



*Still  
waiting...*

The Unfulfilled Promise  
of *Olmstead*



Elaine Wilson was stuck in a Georgia mental institution until the historic *Olmstead* case enabled her to live in her own home in the community.

A call to action by the  
Bazelon Center for Mental Health Law  
on the 10th Anniversary of the Supreme Court's Decision

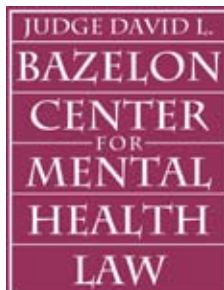
June 24, 2009

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A call to action  
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*"Since the mid-1970s, attention has shifted from establishing rights to implementing them, a far more complex endeavor. It was, bluntly, far easier to convince states to release patients than to provide funds to serve them in the community."*



The late David L. Bazelon, Chief Judge of the U.S. Court of Appeals for the District of Columbia Circuit, in *Questioning Authority: Justice and Criminal Law*, 258 (New York University Press, 1989).

## Preface

The Bazelon Center for Mental Health Law issues this call to action to inform advocates, policymakers and the public about the vital role the Supreme Court's landmark decision plays in enabling people with mental illnesses to benefit from community life. The *Olmstead* decision is now 10 years old. On its fifth anniversary, the Bazelon Center issued the following statement:

"While many Americans with disabilities have made progress since the *Olmstead* ruling, people with mental illnesses have been largely left behind in efforts to implement the decision. Most states are enacting *Olmstead* reforms at a snail's pace, defying the spirit of the ruling and preventing Americans with mental illnesses from participating in their communities.

..."Budget pressures have closed psychiatric hospitals across the country, but few appropriate community services have been adequately funded to help people with mental illnesses live successfully in the community. Instead, states have 'transinstitutionalized' people with mental illnesses to settings as outmoded, isolating and inappropriate as the facilities they were meant to replace.

..."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.

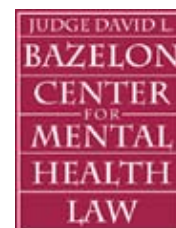
"It's past time for *Olmstead* implementation to move out of the courtroom and into America's communities."

Five more years have gone by. Too many people with mental illnesses remain segregated in board-and-care homes, nursing facilities and other institutional placements, at high cost to strapped state mental health systems, even though supportive community living is cost-effective—and the right thing to do.

***The time for action is long past!***

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Elaine Wilson (left) and Lois Curtis came to Washington in 1999 for the argument of their case before the Supreme Court. Today Ms Curtis is a successful folk artist in Atlanta, living at home with supportive services. Ms Wilson lived in a supported apartment until she died in 2004, at the age of 53.

In 2000, the women participated with Georgia Governor Roy Barnes in a celebration of the 10th anniversary of the Americans with Disabilities Act.



## The *Olmstead* Case

The landmark case now known as *Olmstead* was brought in 1995 by the Atlanta Legal Aid Society on behalf of Lois Curtis and Elaine Wilson, who were confined in a state psychiatric hospital. Hospital staff agreed that the women should be discharged to supportive community programs. But no such placements were available. And the women's history of repeated readmissions attested to the inadequacy of Georgia's community mental health programs.

Eventually, as the case worked its way through the courts, both women moved into supported housing in the community and did very well. The case continued, however, because the situation could arise again.

*Olmstead v. L.C. & E.W.* reached the Supreme Court when the Georgia Department of Human Resources appealed a decision that it had violated the ADA's integration mandate by segregating Ms Curtis and Ms Wilson in the hospital long after treatment professionals had recommended their transfer to community care.

The Bazelon Center mobilized disability advocates, legal and mental health professional associations, consumer groups and powerful allies to file briefs on behalf of the hundreds of thousands of Americans like Ms Curtis and Ms Wilson who were unjustifiably segregated in institutions. Ultimately the Supreme Court found such confinement discriminatory both because it "perpetuates unwarranted assumptions"

that people with disabilities "are incapable or unworthy of participating in community life" and because "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."

*Olmstead* has been called the *Brown v. Board of Education* for people with disabilities. And like *Brown*, it is forcing change very slowly, and then only through determined and vigorous advocacy.

***“I feel stuck here.”***

***“There isn’t any opportunity to interact with people who aren’t patients here.”***

***“Everybody’s like indoors on top of one another.”***

***“I want to experience being out in life again.”***

Testimony in 2009 by people who live in large board-and-care homes courtesy of New York State’s service system for people with mental illnesses.

## ***Olmstead at 10***

***“Unjustified isolation, we hold, is properly regarded as discrimination based on disability.”***

United States Supreme Court Justice Ruth Bader Ginsberg, writing in 1999 for the majority in *Olmstead v. L.C. & E.W.*

**B**ecause of states’ varying approaches to compiling data, it is hard to know precisely how many people remain unjustifiably isolated in psychiatric hospitals, nursing homes and other institutions at any given time. During 2006, a total of 527,725 men, women and children resided at some point in state hospitals and other residential mental health facilities.<sup>1</sup> The median length of stay for adults was 869 days.<sup>2</sup> Currently, more than 500,000 people who have mental illnesses other than dementia live in nursing homes,<sup>3</sup> and even more remain segregated in group homes and other congregate settings. Nearly all of these individuals could live independently in the community with adequate supportive services.<sup>4</sup>

Exactly 10 years ago, the United States Supreme Court held that such “unjustified isolation” of people with disabilities amounts to segregation, and is therefore illicit. The Americans with Disabilities Act means what its mandate of integration says, the court declared: People with disabilities have a right to receive needed services in the most integrated setting consistent with their individual need.

Yet even as they face dire budgetary cuts, states continue to waste money by consigning people with mental illnesses to institutional settings, often pressured by profit-making providers. While the annual cost of housing someone in these places ranges upward from \$60,000, 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.<sup>5</sup> As documented by the media nearly every day, public mental health systems, instead of shifting to such cost-effective approaches, continue to struggle.<sup>6</sup>

**After 10 years, it is time to act.**



The 10<sup>th</sup> anniversary of the *Olmstead* decision offers an opportunity to review the landscape and issue a call to action:

- **to people with disabilities:** Speak out against discrimination and for your right to enjoy the full benefits and responsibilities of community life.
- **to advocates:** Pursue justice through the courts and in the legislatures.
- **to policymakers:** Resist political pressures that perpetuate unwarranted segregation and reform governments' approach to mental health care so people with mental illnesses can live with dignity in the community.
- **to the media:** Educate yourselves and the public about the policy issues and fiscal possibilities involved in enforcing *Olmstead*; shine a light on the impediments to reform.

In this document, the Bazelon Center summarizes the background for the decision and looks at its inadequate implementation to date.

## Implementing *Olmstead* is Sound Economic Policy

*"It goes without saying that the excess costs of untreated or poorly treated mental illness in the disability system, in prisons and on the streets are part of the mental health care crisis. We are spending too much on mental illness in all the wrong places. And the consequences for consumers are worse than the costs for taxpayers."*

Michael F. Hogan, Ph.D.,  
"Spending Too Much on Mental Illness in All the Wrong Places," *Psychiatric Services*, October 2002

The current system is broken in many ways. The continuing failure to provide the community services envisioned in the *Olmstead* ruling wastes public resources. Multiple studies of alternative approaches find that institutional care is more expensive than early and consistent community options. Consider the following:

- The cost of serving a person in supportive housing 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.<sup>7</sup>
- 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.<sup>8</sup>
- 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.<sup>9</sup>
- 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.<sup>10</sup>

## What is Meant by “Services in the Community”

These are some of the services that have proven cost-effective in enabling people with serious mental illnesses to thrive in the community. Much of their cost can be offset with federal dollars.

- ◆ Illness self-management and recovery
- ◆ Functional family therapy
- ◆ Peer support
- ◆ Cognitive behavior therapy
- ◆ Psychiatric rehabilitation
- ◆ Supported housing
- ◆ Medication management
- ◆ Case management
- ◆ Mobile 24-hour crisis services
- ◆ Supported education
- ◆ Supported employment
- ◆ Assertive community treatment
- ◆ Family psychoeducation
- ◆ Integrated dual disorders treatment (mental health & substance abuse)
- ◆ Multisystemic therapy
- ◆ Therapeutic foster care
- ◆ Crisis residential services
- ◆ Acute inpatient care

## What Are “Community Supports”?

In contrast to the prevailing medical model, in 1978 President Jimmy Carter’s Commission on Mental Health recommended that “a major effort be developed in the area of personal and community supports which will:

- a) recognize and strengthen the natural networks to which people belong and on which they depend;
- b) identify the potential social support that formal institutions within communities can provide;
- c) improve the linkages between community support networks and formal mental health services; and
- d) initiate research to increase our knowledge of informal and formal community support systems and networks.”

Report to the President from The President’s Commission on Mental Health (1978)



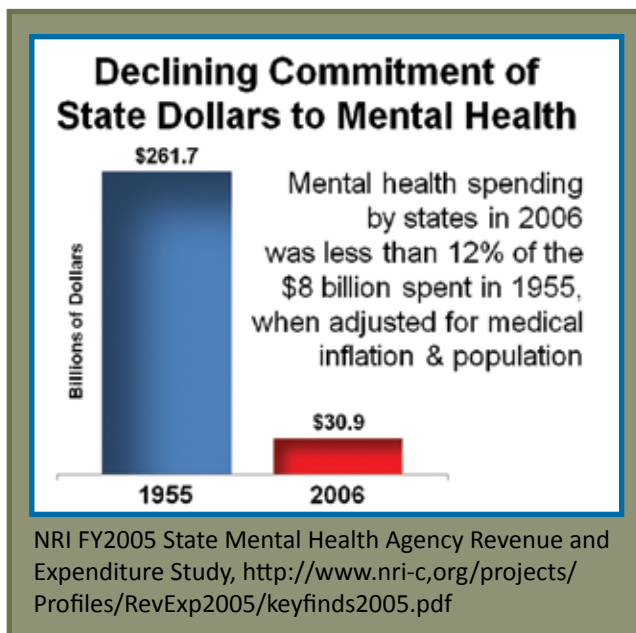
## The Setting for the Supreme Court's Decision

The Bazelon Center and other advocates saw civil rights causes, such as the struggle for racial equality and desegregation, as parallel to the ingrained discrimination against people with mental disabilities. For years our lawyers challenged abuses and indignities in state institutions. A decade ago, they saw the *Olmstead* case as an important new tool to challenge states' reliance on institutional care, which had persisted through the decades as various well-meant policy efforts faltered.

The movement toward community services has a long history. In 1963, President John F. Kennedy called for "a wholly new national approach" to the needs of people with mental disabilities, signing the Community Mental Health Centers Act just three weeks before his assassination. Providers and consumers of mental health services envisioned a nationwide network of innovative community programs to supplant the custodial isolation of state hospitals and provide a range of services that could enable people with serious mental illnesses to take their place in society. To this day, their vision remains unfulfilled.

To be sure, state hospitals' inpatient census has fallen from a high of 550,000 in 1955. But after an initial spate of funding for community mental health centers, public dollars and planners' imagination faded. Instead of being the engine of innovation, the community mental health movement has too often focused on late-stage crisis response and compliance with regulations that don't work. Community mental health centers have had limited opportunities to implement evidence-based practices and have found themselves standing by as harmful outcomes—institutionalized segregation, recurrent hospitalizations, arrests, court involvement and homelessness—became routine for people with serious mental illnesses. Occasional reforms, such as the limits on seclusion and restraint, have demonstrated that only when adverse outcomes are properly framed as "service failures" can improvements be achieved.

The term "deinstitutionalization" originally meant more than a change of address. It reflected the vision of how community mental health could change the landscape and promote integration and rehabilitation. But it grew pejorative as vulnerable people without access to mental health care and other essential supportive services landed on the street or in jail, or moved in with unprepared families. Many more were "transinstitutionalized" into proprietary nursing homes, board-and-care facilities and other settings—even homeless shelters—where neglect and abuse were documented by the media and the very segregation cited by Justice Ginsburg prevailed.



## A Halting History of Community Integration

Interest in community mental health care revived under the Carter Administration, with Mrs. Carter's longstanding involvement in mental health advocacy. The 1978 President's Commission on Mental Health issued recommendations that were codified in the Mental Health Systems Act of 1980, creating a comprehensive federal-state approach to mental health services.

The Carter Commission recommendations embodied the spirit of the community mental health services movement, addressing not only improvements in services offered in the community but also the need to bolster natural, informal social supports. However, in 1981, Congress repealed the Systems Act, lumping its mental health programs into a block grant. The national mandate for community integration flagged again.

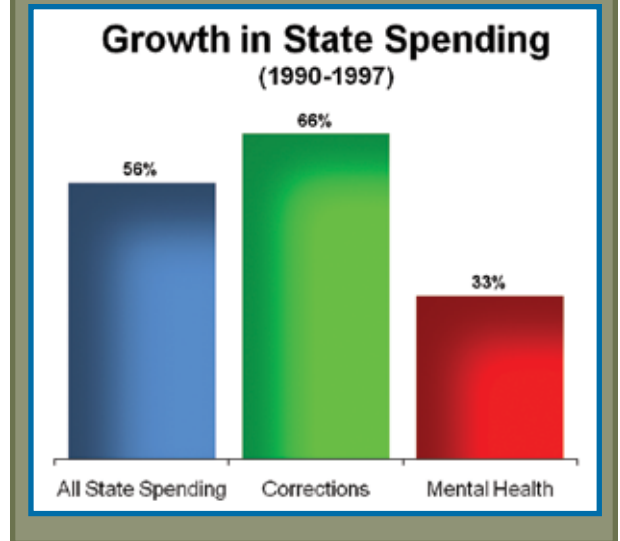
In 1990, President George H.W. Bush took the next important step, signing the Americans with Disabilities Act into law. A civil rights law, the ADA essentially aims to reverse the segregation of a marginalized population. As a product of advocacy by the Bazelon Center and others, the law explicitly includes people with "mental impairments" among those protected against discrimination based on disability. Among the regulations for the ADA's implementation was the "integration mandate," requiring the provision of services in the most integrated setting consistent with individual need.

The result of this halting history was what kept Lois Curtis and Elaine Wilson in the state hospital: the lack of a place for them to live and receive the supportive services they needed to flourish as members of their community. By 1997, when their case was working its way up through the courts, states' funding for mental health services was actually 30 percent *less* than the \$8 billion appropriated in 1955, adjusted for inflation and population growth.<sup>11</sup> In many parts of the country—then, and still today—the community mental health system functioned as a mere shell of the programs envisioned in 1963 and 1978, often serving only as a vehicle for delivering medication, sometimes under court order. A more recent review of state mental health funding found that in the years 1981-2005, similarly adjusted spending declined by 0.2 percent each year, dropping from 2.09 percent of all state spending to 1.98 percent.<sup>12</sup> Given states' budget-cutting in the current dismal economy, this trend may well worsen.

## *Olmstead* Offers an Opportunity

*Olmstead* provided a powerful new tool to break through the barriers imposed by vested interests, bureaucratic and political inertia, lack of funding and "abundant opportunities for the original intention of the [community mental health] program

State spending on mental health lost ground when compared to other programs, particularly corrections.<sup>11</sup>



In a brief to the Supreme Court, 58 current and former mental health and developmental disability commissioners from 36 states listed among barriers to integration:

*“the stigma surrounding mental illness, which has historically generated opposition to community placement in residential neighborhoods..., further complicating the development of housing and employment opportunities.”*

*The commissioners also identified as barriers the positions of “influential state legislators” and labor unions’ “legitimate concerns about the stability of their members’ jobs.” But, they argued, “a civil rights statute like the ADA and its implementing regulations cannot be held hostage to such political or parochial interests.”*

to be understood or misunderstood, inculcated or lost sight of, observed or disregarded.”<sup>13</sup> It was one of many cases brought to enforce Title II of the ADA, which bans discrimination by public services programs on the basis of disability.

The case was hard-fought before the Supreme Court. In an unusual twist, of 26 states that signed on to briefs arguing against federal court interference in states’ operation of mental health and developmental disability systems, 19 withdrew their support for Georgia’s position before the case was heard. The Bazelon Center mobilized more than a dozen briefs filed by disability and civil rights organizations to emphasize the validity of and need for the ADA’s integration mandate.

The Supreme Court’s historic ruling reflected views expressed in many of these briefs. The justices gave states some leeway, however, by allowing them to claim that implementing *Olmstead* in a specific case would “fundamentally alter” their overall services program. A state could make such a defense, Justice Ginsberg wrote, by showing prohibitive costs. To make that showing, a state must document the existence of “a comprehensive, effectively working plan for placing qualified persons with mental disabilities in less restrictive settings, and a waiting list that move[s] at a reasonable pace not controlled by the State’s endeavors to keep its institutions fully populated.”

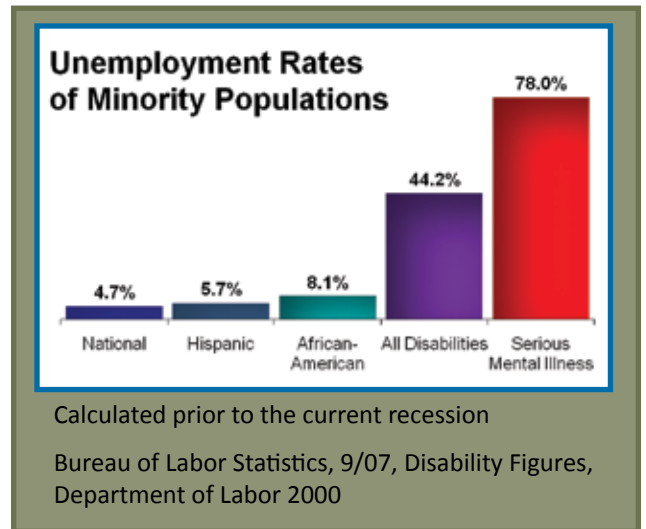
A key activity for advocates would be—and remains—monitoring states’ development and implementation of such plans and, in case after case, opposing states’ arguments that shifting funds from institutions to community is a cost-prohibitive “fundamental alteration” of their program.

Shortly after the Supreme Court issued its landmark decision, the Bazelon Center published *Under Court Order: What the Community Integration Mandate Means for People with Mental Illnesses*. Saying that the decision “opens up significant opportunities for expanding community mental health systems and for real and substantial policy changes in the states,” this report outlined what states would have to do to comply with *Olmstead* and explained how they could access federal dollars to help pay for it.

## Glacial Progress in National Policy

Some positive steps have been made in the decade since the court spoke. On the policy front, they have taken people with mental illnesses a few paces down the long road toward integration and recovery.

President Clinton hosted the first White House Conference on Mental Health and the U.S. Surgeon General issued a landmark report in 1999, highlighting mental illness as a public health problem that warrants national concern and documenting scientific evidence for treatment of mental disorders. The report emphasized the disconnect between increasing knowledge about effective treatment for mental illnesses and what is actually available to most people who need it. “Promoting mental health for all Americans will require scientific know-how,” wrote Surgeon General David Satcher in the preface, “but, even more importantly, a societal resolve that we will make the needed investment.”<sup>14</sup>



The same year, people with disabilities who live in the community began to benefit from the Ticket to Work Act, which allows them to keep crucial Medicaid coverage even as they begin earning income. Nonetheless, barriers to employment remain high for people with mental illnesses, including the “stigma and a now unwarranted sense of hopelessness about the opportunities for recovery from mental illness” cited by the Surgeon General. As a result, although most mental health consumers say they want to work, the unemployment rate for people with psychiatric disabilities tops 70 percent.

In a 2001 executive order on “Community-Based Alternatives for Individuals with Disabilities,” President George W. Bush requested federal resources in support of *Olmstead*: “The Federal Government must assist States and localities to implement swiftly the *Olmstead* decision, so as to help ensure that all Americans have the opportunity to live close to their families and friends, to live more independently, to engage in productive employment, and to participate in community life.”

President Bush also convened the New Freedom Commission on Mental Health to study the nation’s mental health system and recommend changes consistent with the ADA and the *Olmstead* decision. After declaring America’s mental health system “a shambles” in its interim 2002 report, the New Freedom Commission called for the system’s “transformation,” for the first time setting “recovery” as the goal of public mental health services.

## Then What?

The good words were followed up with—not very much. The New Freedom Commission’s report was released to no fanfare and Congress appropriated only \$19.8 million for grants to help states plan their transformation in 2005. (The 2009 budget contains \$26 million.)

After the *Olmstead* ruling, the Centers for Medicare and Medicaid (CMS) issued a series of policy memos encouraging states to shift Medicaid funds from institutions to home- and community-based services. Other federal agencies

also addressed *Olmstead* issues, but given Medicaid's preponderance in funding community mental health services, the response by CMS was critical. Since this promising beginning, however, the agency has done little.

Medicaid resources remain more readily available for institutional care than community services. Nursing-home care is fully covered, as are hospital and residential programs for children. Psychiatric hospital care for people over the age of 65 can be covered if states so choose, and states receive federal funds for uncompensated care in state mental hospitals. And in 2007 CMS issued regulations that significantly constrained the Medicaid options that cover the intensive community services that people with serious mental illnesses most need—rehabilitation services and case management. Fortunately, those damaging regulations have recently been withdrawn.

In another positive move, Congress in 2005 began a series of policy changes to encourage Medicaid coverage of community services. Several small demonstration programs have been funded and a new option allows states to provide at least a limited array of home- and community-based services to people who are otherwise vulnerable to institutional care.

Few resources have been available, however, for the federal agency with specific authority for mental health services, the Substance Abuse and Mental Health Services Administration (SAMHSA). States' major source of support from SAMHSA is the mental health block grant. This program has received level funding for many years, losing ground due to inflation. When expressed in constant dollars to reflect purchasing power, 2005 block grant spending was barely over half the 1983 total of \$230 million.

Some lesser efforts by SAMHSA include grants to states to help fund staff in the state mental health authorities to coordinate *Olmstead* implementation.

Housing is equally critical to enable people to move from institutions into the community. Decades ago this generally meant group homes, board-and-care facilities and other congregate settings, but even small group homes may needlessly segregate their residents from the larger community, contrary to the *Olmstead* mandate. Further, neighbors' opposition to group homes ("NIMBY") often made their creation politically contentious.

The Bazelon Center has advocated vigorously for a different approach: supportive housing—scattered-site permanent homes with access to case management

Recommendations for action abound, from the New Freedom Commission, the Institute of Medicine (IOM), the National Council on Disability (NCD) and many other public and private entities. This excerpt from a March 2009 NCD report shows why so many of them die on the vine:

*The [Medicaid] home- and community-based services that most people with disabilities want and need are optional, meaning that Federal law does not require states to provide them, although it does make the provision of nursing home services mandatory. Community-based services are provided under waiver programs, which receive far more limited and far more tenuous funding, making them an easy target for state budget cuts during economic downturns. Few assaults on individual dignity and self-determination are harsher than being forced to leave one's home and community to live in a segregated environment for these reasons. [emphasis added]*

National Disability Policy: A Progress Report,  
March 31, 2009



and other support services on a flexible, as-needed basis.<sup>15</sup> In addition to being less costly than any form of institutionalization, most such housing can be funded with federal dollars, including Medicaid and rental-assistance programs. And even as Housing and Urban Development (HUD) funds for low-income rental housing, slashed during the 1980s, have continued to shrink, federal programs to develop supportive housing have gained increasing support.

There are grounds for optimism on other fronts as well. A significant amount of current stimulus money is designated for healthcare—\$137 billion, of which \$87 billion is targeted to help states with Medicaid and continuation of health insurance (COBRA) for people who have lost jobs. Healthcare reform is high on the Obama Administration’s agenda and, with parity of coverage finally enacted last year and the President’s consistent support for it, mental health is likely to be included in overall healthcare. The question remains how well integrated it will be.

### Call to Action by the Federal Government

Given that *Olmstead* concerns basic civil rights, the federal government can and should play a far more important role in the decision’s implementation. Several federal agencies are key, including HUD, the Justice Department, the Education Department, the Department of Health and Human Services and its agencies (among them SAMHSA and the Administration on Children, Youth and Families), the Social Security Administration and CMS. Congress and the federal agencies should:

- Make available to all Americans health coverage that includes coverage for mental health services on a par with coverage for medical and surgical care.
- Include in healthcare reform incentives that adequately address the needs of people with serious mental illnesses—for example, coverage of psychiatric rehabilitation, peer support and case management services, linkages between private plans and the public mental health system, and comprehensive systems that address a person’s total health care needs, such as medical homes that specialize in serving individuals with serious mental illness.
- 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.
- Amend Medicaid to give states the option to provide home- and community-based services to more people, especially to children and those who are now on Medicaid but ineligible for those services.

CMS, as the agency administering the Medicaid program, has a critical role in

*“In this transformed system, consumers’ rights will be protected and enhanced. Implementing the 1999 *Olmstead v. L.C.* decision in all States will allow services to be delivered in the most integrated setting possible—services in communities rather than in institutions. And services will be readily available so that consumers no longer face unemployment, homelessness, or incarceration because of untreated mental illnesses.”*

Report of the New Freedom Commission on Mental Health, July 2003

*Olmstead* implementation. CMS should:

- Issue letters to state Medicaid directors highlighting both ways for states to facilitate integration and options for financing services in integrated settings.
- Expand access to Medicaid to ensure that significant numbers of uninsured people with serious mental illnesses have access to the broad home and community services that Medicaid can fund (and private insurance does not). This requires expanding Medicaid eligibility to childless adults up to at least 150 percent of poverty.
- Expand the array of home- and community-based services that states may provide through the regular Medicaid program (currently a waiver is needed to provide a more expansive array).
- 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, paying for therapeutic foster care for children and supportive housing for adults.
- Aggressively enforce current requirements for screening of individuals prior to nursing-home placement in order to avoid inappropriate Medicaid expenditures for institutional care and the “dumping” of people with mental illnesses who should be served in their home communities. This mandate is known as Pre-Admission Screening and Resident Review (PASRR).
- 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.

Congress and the Department of Housing and Urban Development must also act to help states expand the supply of supportive housing. They 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).<sup>16</sup>



- 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.



The Department of Justice (DOJ) must also play an important role in enforcement of *Olmstead*, in some cases along with other agencies. DOJ 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 the Department of Health and Human Services should also enforce *Olmstead* vigorously. Its enforcement efforts should not be driven entirely by individual complaints; rather, evidence of systemic issues, including evidence other than complaints, should inform OCR’s activities.

## Hard Truths About State Activity

While there are pockets of progress across the country, no state has adequately fulfilled the *Olmstead* mandate of serving people with mental illnesses in the most integrated setting, consistent with individual need.

Implementation of the *Olmstead* mandate is impossible unless a state has carefully determined how many people with disabilities are served in unnecessarily segregated settings and what community-based services are necessary to support their reintegration and recovery. The state must then plan for and take concrete

actions to offer people these services in the most integrated setting appropriate for their needs. The hard truth is that, after 10 years, progress in planning for integration of people with mental illnesses has been incremental at best.

Aside from ingrained prejudice and public fears about mental illness, integration is thwarted by powerful interests vested in preserving the status quo at the expense of the civil rights of people with mental illnesses. The state commissioners identified some of them in their *Olmstead* brief, among them the nursing home lobby and advocacy by unions to preserve jobs in state facilities. Their political force is fed by traditional rejection of mental health consumers' voice and a community mental health movement that has lost much of its spirit and is preoccupied with reactive crisis services and compliance with convoluted regulations. As powerful as these actors may be, government must not compromise or abdicate its role in safeguarding its citizens' rights.

When progress occurs it is frequently in reaction to an emergency, such as a lawsuit or a media exposé, not as an affirmation of individual rights. Rather than examining what led to the crisis and addressing its root cause (e.g., lack of access to appropriate community services), public agencies too often respond with a superficial fix, or worse, with restrictions of individual rights—arrest, court-ordered treatment or institutionalization. The Supreme Court recognized that vindicating *Olmstead* rights is a major undertaking and that cost and other constraints may slow things. But the justices envisioned that plans would be in place to ensure that that people do not live out their lives on waiting lists for services that never materialize.

There is ample evidence that *Olmstead* outcomes are illusive nationwide. For example, fewer than half of the people with mental illnesses who live in nursing homes have been screened for appropriateness of admission as required by the PASARR mandate.<sup>17</sup> The same federal law requires a determination whether the person could be served in a more integrated setting, but such a finding was not made for many of these residents.

Recidivism is also a recurring problem: about one in 10 of those discharged from state hospitals are readmitted within 30 days and one in five, within 180 days.<sup>18</sup> The decline in the state hospital census has stalled for the first time in more than 50 years, and hospital budgets still consume nearly one third of state mental health agency budgets.<sup>19</sup>

The number of people who are chronically homeless (the category that includes those with serious mental illnesses) is on the gradual decline, from 171,000 in 2005 to 124,000 two years later—a result of the financing and development of specialized housing programs such as Housing First initiatives and the federal Shelter Plus Care program.<sup>20</sup> Still, far too many people

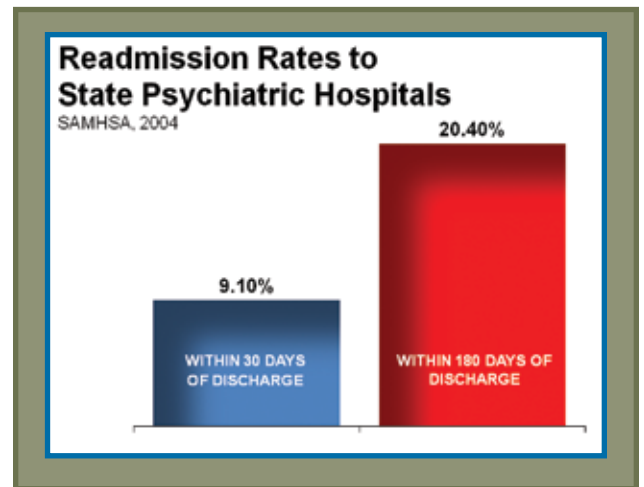
A recent study of 177 people with psychiatric disabilities in Illinois—the state with the highest number of adults under 65 who live in nursing homes—compared costs of public services for two years before and after they moved into supportive community-based housing. The study found a 39-percent reduction in the cost to the state's taxpayers when services such as case management and healthcare replaced emergency rooms, nursing homes and jails.

The Heartland Alliance, Mid-America Institute on Poverty, *Supportive Housing in Illinois: A Wise Investment* (April 2009)

with serious mental illnesses are incarcerated—16.9 percent of all jail inmates, a rate three to six times higher than the general population.<sup>21</sup>

Needed now is a surge of activity in and by the states, with support from the federal government. One might expect that recognition of basic rights, including the right to be free of discrimination via unwarranted institutional confinement—affirmed by a presidential commission, Congress, the Surgeon General and the Supreme Court—would, in itself, spur real change. Beyond this are the clear financial incentives to pursue the *Olmstead* course.

A growing body of evidence shows that states can vindicate the rights of people with mental illnesses under the ADA and at the same time reduce their expenditures by the use of optional Medicaid services, supportive housing and other approaches to serving people with mental illnesses in the community. Still, most states maintain their reliance on costly congregate care—or even worse, abandon people with mental illnesses to the streets and the criminal justice system.



### Call to Action by States

- Lose the silo mentality. People with mental illnesses are being unnecessarily segregated in nursing homes, jails, group homes and residential treatment centers, not just in state hospitals. Bureaucratic responsibility for these entities and their funding tends to be dispersed among multiple state systems; solutions must be cross-system.
- Assess the costs of unnecessary institutionalization in all systems and the consequences of inadequate access to needed services.
- Reallocate funds from segregated settings such as hospitals, nursing homes and board-and-care homes to develop supportive housing for people with mental illnesses.
- Uncover, expose and overcome political resistance to a statewide community-care model. Seldom discussed openly, such self-interest has kept institutions open and unneeded beds filled, perpetuating archaic models of service delivery and subjecting people with mental illnesses to unwarranted segregation from their communities.
- Target funding and services to older people with mental illnesses, who have remained segregated in nursing homes in even larger numbers than other groups.<sup>22</sup>
- Understand the options that states have to obtain federal funds for community-based services—from Medicaid, HUD and SAMHSA—and adjust systems in order to secure these funds.

- Focus state policy on enabling people with serious mental illnesses to obtain federal entitlements—disability benefits, food stamps and other support for basic living. Community success requires more than just treatment.
- Address provider resistance to furnishing up-to-date evidence-based services. Offer training, technical assistance, incentives and follow-up support to encourage high-quality community services. With improved outcomes, fewer people will need repeated institutional placements.



Folk artist Lois Curtis epitomizes the goal of integration, leading a full life among friends in the community. But that's because, when in the Georgia hospital, she was diagnosed with both mental illness and mental retardation. Today she lives in a "host home" with one other woman and participates in a customized employment program for people with developmental disabilities that has enabled her to become a successful businesswoman. She is saving to buy her own home.

Georgia has no such housing or services for people with mental illnesses. Had Ms Curtis not qualified under the state's Medicaid waiver for people with developmental disabilities, she might still be confined—or homeless.

## Back to Court

While the *Olmstead* case challenged confinement in a psychiatric hospital, states have devoted somewhat more energy (and resources) to implementing the decision for people with developmental and intellectual disabilities who had been housed in state institutions and Medicaid-funded "intermediate care facilities." When Lois Curtis and Elaine Wilson were moved from the state hospital to community residential programs, it was because she has dual diagnoses of mental retardation and mental illness. Their housing was provided through the state's developmental disabilities program.

This is not to say that people with intellectual disabilities are not still institutionalized; they are, by the thousands. Yet hundreds of thousands of people with psychiatric disabilities currently live in places that are just as isolating as state hospitals: nursing homes, large group homes, board-and-care homes, even many smaller group homes. Yet when challenged on *Olmstead* grounds, states often claim that these facilities are "in the community" by virtue of their street addresses.

Many state mental health commissioners, like the 58 who filed a friend of the court brief in *Olmstead*, had been active in the community mental health movement and are well aware of its unmet potential. But they are bound by political constraints—to the point of even hoping to be sued<sup>23</sup>—and therefore often resist closing institutional beds and reallocating funds to truly integrated settings, such as supportive housing. In part this is due to the power of the nursing-home and board-and-care industries, but bureaucratic inertia likely plays a role as well.

As long as institutional beds remain open unnecessarily and money cannot be reallocated from them to develop

more integrated settings, the tough economy makes it difficult for states to devote enough to develop supportive housing. Some state governments sued under *Olmstead* have dug in their heels, claiming that the up-front cost to develop alternatives to institutional care would divert dollars from and thus “fundamentally alter” their mental health program.

To counter such claims and clarify the real-world meaning of *Olmstead*, advocates have turned to the courts. Though litigation is often the only effective way to promote progress in the face of politically motivated resistance or bureaucratic inertia, it’s by definition a slow process. Two federal class actions on the Bazelon Center’s current docket demonstrate the possibility of progress through judicial action.

➤ In 2008, the City of San Francisco and plaintiffs’ attorneys settled *Chambers v. San Francisco* “in recognition and support of class members’ goals to live in the most integrated setting appropriate to their needs and preferences.” The city agreed to lease 500 scattered-site apartments for people with disabilities who were confined in or at risk of admission to the huge Laguna Honda nursing home, and to create a new community-integration program for them. Each participant will have a transition plan creating links to supportive services, such as attendant and nursing care, vocational rehabilitation, substance abuse treatment, mental health services and assistance with meals.<sup>24</sup>

➤ *Disability Advocates, Inc. v. Paterson*, in trial as this is written, challenges New York’s use of large proprietary adult homes to serve people with mental illnesses. In a February 2009 order denying the state’s request for summary judgment, the federal court found “immaterial” the state’s claim that *Olmstead* does not apply because the adult homes are privately owned, noting that the ADA bans “unjustified segregation of individuals with disabilities...in the *administration* of state programs.” The judge also expressed doubts about the state’s assertion that the adult homes are “integrated community-based settings unlike the hospitals” from which most of their residents were transferred.<sup>25</sup>

Other lawsuits in earlier stages of development by the Bazelon Center include challenges to the confinement of people with mental illnesses in proprietary nursing homes in Connecticut and Illinois.<sup>26</sup>

Aside from the inappropriateness and illegality of such confinement, states could save money by relying instead on the federal dollars available for many community mental health and supportive housing programs. The state must pay the full cost to house adults under 65 who have mental illnesses residing in IMDs such



A ward at Laguna Honda in San Francisco

*“I am 47 years old and have been at Laguna Honda for seven years,” said Mark Chambers, a computer systems manager before suffering a head injury. “I don’t want to spend the rest of my life here. I want to be part of the world outside.” Planning is underway for Mr. Chambers’ move to supportive housing in the next few months. So far, an average of 10 plaintiffs a month have been able to move into scattered-site apartments.*



as psychiatric hospitals and some nursing homes, while federal Medicaid dollars contribute from 50 to 77 percent of the bill for mental health and rehabilitation services in the community. People who receive monthly disability benefits (e.g., SSI) or other income contribute to the rent for supportive housing. Federal and/or state housing funds cover the rest.

Across the nation, a network of mental health advocates is working to implement *Olmstead*. Many turn to the Bazelon Center for technical assistance and strategy coordination. While these advocates are vigorous in pursuing *Olmstead* claims, over the 19 years the ADA has been in effect, courts have often interpreted very narrowly the scope of the law’s protection. Congress last year amended the ADA to return its meaning to that originally intended.<sup>27</sup>

In addition, the disability and civil rights communities have joined in recent years to oppose confirmation of nominees to the federal appellate bench who have records of criticizing the ADA or disavowing the rights of people with disabilities. President Obama called “empathy” a desirable characteristic for his first nominee to the Supreme Court—an appellate judge who appears to fully understand the language and purpose of the ADA. We agree, and call upon the President to nominate, and the Senate to confirm, to the federal bench—at every level—only individuals who will be aware of how their decision-making will affect the millions of people with disabilities in this country.

## Exemplary Community Programs Exist

Pockets of progress exist around the country. New approaches that support community living by people with mental illnesses have been developed in the decade since the Supreme Court’s historic decision—some by nonprofits and others through government initiatives.

One of the most dramatic in its cost-effectiveness is Housing First, pioneered by Pathways to Housing in New York City for homeless people with mental illnesses and/or substance abuse. People placed in apartments through this program have no requirement of sobriety or service compliance, yet they have been even more successful than others whose housing is contingent on receiving treatment. The program has expanded in New York and Washington D.C., with case management and a range of supportive services available. The Housing First model has been adopted by providers in other cities and has been endorsed by HUD.<sup>28</sup> Cost savings are dramatic. Pathways cites its annual cost for a New York apartment with extensive support services as \$22,500 per client, compared to \$175,000 in a state psychiatric hospital.

Mental health services have also changed. For the many people who struggle with substance abuse in



addition to mental illness, integrated mental health and addiction treatment is now recognized as evidence-based. Peer support, provided by trained consumers of mental health services, is ever more widely used and is now covered by Medicaid as a rehabilitation service.

Pilot programs of self-directed care, which had proven effective with older adults and people with developmental disabilities, are now having positive outcomes for mental health consumers. Self-directed care consumers participate in designing their care plans, budgeting many of the funds and choosing from an array of services—from education to eyeglasses—that will help them achieve recovery. By allowing participants to hire neighbors and obtain services from a wide range of other sources in the community, these programs reinforce the informal networks called for so many years ago by the Carter Commission.

Nonetheless, far too many community mental health programs remain crisis-driven and offer little beyond medication. It is not unheard of for people with serious mental illnesses to receive “therapy” via a 15-minute appointment with a psychiatrist every six weeks or so—and even then, with a different psychiatrist each time. Uninsured individuals who do not qualify for Medicaid receive particularly limited services.

Too many people remain unjustifiably isolated. States now have tools to implement the *Olmstead* order, in the form of federal dollars for supportive housing, Medicaid-funded rehabilitation services, legal mandates and technical assistance like the Bazelon Center’s.

- **State legislators** must champion the civil rights of people with disabilities and reject the demands of those who benefit from their unjustified isolation—the nursing home lobby and the owners and operators of board-and-care facilities and the like.
- **State administrators** must work with unions to retrain institutional staff for service in the community.
- Above all, **state policymakers** must refocus their budgets and bureaucracies to create a network of innovative, humane and effective services to meet the needs of people with mental illnesses in the community. Only then will these citizens be able to overcome the fears of families who have been frustrated by the history of unsuccessful deinstitutionalization and a public that, based on sensational media coverage, grossly underestimates the true capacities of people with mental illnesses.

PEOPLE, Inc., epitomizes peer support. The name stands for Projects to Empower and Organize the Psychiatrically Labeled. Operated entirely by mental health consumers, the nonprofit organization provides a full range of services, including advocacy, education, housing, employment support, socialization, crisis care and training in suicide prevention.

[www.projectstoempower.org](http://www.projectstoempower.org)

**What’s lacking—and urgently needed—is political will.**



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Notes continue on page 20

## *Olmstead Works*



*Irene Kaplan in the New York City “adult home”— and enjoying breakfast in her supported apartment. Photos by Erica McDonald*

### **From the trial transcript:**

Attorney: Now, you lived in the adult home for 16 years, correct?

Irene Kaplan: Yes.

Q And...you moved out in April, to your own apartment, correct?

A Yes.

Q How do you like living in your new apartment?

A I love it.

Q Do you have a roommate in your new apartment?

A Just my cat.

Q And you always had a roommate while you were living at the adult home?

A I had no choice.

Q Do you cook your own meals now?

A Yes.

Q What’s different about cooking your own meals versus having them cooked for you?

A I can limit what I eat or I can expand my choices. I can have as much salad as I like. I can have as little grease as I like. I can eat foods that were not permitted in the home. ...I do my own shopping. I do my own food selection. It’s free. It’s freedom for me.... It’s being able actually to live like a human being again.

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*The Bazelon Center for Mental Health Law is the leading national legal-advocacy organization representing people with mental disabilities. It promotes laws and policies that enable people with psychiatric or developmental disabilities to exercise their life choices and access the resources they need to participate fully in their communities. For comprehensive information about Olmstead and other system-reform cases advancing the rights of people with disabilities, see [www.bazelon.org/incourt/](http://www.bazelon.org/incourt/).*

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