage the use of homes or homelike settings, by paying for therapeutic foster care for children.

- Accelerate its actions toward aggressive enforcement of current requirements for screening of individuals prior to nursing-home placement. The intent of this underutilized mandate—known as Pre-Admission Screening and Resident Review (PASRR)—is to avoid inappropriate Medicaid expenditures for institutional care and the "dumping" of people with mental illnesses who should be served in their home communities. While pre-dating enactment of the ADA, PASRR should serve as a powerful tool to avert unwarranted institutional segregation.

- Enforce the "IMD" rule that prohibits Medicaid payment for mental health services to people between the ages of 22 and 65 in an "institution for mental diseases"—a facility in which a significant percentage of residents have mental illnesses.

We are heartened by recent actions by CMS and the Department of Housing and Urban Development to promote supportive housing for people with serious mental illness, using HUD funds and Medicaid. In addition, Congress should:

- Enact and fully fund the Melville Supportive Housing Investment Act to improve Section 811 Supportive Housing for Persons with Disabilities. Once the law is enacted, the administration should initiate HUD planning to implement its provisions expeditiously.
- Ensure dedicated support for the National Housing Trust Fund to produce or preserve 1.5 million homes and 200,000 new Housing Choice vouchers per year for the next 10 years. HUD regulations and guidelines for implementation of the Fund must prioritize creation of new affordable supportive housing for people with disabilities who have SSI-level incomes. (In most urban areas, market rent exceeds monthly SSI disability payments).
- Sustain existing supportive housing by renewing with predictability and stability its funding for rent and operating subsidies and services.
- Create incentives within the HOME program to encourage state and local housing officials to prioritize permanent supportive housing. For example, a percentage of HOME funds could be set aside for permanent supportive housing.
- Increase federal funding for re-entry supportive housing vouchers and services for people with mental illnesses leaving correctional facilities. One way is through creation of a bridge rental-voucher program in which the Justice Department's Bureau of Justice Assistance awards grants for vouchers to state and local jurisdictions.
- Make clear that states violate *Olmstead* when they direct SSI money to uses that promote segregation of individuals with disabilities in private facilities (including board and care homes).
- Ensure that the Section 8 housing certificates allocated to individuals with disabilities are actually in the hands of such individuals.

We have been working closely with leadership within the Department of Justice (DOJ) and highly commend its increasing attention to the ADA rights of people with serious mental illness. DOJ, in some cases along with other agencies, should:

- Vigorously enforce *Olmstead*, including by filing cases that raise solely *Olmstead* claims.
- Adopt legal positions that would make *Olmstead* enforcement more effective.

The Office of Civil Rights (OCR) of HHS should also enforce *Olmstead* vigorously. OCR should:

- Broaden its enforcement efforts beyond those primarily driven by individual complaints; rather, evidence of systemic issues, including evidence other than complaints, should inform OCR's activities.

What we conclude is lacking for people with mental illness to fully realize their rights under the ADA and *Olmstead*—and what is urgently needed—is political will. Fulfillment of the promise of the ADA is important to all of us not only because it will represent a more just society, but also because America will fully benefit from the now unrealized contributions of people with mental illness.

Thank you for this opportunity to testify. I look forward to your questions.