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December 27, 2001

Dear Colleague:

The *Olmstead v. LC* Supreme Court decision of 1999 mandated states to provide individuals with severe disabilities and special needs access to health care in community-based settings. As states shape responses to this landmark disability rights case, the need to explore appropriate housing and community service models for people with disabilities and special needs, and expand existing programs, is evident.

To help states develop effective supportive housing approaches, the Center for Health Care Strategies convened a group of stakeholders, including supportive housing and Department of Housing and Urban Development representatives, state Medicaid officials, and policy experts, for a small group consultation in May 2001. We asked Ann O'Hara and Steven Day of the Technical Assistance Collaborative to draft the enclosed report, *Olmstead and Supportive Housing: A Vision for the Future*, as a basis for discussion at the meeting.

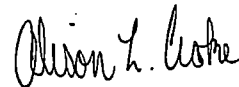
This report offers an overview of available housing models, including a summary of residential services models of the past and a preview of innovative programs that are successfully being piloted in some communities. A discussion of creative and realistic funding strategies also is included. Lastly, the report offers a thorough review of states' current *Olmstead* planning efforts related to supportive housing.

We hope that this report will help spur more states and communities to expand community-based supportive housing opportunities for people with disabilities. To order additional copies of this paper, please visit our web site at www.chcs.org.

Sincerely,



Stephen A. Somers, Ph.D.
President



Alison L. Croke
Program Officer



Implementing *Olmstead*

Wendy Wilkinson
Project Director
Southwest Disability and Business
Technical Assistance Center
ILRU (Independent Living Research
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Houston, Texas

In *L.C. v. Olmstead*, 527 U.S. 581 (1999), the United States Supreme Court ruled that placing in institutional facilities individuals with disabilities who are capable of living in community settings constitutes a form of discrimination under the Americans with Disabilities Act (ADA). 42 U.S.C. § 12132. In so ruling, the Court gave great power to the "integration mandate" found in Title II of the ADA that applies to state entities. It requires that public entities administer programs, "in the most integrated setting appropriate to the needs of qualified individuals with disabilities." 28 CFR § 35.130. The Court also recognized Congress's intent to set forth a "comprehensive view of the concept of discrimination" in the ADA that does not require a demonstration that people with disabilities were treated differently than a comparison class of individuals with no disabilities. *Olmstead*, 527 U.S. 581, 598. In this case, segregation of persons with disabilities in institutions (and the consequences of that segregation) was viewed as inherently discriminatory. Living in institutions "severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment." *Id.* at 601.

The case originated in Georgia where suit was brought against the state on behalf of two women with mental disabilities who were institutionalized. They were denied

placement in the community even though their treating professionals said they were ready for such placement.

This ruling, the Supreme Court's most powerful and sweeping decision on the ADA to date, challenges our society to make great changes in the support mechanisms many individuals with mental and physical disabilities need to maintain independence. Current systems of support that maintain many people with disabilities reflect a distinct institutional bias. As our society rises to meet the challenge presented in *Olmstead*, it is important to remember that institutionalization of persons with disabilities is far more insidious than segregation. As the Court noted, it means absolute isolation of a person from any kind of societal opportunities, in a place where an individual has no decision-making power over how their simple daily life activities are structured. *Id.*

Barriers to Implementation

Implementing *Olmstead* presents a tremendous and complex challenge for states. A multitude of barriers to achieving the integration goals embodied in *Olmstead* exist. Barriers include the institutional bias extant in federal and state programs that

provide support services for individuals with disabilities, the lack of comprehensive community support systems that permit individuals to be successfully integrated in communities, and the language in the decision itself that gives states

considerable latitude in developing deinstitutionalization plans.

In *Olmstead*, the Court gave states the power to influence the process of determining who is eligible for community placement, the authority to maintain support for institutional facilities and an affirmative defense to placing individuals with disabili-

ties in community settings. The Court said states may rely on the expertise of its own professionals in assessing whether individuals are eligible for community placement, but did limit what factors may be considered in this process. Assessments must be focused on whether the individual is qualified for community placement, not on a state's ability to accommodate the individual in the community. In addressing a state's responsibility to "deinstitutionalize" its system and open up community placement options, the Court stated that institutions do not have to be phased out completely and that "a range of facilities" may be maintained to administer necessary services. *Id.* at 597. It further qualified the obligation to place individuals in community settings by also stating that it should occur when the individual can be "reasonably accommodated, taking into account the resources available to the State and the needs of others with mental disabilities." *Id.* at 607. This language muddled the waters a bit in terms of what defenses are available to states under Title II of the ADA. Title II allows states one defense to providing services in an integrated setting. The statute permits states to provide segregated programs or services, if they can demonstrate that providing services in an integrated setting would impose a fundamental alteration in the program they are administering. The term "reasonable accommodation" is only found in Title I, the employment section of the ADA. These defenses are different and intended to be used in different arenas. To date, however, the biggest barrier has been the Court's language permitting states to maintain a "range of facilities." As a result, states can factor in the support they are providing through all programs, including community integration programs, assistive living, and traditional institutional care, in determining the range and comprehensiveness of the options for community placement they will offer. This creates a tension in achieving the integration goals of

Continued on page 12

BOOK REVIEW

Playing With Time

By Phyllis Griffin Epps
Research Professor

The Forgetting – Alzheimer's: Portrait of an Epidemic

David Shenk
Doubleday (2001)

The Forgetting – Alzheimer's: Portrait of an Epidemic is a chronicle of both the pathology and the history of Alzheimer's disease. Author David Shenk describes how the disease affects the physical structure of the brain and the efforts in the research community to understand more about the disease in hopes of developing effective treatment. Through vignettes and anecdotes, Shenk tries to capture the effects of the disease on the behavior, consciousness, and identity of the individual. Between each task, Shenk takes note of how what he learns shapes his views on life and loss.

The book is prompted by the prevalence of the disease and the increase predicted for its occurrence in the coming decades. As the generation commonly known as "baby boomers" reaches senior status, its members and their parents will continue to benefit from advances in medicine that have contributed to greater longevity. Some baby boomers are encountering Alzheimer's disease as caregivers for their parents. The same generation, which collectively enjoys more wealth and wields greater significant political influence than its predecessors, will soon enter the age range within which symptoms often first appear in afflicted persons. Consequently, the issues associated with the care of the elderly ("eldercare"), including the cost and availability of relevant services, are expected to gain prominence.

Shenk documents the history of Alzheimer's Disease from the work of Alois Alzheimer in the first decade of the twentieth century to the vaccine patented by Elan Pharmaceuticals in 2000. He relates each stage with an air of mild surprise at the presence of politics in medical research. Noting greed, jealousy, and other vices, Shenk portrays the community of researchers as achieving progress only through adversity, competition, and resentment. The Alzheimer's research community is depicted as polarized between those who emphasize neurofibrillary tangles and those who view

beta-amyloid plaques as the key to treating the disease. It is the "outcast scientist" who advances the science as a whole but only by countering the preceding, established school of thought. Allen Roses and the initial resistance to his work on genetic traits as a predictor of susceptibility to Alzheimer's are cited as an example. The challenge, Shenk implies, lies in recognizing which nonconformist theories deserve more than crackpot status.

The challenge may not be quite so large as Shenk implies, however. Medical research has benefited from the standards applied to novel theories. One wonders if the system of peer review does not deserve more credit than Shenk allows. While personal relationships and the promise of wealth are powerful motivators, other equally powerful incentives exist to ensure that a theory gains acceptance because it has merit. If Ruth Itzhaki's hypothesis linking herpes with Alzheimer's has value, one must have faith that the same spirits of greed and competition will root it out for proper exploitation.

The Forgetting is organized into three parts: the early, middle, and late stage, respectively. Each part is structured to reflect not only the three stages characteristic of Alzheimer's disease, but also the history of its management and recent growth in public awareness of the disease. The middle stage of the book, for example, describes the middle stage of the disease, which is characterized by the unambiguous deterioration of cognitive abilities. The members of a support group introduced in an earlier chapter have reached the middle stage of the disease. The history of the disease has progressed from its discovery to the creation of the NIH National Institute on Aging in the 1970's. A research conference introduced in the prologue is now in full swing. The result, while interesting, requires discipline of the reader.

What could be the cleverest aspect of the book is also the most annoying. From the beginning, Shenk introduces a literary style that proves somewhat distracting. Simply put, Shenk plays with time. Within a chapter, the narrative jumps forward, skips backward a bit, and drifts between anecdotes with little or no transition. It is as though Shenk intended to capture the "hiccups of logic" he describes as effects of Alzheimer's on an individual's sense of time

and recollection. As the ability to make new memories is lost, the ability to fix old memories in time also fades. The individual is left with a series of disjointed, if not confusing, thoughts. The style successfully conveys a sense of disorientation, but distracts and detracts from the power of the content. To the credit of the author, this effect does not worsen as the book progresses into the two later stages.

Shenk's approach to the narrative is consistent with the appreciation of a sense of time that is a theme of the book. Shenk hopes to impress upon his audience the "essential humanity" of Alzheimer's. At his worst, he leaps from one celebrity to another, relating anecdotes about Ronald Reagan, Ralph Waldo Emerson, and Jonathan Swift (the latter two of whom were never diagnosed) that do little to advance his point. At his best, Shenk forces his audience to consider what the disease teaches about the dark side of human longevity, memory as the foundation of identity and self-awareness, and the unappreciated beauty in the present. Even as he recoils from the regression of sufferers into a state of consciousness like that of infants and the terrible effects of the disease on family and caregivers, Shenk considers what lessons would be lost if the disease were eradicated.

In short, *The Forgetting* is a solid primer on Alzheimer's disease. Moreover, the book chronicles its author's journey in discovering the sadness, wonder, and poignancy that accompany the disease.

List of Books Submitted for Review

- Legal Aspects of Health Care Administration, 8th ed., by George D. Pozgar (Aspen 2002)
- Pharmaceutical Medicine, Biotechnology, and European Law, by Richard Goldberg and Julian Lonbay (Cambridge University Press 2000)
- Managing Ethically: An Executive's Guide, edited by Paul B. Hofmann and William A. Nelson (Health Administration Press 2001)

Nursing Home Reform in Florida

Continued from page 6

ployer actively and knowingly participated in the employee's conduct; (2) the officers, directors, or managers of the employer condoned, ratified, or consented to the employee's conduct; or (3) the employer engaged in conduct that constitutes gross negligence that contributed to the loss, damages, or injury suffered by the claimant. It also created new standards relating to the pleading and recovery of punitive damages. To recover punitive damages, a claimant must prove by clear and convincing evidence that a defendant was personally guilty of intentional misconduct or gross negligence.

The legislation also addressed employers' vicarious liability. Where the fact finder determines that the wrongful conduct proven was motivated primarily by unreasonable financial gain and determines that the unreasonably dangerous nature of the conduct, together with the high likelihood of injury resulting from the conduct, was actually known by the managing agent, director, officer, or other person responsible for making policy decisions on behalf of the defendant, the claimant may be awarded an amount of punitive damages not to exceed the greater of four times the amount of compensatory damages awarded to each claimant or the sum of \$4 million. It sets no cap where there is specific intent to harm.

Quality of Care Reforms

Florida, like most of the nation, is suffering a severe shortage of nurses and nursing assistants. For several years, the dearth of direct-care staff in nursing facilities has been high on the Legislature's long term care agenda. Many patient advocates, including direct-care staff in nursing homes, believe that the litigation and liability insurance crises have resulted from the industry's unwillingness to adequately staff facilities and the regulatory agency's unwillingness to hold them accountable.

With the passage of Senate Bill 1202, the 2001 Florida Legislature took a major step toward a remedy for poor care, a step few states have been willing to take. For the first time, the statutes now require minimum staffing levels in nursing homes. The industry has been put on notice that Florida will not tolerate the neglect of its frail elderly and disabled citizens in nursing homes.

The new legislation establishes statutory staffing standards for certified nursing assistants in nursing homes at 2.3 hours per resident per day on January 1, 2002, in-

creasing to 2.6 hours per resident per day on January 1, 2003, and increasing to 2.9 hours per resident per day on January 1, 2004. In addition, it requires for licensed nurses 1.0 hour per resident per day on January 1, 2002. The minimum staff-to-resident ratios at any time are 1/20 for certified nursing assistants and 1/40 for licensed nurses.

Under the new law, a nursing home that has failed to comply with state staffing standards for two consecutive days must suspend accepting new admissions until the facility has met minimum staffing standards for six consecutive days.

Nursing homes now must maintain an internal grievance procedure to resolve resident concerns quickly and without external intervention to the extent possible. Nursing homes and assisted living facilities now are required to establish an internal risk management and quality assurance program. Quality-of-Care Monitors are now required to visit each nursing facility at least quarterly and include in their assessments the operations of internal quality-improvement and risk-management programs and adverse incident reports.

Numerous other quality of care provisions and regulatory enhancements were

Nursing homes and assisted living facilities now are required to establish an internal risk management and quality assurance program.

enacted, including mandatory fines at increased levels for each violation class; a requirement that nursing homes have all cost reports filed, fines paid, overpayments reimbursed, and penalties paid before a license can be renewed; authorization for the agency to impose fines, notwithstanding the nursing home's correction of the violation; and a requirement that the agency revoke or deny a nursing home license if the licensee or controlling interest operates a facility in Florida that has had two moratoria imposed by final order within any 30-month period, is conditionally licensed for 180 days or more, is cited for two class I deficiencies in the same survey, or is cited for two class I deficiencies in separate surveys or investigations within a 30-month period.

Conclusion

The above summary of substantive legislation enacted by the 2001 Florida Legislature and the description of the political environment in which it was formulated provide evidence that long term care reform has begun in Florida. As the fourth largest state and the state with the highest percentage of elderly persons, the Florida experience may stand as a harbinger of what is yet to be faced by other states with a growing elderly population. Clearly, aggressive steps are being taken here to cope with the demands for high quality long term care.

The process has begun, and progress has been made, but the successful transition from reliance on high cost, institutional arrangements to modern, innovative, cost-effective, home- and community-based care models is the frontier that Florida, like the rest of the nation, must challenge.

NOTES:

A more complete summary of CS/CS/CS/SB 1202 can be found on the Web site of the Florida House of Representatives Committee on Elder and Long Term Care at

http://www.leg.state.fl.us/committees/index.cfm?mode=Committee%20Pages&view_mode=View%20Page&Committee_ID=1148&Tab=committees&submenu=1.

Representative Green thanks Staff Director Tom Batchelor, Ph.D., for all his work on this article.

Implementing Olmstead

Continued from page 7

Olmstead because it reduces the incentive for states to actively develop community placement options.

Although the decision permits states some discretion as they develop their Olmstead plans, the decision clearly compels states to undertake some activity to develop community-based services and supports for individuals with disabilities. At a minimum, states must be able to demonstrate that they have comprehensive, effectively working plans for placing qualified persons with disabilities in community based environments, waiting lists that that move at a reasonable pace, unencumbered by a state's financial incentives to maintain the population in its institutions. See *Olmstead*, 527 U.S. at 605-606.

Attitudinal Barriers

Successful integration of individuals with

disabilities into the community requires a paradigm shift in attitudes toward individuals with disabilities. The Court in *Olmstead* recognized the tremendous impact that institutionalization of people with disabilities has had on our society's perceptions of this population. Placing in institutions individuals capable of living in the community perpetuates stereotypes that people with disabilities are "incapable or unworthy of participating in community life." *Id.* at 600. Individuals with disabilities are deemed unable to care for themselves. These stereotypes are ingrained in our society and internalized by many persons with disabilities. Moving people with disabilities from institutions into community settings requires much more than developing a plan to shift resources and move people according to a timeline. Education and public awareness activities targeted at both persons with disabilities and the general public must be undertaken.

Developing *Olmstead* Plans

The decision gave states a mandate to change their systems but provided little guidance on how this is to be accomplished. Open questions regarding implementation remain. The lack of a roadmap to achieving community integration in the decision clearly dictating how states should move from point A to B should be used as an opportunity by advocates to guide the development of *Olmstead* plans in their states. The ADA permits states to develop broader proscriptions against disability discrimination at the state level. *Olmstead* provides similar opportunities.

Individuals with disabilities should work at the state level to make sure their state "affirmatively" implements *Olmstead*. States' funding choices should be monitored, as well as their opportunities to obtain federal funds to develop community support services, housing options, and other services that help people with disabilities maintain their independence in the community. In *Lewis v. New Mexico Department of Health* (2000 WL 519248, *18 (D.N.M.)), the court found that the New Mexico governor's actions in failing to provide waiver services that would have allowed individuals with disabilities to live in the community were sufficient to raise a claim under Section 1983. The court distinguished between gubernatorial actions limited to general budget and policy recommendations that would not be actionable and the specific activities of the governor, which had caused the plaintiffs to be denied waiver services with reason-

able promptness. In this case, the governor vetoed funds for the DD waiver program, directed the head of the Department of Health not to submit department budgets for increased funds, and submitted a \$2 million budget instead of the \$5.5 million budget requested for the waiver programs. The governor took these actions even though he was aware that several hundred people were on waiting lists for community placement.

Filling in the roadmap outlined in *Olmstead* is a complex exercise. A number of states, policymakers, and advocates have made some progress in identifying the elements that must be addressed in developing successful, effective, working integration plans. The elements identified as integral to the success of these plans and the progress made thus far in implementing them highlight the enormity of the undertaking.

As a first step, in order to assure that plans are driven by the principle of consumer self-determination, disability advocacy organizations, persons with disabilities, and family members of individuals with disabilities need to be involved in developing and overseeing the implementation of their states' plans. These groups and individuals must be involved from the start. Plans should mandate their involvement on advisory committees.

Other essential elements include:

- **Flexibility.** Plans should be dynamic and flexible. They should be designed to respond to changes in federal and state policies and programs, able to accommodate wide-ranging, individualized consumer needs, and capable of expanding to accommodate increases in the numbers of persons identified as being "qualified" for community placement.
- **Ongoing oversight.** Plans should include a process for continuous oversight of implementation to assure adherence to timelines, provide ongoing assessment of the needs of the different populations served, and assess the adequacy of services being provided.
- **Clear definitions of institutional settings.** What constitutes an institutional setting should be identified. Obviously, the list should include state schools and public and private nursing homes. With group homes, acceptable placements should be clearly defined. In *Rolland v. Cellucci* (191 F.R.D. 3, *12, 2000) concern was expressed about the size of community residences. The plaintiffs cited professional consensus that living arrangements with

more than four to six people inhibit an individual's ability to develop and grow. The plaintiffs were concerned that the state would amend its regulations and permit up to 16 individuals to live in group homes.

- **Clear process for identifying eligible individuals.** Systems for continuous identification of individuals, children, and adults that are inappropriately placed in institutional settings or are in danger of entering such facilities must be developed. The plan should include a mandate that institutions review all potential new admissions for possible community placement and use the federal Medicaid requirements that require that nursing homes conduct needs assessments of residents on a regular basis to assess the capacity of residents to be moved to the community. The Minimum Data Set assessment requires that the discharge potential of residents be evaluated. Using this, residents could be evaluated for community placement and provided information about com-

Systems for continuous identification of individuals, children, and adults that are inappropriately placed in institutional settings or are in danger of entering such facilities must be developed.

munity services.

- **Ongoing training and education.** Ongoing training and education of all involved in the identification process on the diverse needs of the different populations they will encounter is crucial so support needs will be appropriately identified. Basic standards and practices should be developed to accommodate different groups that have similar needs or share eligibility requirements for certain programs, such as children with disabilities, adults with long term care needs, or adults that have disabilities with acute episodes that may require more intensive services from time to time.
- **Fair placement practice.** A uniform system of placing individuals in communities, guided by the principle of equal access for all, should be established. Individuals should be served on a first come,

Continued on page 14

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Center for
Health Care Strategies, Inc.

Consumer Action Series

Olmstead and Supportive Housing: A Vision for the Future

By Ann O'Hara and Stephen Day,
Technical Assistance Collaborative, Inc.

Foreword by Alison Croke and
Stephen Somers
Center for Health Care Strategies

*Funded through a grant from The Robert Wood
Johnson Foundation.*

December 2001

The Center for Health Care Strategies (CHCS) is a nonprofit policy resource center that promotes high quality health care services for low-income populations and people with chronic illnesses and disabilities. We achieve this objective through providing grants and “real world” training and technical assistance to state purchasers of publicly financed health care, health plans, and consumer groups. Our projects aim to improve access to care, increase use of effective preventive care services, prevent unnecessary hospitalizations and institutionalizations, promote clinical quality using accepted standards of care, and build organizational capacity to improve managed care services.

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Table of Contents

Foreword	3
Executive Summary	5
Overview of Supportive Housing	7
The Continuum Model	7
The Supportive Housing Model	8
Supportive Housing for Elders	9
Supportive Housing for People with Disabilities	9
Supportive Housing for Homeless People	10
Roles and Responsibilities of Housing and Services Systems	11
The Housing System	11
The Support Service Systems	12
Supportive Housing and State <i>Olmstead</i> Plans	15
Review of State <i>Olmstead</i> Plans	16
Funding Approaches for Supportive Housing	19
Housing Resources	19
Housing Resource Issues	21
Housing Resource Opportunities	21
The Role for Medicaid and Other State Programs	23
Service Resource Issues	24
Service Resource Opportunities	25
Conclusion: A Vision for Change	27
About the Authors	29

Foreword

The Supreme Court's *Olmstead v. L.C.* decision of 1999 had major implications for consumers, multiple state and federal agencies, and health care providers. To respond to this decision and to begin to offer technical assistance to its stakeholders, the Center for Health Care Strategies (CHCS) launched a variety of initiatives, including one focused on supportive housing, the subject of this report, *Olmstead and Supportive Housing: A Vision for the Future*. Such housing can and should be a key component of community-based options for consumers with disabilities.

Under the auspices of The Robert Wood Johnson Foundation's Building Health Systems for People with Chronic Illnesses program, CHCS managed a subset of grants related to community-based housing options for people with disabilities. We assembled these grantees, along with other stakeholders (including funders, Department of Housing and Urban Development representatives, state Medicaid officials, and policy experts) for a small group consultation in May 2001. We asked Ann O'Hara and Stephen Day of the Technical Assistance Collaborative to draft this paper as a basis for dialogue at the meeting. Through a lively and thought-provoking discussion, participants analyzed current strategies and offered new ideas, and CHCS worked with the authors to incorporate them into this final report.

This report offers a basic primer on supportive housing, as well as a thorough review of states' current *Olmstead* planning efforts in this area. We hope that this report will help spur more state and local stakeholders to expand community-based supportive housing opportunities for people with disabilities.

Sincerely,

Stephen A. Somers, Ph.D.
President and CEO,
Center for Health Care Strategies

Alison L. Croke
Program Officer,
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Executive Summary

On June 22, 1999, the United States Supreme Court issued its decision in *Olmstead v. L.C.* – a landmark disability rights case. The lawsuit, brought against the State of Georgia, questioned the state's continued institutionalization of two disabled individuals after physicians had determined that they were ready to return to the community. The Supreme Court described Georgia's action as "unjustified isolation," and determined that the state had violated these individuals' rights under the Americans with Disabilities Act (ADA).

The Court explained that unjustified isolation was a form of discrimination. It reflected two 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 ... Second, 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.

The Supreme Court was careful to say that the responsibility of states to provide health care in the community was "not boundless." States were not required to close institutions nor were they to use homeless shelters as community placements. Without imposing specific requirements, the Court said that if "... the state were to demonstrate that it had a compre-

hensive, effectively working plan for placing qualified persons with mental disabilities in less restrictive settings, and a waiting list that moved at a reasonable pace not controlled by the state's endeavors to keep its institutions fully populated, the reasonable modifications standard [of the ADA] would be met." The Court specified that the state must provide community placement and services without displacing others on a waiting list for similar benefits and without unduly burdening the state's resources.

Although the *Olmstead* decision confirmed the ADA's community integration mandate, the words "housing" or "supportive housing" do not appear in the decision. Instead, the Supreme Court used terms such as "community placements" and "less restrictive settings." Nonetheless, the *Olmstead* decision could have a profound impact on future state policies and approaches to provide community-based housing and support services for people with significant disabilities. As a result of the *Olmstead* decision, thousands of people currently living in "more restrictive settings" such as public institutions and nursing homes must be offered housing and community-based supports that are consistent with the integration mandate of the ADA.

Planning and strategy development at the state level related to the *Olmstead* decision presents a number of important opportunities. These include:

- The opportunity for substantial involvement of consumers and other stakeholders in the design of new housing and service resources.
- The opportunity to build on knowledge and evidence developed over the past 20 years about what housing and community service models best meet the needs and choices of people with disabilities.

Thus, as state agencies plan for the implementation of new policies consistent with the Supreme Court's *Olmstead* decision, they will make extremely important choices and policy decisions about the models of housing and supports to be offered to peo-

ple with significant disabilities. Simply put, these choices are about replicating the outdated residential services models of the past, or moving toward the future by building on recent innovations linking housing and supports for people with special needs through the supportive housing approach. This report presents a discussion about those choices.

Overview of Supportive Housing

Recent years have seen remarkable shifts in approaches to community-based housing and support needs for three vulnerable low-income groups, including:

- Frail elders.
- People with significant disabilities.
- Chronically homeless people.

These new approaches are collectively referred to in this report as supportive housing.

In preparing this report, it became clear that current literature and existing policies may not sufficiently reflect the common principles, approaches, and issues which have influenced the development of models of supportive housing for these various sub-populations. These similarities reflect common problems and needs among all three groups, including:

- Extremely high rates of poverty.
- The desire to live in normal housing rather than in segregated and restrictive settings.
- The need for long-term supports and services in order to live as independently as possible.
- The desire for personal control, autonomy, and choice in one's living situation.

It also is clear that best practices in the development of supportive housing – particularly for people with significant disabilities potentially affected by the *Olmstead* decision – continue to evolve as disability policy shifts from the continuum housing model to the supportive housing approach.

The Continuum Model

Prior to the mid-to-late 1980s, housing and services for people with disabilities were almost exclusively organized according to a continuum of facilities, especially for people with significant disabilities. According to the continuum model, individuals with the most significant disabilities live in and receive services at the most restrictive point on the continuum while individuals with the mildest disabilities will be served at the least restrictive point. Thus, individuals must move to a different residential setting to access services appropriate to their skills, capacities, and choices.

Following this theory, the most intensive services are provided in the most restrictive settings (e.g., nursing homes). These settings tend to be highly segregated and have the highest per-person costs. To move from a more restrictive to a less restrictive setting in the continuum model, an individual must acquire more independent living skills and need fewer services. The least restrictive settings, which are also the most integrated, provide the least intensive services and are expected to cost much less.

During the 1990s, the supportive housing model began to replace the continuum model in a few public systems of care and within some programs that serve chronically homeless people. However, the continuum

A lack of a common definition of supportive housing among policymakers and disability groups leads to fragmented approaches to service delivery.

model still guides both policy and practice for people with significant disabilities in many localities.¹ The variance between these two models – and the principles and values that underpin the supportive housing paradigm – are important considerations for housing and service approaches developed in response to the *Olmstead* decision.

The Supportive Housing Model

The supportive housing model evolved as an outgrowth of efforts to link “normative” permanent housing options (e.g., apartments, condominiums, single family homes, etc.) with supports and services needed or desired by residents. The supportive housing model is an outcome of both the “independent living” movement begun by people with physical disabilities and the “support/empowerment” movement that emerged in the fields of developmental disabilities and mental health. Supportive housing also is an outcome of efforts to develop successful models of permanent housing linked with supports for long-term and chronically homeless people.

Numerous terms have been used to describe – as well as to distinguish among – various supportive housing approaches, including supported housing, supportive housing, special needs housing, service-enriched housing, and permanent supportive housing. For example, within mental health literature and research, distinctions are made between “supportive housing,” meaning housing with site-based services, and “supported housing,” which refers to scattered-site housing models with mobile

supports which may – or may not – be provided in the person’s home. The lack of a common definition within disability policy typifies the segmented approaches that evolved as supported housing was developed for disparate groups, including frail elderly people, people with disabilities, and chronically homeless people.

Common principles of supportive housing include:

- All groups have a similar need for government funded housing assistance because of extreme poverty.
- Control over one’s environment and housing choice is essential.
- Housing must be permanent, as defined in landlord/tenant law.
- Housing must be “unbundled” from supportive services and not made contingent on the receipt of services. However, supportive services must be available and accessible if needed and desired.
- Supportive services must be flexible and individualized, rather than defined by a “program.”²

It is important to note that for people with significant disabilities, integrated and scattered-site approaches are strongly preferred in order to reduce stigma and facilitate community integration. On the other hand, higher density permanent supportive housing approaches have been successful for chronically homeless people and for assisted living programs for the frail elderly.

Regardless of the group to be served, supportive housing practitioners continue to struggle with the issues of housing afford-

¹ It should be noted that many individuals with disabilities reside in nursing homes or in large board and care type facilities, as well as in state facilities or in continuum-model congregate facilities such as group homes. Individuals living in nursing homes and board and care facilities may also receive a high priority for moving to supportive housing environments.

² This does not imply that larger scale affordable housing options should not be developed, or that services should not be organized to attain economies of scale. Choices related to economies of scale must be decided in the context of the individuals to be housed, the environment in which housing and services will be provided, and the availability and feasibility of housing funding resources. Nonetheless, even larger scale facilities with co-located services can and should address individual resident choices with regard to housing and services, as well as assure rights of tenancy.

ability, financing of services and supports including service coordination, and the lack of effective coordination between housing and services agencies in all stages of the process. As a result, new supportive housing opportunities are extremely limited in all states and virtually non-existent in some states.

The development of supportive housing for people with disabilities continues to be a low policy priority in most state governments. State Medicaid, health and human services agencies, and housing departments continue to have difficulty communicating

Collaboration among multiple state agencies, with housing as the lead, is necessary to develop adequate supportive housing programs.

with each other and conceptualizing their respective roles and responsibilities in a supportive housing initiative. As a result, there is little meaningful interagency collaboration or policy development that encourages state housing, health, and human services

agencies to collectively “think outside the box” and develop sustainable supportive housing approaches that serve multiple populations, blend funding from multiple sources, and which can be replicated at scale.

Supportive Housing for Elders

Supportive housing may have originated with the development of alternative models of elderly housing – including the congregate housing model – that emerged in federal and state subsidized housing programs in the 1970s. During that time, policy makers began to distinguish between the housing needs of elders and the housing and support needs of “frail” elderly households – that is, elders “aging in place.” Some of these elders lived in public and assisted housing developments and began to need additional support in order to remain there.

Experts agreed that many frail elders moved unnecessarily to more costly long-term care settings – including Medicaid-funded skilled nursing facilities – because of the lack of coordinated and flexible in-home supports and services that could help them remain at home. From these early public efforts emerged community programs to provide mobile and flexible supports to help elders remain in their homes, as well as new “assisted living” projects for the elderly, now a burgeoning industry for both the for-profit and non-profit housing sectors.

Supportive Housing for People with Disabilities

As new models of housing and services for frail elders were being implemented, new housing approaches for people with disabilities were emerging, beginning with the independent living movement. The goal of the independent living movement is for people with disabilities to control their own lives and become self-empowered, to become socially and economically productive, to achieve self-direction, and to have the opportunity to live in permanent, independent, affordable, and accessible housing. To achieve these goals, more than 300 independent living centers have been created that provide various combinations of services, including attendant care, financial assistance, peer counseling, advocacy, referral, transportation, and assistance with housing.

The vision of the independent living movement has been central in the disability rights movement, and to most federal and state disability rights legislation in this country since the passage of the Rehabilitation Act of 1973. Recently, the independent living movement has focused its efforts on several key housing policy issues, including the elimination of “project-based” models of housing owned by

service providers. Although the core principles within the independent living movement are intended to apply to all people with disabilities, the independent living paradigm has most clearly represented people with physical, rather than mental disabilities, particularly at the federal policy level.

In the fields of mental retardation/developmental disabilities and mental health, supportive housing emerged from the “support/empowerment” paradigm, which asserts that mental health professionals have too much control over the lives of people with disabilities. In the support/empowerment paradigm, the “placement” approach to housing (in which professional assessments constitute the main basis for housing selection) is replaced by the principles of consumer choice and control over both housing and support services. This approach leads to the separation of housing from services, an emphasis on normal, integrated, scattered-site housing to reduce stigma, and rights of tenancy under landlord/tenant laws. This model also emphasizes that people with significant disabilities – like other extremely low income groups – should have more access to government housing programs to make housing truly affordable, and that scarce resources within systems of care should be spent on expanding community-based services rather than on paying for housing.

Perhaps these goals are best illustrated by the Home of Your Own Demonstration Program, which was funded for many years by the U.S. Department of Health and Human Services’ (HHS) Administration on Developmental Disabilities. This initiative asserted that the “highest and best” approach to giving people with significant disabilities control over their lives was to give them the opportunity to own their own homes. While noble in its goal, the

approach failed to adequately consider the affordability problems of homeownership for people with significant disabilities receiving Supplemental Security Income (SSI) benefits.

Supportive Housing for Homeless People

Since the enactment of the Stewart B. McKinney Act in 1987, the term “supportive housing” also has been commonly used to describe permanent housing for chronically homeless people who need access to ongoing supports to maintain housing stability and also for some housing programs for people with HIV/AIDS. Under the U.S. Department of Housing and Urban Development (HUD) McKinney-Vento Homeless Assistance programs, a third iteration of supportive housing has

emerged, which targets people with severe mental illness or other disabling health conditions who are homeless, as well as homeless people with chronic substance abuse who may not qualify for federal disability benefits.

Models of permanent supportive housing for homeless people usually include funding from at least one HUD McKinney-Vento Homeless Assistance program. These models differ in several ways from the principles and models of supportive housing within disability policy. In major urban areas, for example, permanent supportive housing projects for homeless people may have 50 to 100 units or more, and provide an array of site-based services and supports. To a certain extent, the complexities of aggregating sufficient capital, operating, and supportive services resources, and the efficiencies that can be achieved with larger site-based mod-

Large-density programs (50 to 100 units or more) for homeless people dominate disability housing policy. This approach is not favored by disability advocates.

els, have driven the most common models of supportive housing for homeless people. However, these high-density approaches are not favored by most housing advocates for people with significant disabilities.

Roles and Responsibilities of Housing and Services Systems

States and localities implementing effective approaches to supportive housing have found that supportive housing means new roles and responsibilities for housing, health, and human services agencies and providers. These new roles stem from the “unbundling” of housing and services and new relationships between housing and services agencies. Ideally, the two systems work together to ensure that both the housing and services components come together in a coordinated and seamless approach that also is financially feasible. In order to accomplish this goal, housing and services systems need to:

- Develop a more thorough understanding of the “imperatives” that define and drive their respective systems.
- Work together to define and overcome the barriers that prevent the development of supportive housing consistent with the principles outlined above.

The Housing System

The role of the affordable housing system in supportive housing is to:

- Acknowledge the need for supportive housing by making it a priority activity.
- Provide the resources to ensure affordability and housing quality for the lowest income people.
- Develop housing policies and practices, including new relationships with service providers, which are consistent with Fair Housing Laws and accommodate the needs of people with disabilities.

Despite the growth in supportive housing, most housing funders and providers still do not prioritize the housing needs of people with disabilities. Instead, self-sufficiency programs and homeownership initiatives benefiting higher income groups now dominate the housing policy agenda. HUD data show that people with disabilities use only 12 percent of HUD’s subsidized resources, but represent at least 25 percent of the households with “worst case” housing needs. HUD’s latest housing needs report indicates that the number of family and elderly households with severe housing problems declined by eight percent during the past two years, while the housing needs of people with disabilities receiving SSI increased. Despite these clear trends in housing needs, federal policy makers, state housing officials, and public housing authorities rarely give the housing needs of people with disabilities high priority.

Housing affordability is another responsibility of the housing system. Not all affordable housing programs are affordable for the lowest income people. Nationally, in 2000, people receiving monthly SSI benefits had incomes equal to only 18.5 percent of median income.

Most housing funders and providers do not prioritize the housing needs of people with disabilities.

According to federal standards of housing affordability, households below 50 percent of median should pay no more than 30 percent of their income – approximately \$150 per month for an individual receiving SSI – for housing costs.

In supportive housing, the housing system also must accommodate the special needs of residents. These accommodations can include accessibility modifications, but must consider as well the important role that supportive services play in helping people with disabilities access government housing programs and meet the obligations

of tenancy. In the ideal model of supportive housing, the owner of the housing becomes a “benevolent” landlord whose first approach to tenancy problems is to seek additional support for the tenant.

The Support Service Systems

The challenge for the multiple systems of care currently serving people with disabilities is to match the vision of independent supportive housing by delivering flexible, responsive, and individualized services that meet the varying needs and choices of people

Support service systems have the responsibility to be accessible, responsive, and enhance care coordination activities.

with disabilities in community settings. This challenge requires more than tinkering with service definitions or building programmatic addenda onto the edges of current systems. It requires fundamental but positive

changes in the manner that services are organized, delivered, integrated, and incentivized through financing methodologies.

The fundamental changes necessary in service systems currently assisting people with disabilities include:

- Implementation of evidence-based best practice service models.
- Conversion of facility-based services to mobile services.
- Assurance of accessibility and responsiveness.
- Integration across multiple systems.
- Coordination of care within supportive housing environments.

Fundamental changes in service delivery models and approaches are now strongly supported by multiple research studies. Evidence-based best practice services for all people with disabilities incorporate many of the same essential elements as are incor-

porated in supportive housing, including choice, control over one’s environment, flexible services tailored to each individual’s needs and choices, integration in normal community settings, and an emphasis on empowerment, independence, self-determination, and self-sufficiency. Thus, perhaps the primary responsibility of service systems is to do what they should do as a matter of course: implement evidence-based service models.

Inherent in the implementation of best practice service models is the conversion of place-based congregate service models to mobile, *in-vivo* service models. For example, Assertive Community Treatment models for people with serious mental illness take the psychiatrist, the nurse, and the case manager out of the clinic and away from the office encounter, and instead deliver services to consumers in their homes, in their places of work, or in other natural settings. Home care approaches for elders³ and many independent living centers for people with physical disabilities also are based on the mobile services model.

A parallel responsibility of service systems is to assure that their services are accessible and responsive. Implementation of mobile, as opposed to place-based, services is critical to fulfilling that responsibility. To be accessible and responsive, services for people with disabilities living in supportive housing settings must be available 24 hours a day, seven days per week. They must be available exactly when a person with disabilities or their neighbor, landlord, or family member calls for help. Services also must be appropriate to what people need and choose, must be welcoming and customer friendly, must be culturally competent, and must assure physical accessibility.

³ Such as the PACE program and Medicaid assisted-living initiatives.

The accessibility and responsiveness of services also depends on the elimination of financial and regulatory barriers to accessing the variety of different services and resources an individual with disabilities needs and chooses at any given time. Many people with disabilities need services and resources from multiple service systems with a myriad of funding sources and payment mechanisms. It is the obligation of the service systems to coordinate multiple services, eligibility requirements, and payment sources in order to meet the specific individual needs of each person with disabilities. In the course of integrating multiple services and funding streams, service systems should focus their collective efforts to reduce the stigma, inefficiency, and competition for scarce resources that characterize the current categorical, disability-specific systems of care.

Finally, service systems have a responsibility to enhance their care coordination activities, since care will be delivered within scattered-site, affordable supportive housing as opposed to within congregate

facilities in which the “program” is already coordinated within the living environment. Service systems need to welcome housing managers into the care coordination process and, if the tenant agrees, keep them informed about issues that pertain to their housing status. Service systems need to provide the necessary supports to assist people to be successful tenants, and should work with housing sponsors and landlords to assure that tenancy is supported. The “benevolent landlord” only can be benevolent as long as the service system is there with the right services and other resources when needed.

Federal and state policy-makers need to address housing issues by using scarce resources for providing supportive services, not solely by assisting people with disabilities to own homes.

Current Best Practice Models

To be considered a best practice model of supportive housing, the program should maintain the principles of the supportive housing model outlined in this report, including separation of housing from supports, tenancy, affordability, choice, autonomy, and availability of flexible and individualized supports. Detailed descriptions of these programs are available at www.chcs.org.

Polk County Iowa Health Services – This county mental health/mental retardation authority used bond-financing, “bridge rental subsidies,” as well as de-categorized funding from state human services appropriations, to leverage Section 8 funding from the local Public Housing Authority (PHA) and provide flexible and individualized community-based supports to people with disabilities living in supportive housing.

Massachusetts Housing Finance Agency Elderly CHOICE Program – A mixed income structured production program for assisted living that uses Medicaid Adult Foster Care payments to fund services for frail elders receiving SSI.

Ohio’s Supportive Housing Non-Profits – Ohio uses non-profit housing corporations⁴ funded by county mental health and mental retardation systems that have access to Ohio’s Department of Mental Health/Mental Retardation capital funding for housing, “bridge subsidies,” and county funded services, to leverage permanent rental assistance resources from HUD.

Corporation for Supportive Housing (CSH)⁵ – In Connecticut, CSH formed a partnership with the state government to implement two structured supportive housing production programs that have dedicated state funding for service coordination in supportive housing. In the San Francisco Bay area, CSH has created an organized network of non-profit supportive housing providers who work with multidisciplinary Integrated Services Teams to access larger systems of care in the community.

The Arc of the United States Demonstration Projects in Maryland and Minnesota – The Arc of Ann Arundel County, Maryland and The Arc of Hennepin County, Minnesota have demonstration projects underway designed to link people with Medicaid Home and Community-Based Services waivers to Section 8 vouchers. The vouchers are being provided by the PHA for “shared housing,” scattered-site housing, as well as home-ownership models of supportive housing.

Oakland County, Michigan Challenge Grant and “Bridge Subsidy” Programs – To serve people leaving institutions as well as those at-risk, Oakland County leveraged the savings from de-institutionalization to create Assertive Community Treatment Teams and “bridge subsidy” funding that was eventually replaced by Section 8 vouchers targeted by Congress for people with disabilities.

⁴ The original models of these were created and financed under The Robert Wood Johnson Foundation’s nine-city demonstration program on chronic mental illness. Those organizations continue to thrive today.

⁵ CSH programs receive primary funding from The Robert Wood Johnson Foundation, the Ford Foundation, and the Pew Charitable Trusts. Local philanthropic contributions also are used to support the eight CSH program sites.

Supportive Housing and State Olmstead Plans

As a result of the *Olmstead* decision, and with financial support from the Center for Health Care Strategies (seven states) plus new funding from the federal Department of Health and Human Services (more than 40 states), states are reviewing whether current policies and practices in their health care and service delivery systems comply with the ADA. Because the Supreme Court was careful to stipulate that people in institutions or other “restrictive settings” may not displace people already living in the community who are on waiting lists for services, a state’s response to *Olmstead* could broadly target the following groups:

- Frail elders at risk of institutionalization as well as institutionalized elders who could live in the community with appropriate housing and supports.
- Adults with disabilities who are currently institutionalized, including people in state facilities, nursing homes, or other restrictive settings.
- Adults with disabilities at-risk of institutionalization, including those in “restrictive” community settings, people living at home with aging parents or living elsewhere in the community, and on residential services waiting lists.
- Adults with disabilities who are homeless as a result of being de-institutionalized.

Two agencies within the U.S. Department of Health and Human Services – specifically the Centers for Medicare and Medicaid

Services (CMS) and the Office for Civil Rights – are responsible for providing information and guidance to the states on how to comply with the ADA mandates in *Olmstead*. On January 14, 2000, HHS sent a letter encouraging governors to develop and implement the kinds of comprehensive working plans that the Court had suggested, “[to ensure] that individuals with disabilities receive services in the most integrated setting appropriate to their needs.”

CMS also sent letters to all state Medicaid directors encouraging them to work together with the state human service agencies toward the shared goal of integrating individuals with disabilities into the social mainstream, promoting equality of opportunity, and maximizing individual choice. HHS also has issued numerous policy clarifications designed to help Medicaid beneficiaries transition to “less restrictive settings” and expedite Medicaid funding for community-based services.

HHS has made a concerted effort to engage HUD staff in *Olmstead* discussions. In 2000, HUD announced its intent to create the Access 2000 Demonstration program, which will provide 400 Section 8 vouchers linked with HHS Nursing Home Transition Grants. In June 2001, HUD awarded these Section 8 vouchers to 11 Public Housing Authorities (PHA). Five of these are state level PHAs that are participating in state *Olmstead* planning.

Review of State *Olmstead* Plans

A review of state *Olmstead* planning documents indicates that, with a few notable exceptions, states have not yet addressed the issue of developing supportive housing

With a few exceptions, most states' *Olmstead* plans do not address the issue of developing supportive housing strategies. States need assistance in bringing key housing decision makers into discussions.

strategies within their *Olmstead* planning efforts. In the vast majority of states, the lead agency for *Olmstead* planning is either the health and human services department or the state Medicaid agency. And, while state housing agency staff may have participated in *Olmstead* planning activities

in some states, there is no indication that their participation has resulted in new policies to expand supportive housing.

Olmstead-related activities in 15 states – Arkansas, Connecticut, Delaware, Illinois, Indiana, Iowa, Maine, Maryland, Missouri, Montana, North Carolina, North Dakota, Pennsylvania, Texas, and Ohio – were reviewed for this report. Thirteen states have cited the lack of affordable housing as a significant barrier to achieving the integration mandates within the ADA. Eight states point out that certain housing agencies – including HUD, state housing finance agencies, public housing authorities, or housing non-profits – are very important to the implementation of state *Olmstead* planning efforts. Five states mention specific HUD housing programs such as Section 8 vouchers for people with disabilities or the Section 811 Supportive Housing for Persons with Disabilities program. Three states have, or recommend

establishing, housing task forces to further explore the housing issues within *Olmstead* planning.

At least two states, Maryland and Pennsylvania, have interagency efforts underway to expand supportive housing in conjunction with *Olmstead* planning. In Maryland, an interagency Systems Integration Task Force is studying *Olmstead*-related housing issues as part of the Governor's Community Access Steering Committee. The Task Force has completed its initial review of affordable housing programs and policies for people with disabilities in the state and has concluded that new housing strategies, and stronger partnerships with housing providers, must be developed in order to address the serious shortage of supportive housing in the state. Pennsylvania's Common Ground Initiative has worked to bring advocates for all disability groups together to identify local strategies and approaches that can be supported by state policies and work to develop "generic" supportive housing for people with physical and mental disabilities.

Several states suggest that SSI supplements, or Medicaid, should be expanded to cover housing costs. In most instances, these states also urge HUD to provide more funding for housing for people with disabilities. This dual policy approach suggests a lack of clarity regarding which government agencies and programs actually should pay for housing and a lack of confidence that the

affordable housing system can help states respond to the housing needs of people with significant disabilities.

A few states, including Texas and Ohio, have developed housing strategies, including the use of state funds to temporarily pay for housing costs until federal subsidies can be obtained. The Texas approach is based on earlier successful efforts in the state to provide state-funded transitional rent subsidies that are used to select housing in the private rental market. Texas developed a budget request of \$4.3 million for FY 2002 to fund this initiative. Individuals receiving these subsidies will be expected to transition to a Section 8 voucher as soon as one can be obtained. The Texas program replicates Ohio's Housing Assistance Program, which has worked successfully for many years.

Four states mention the goal of homeownership, including expanding the Home of Your Own initiative, in conjunction with *Olmstead*. However, there is no discussion of the affordability of homeownership or the resources that would be needed to make homeownership affordable. Currently, only the state of Maryland has a homeownership program that provides interest rates as low as one percent, as well

as substantial amounts of down payment assistance for people with disabilities receiving SSI benefits.

From this review, it appears that state *Olmstead* planning groups will need assistance to develop supportive housing goals, strategies, and action plans that can be incorporated within comprehensive, effectively working plans. States also may need assistance to bring key housing decision makers at the state and local levels into housing strategy discussions. Unless this happens, states may well fall back on outdated continuum models of the past that, while providing a community placement that is a "step-up" from living in a nursing home or institution, may not address the goals of integration, personal control, and autonomy that are so important to people with disabilities.

Supportive Housing Financing						
Program	Capital	Operating Subsidy	Project-Based Subsidy	Tenant-Based Subsidy	Homeownership	Accessibility
HOME	✓			✓	✓	✓
Community Development Block Grants	✓				✓	✓
Low-Income Housing Tax Credits						✓
McKinney-Vento Supportive Housing Program*	✓	✓	✓	✓		
McKinney-Vento Shelter +Care*			✓	✓		
McKinney-Vento Single Room Occupancy Program*			✓			
Section 202 Elderly	✓	✓				✓
Section 811 Disabled	✓	✓				✓
Section 8**			✓	✓	✓	
Public Housing		✓				✓
State Capital	✓					✓
State Bonds	✓					✓
Housing Opportunities for People with AIDS	✓	✓		✓		✓
Philanthropy	✓					✓
“Bridge” Subsidies			✓***	✓		
Medicaid						✓

* Homeless only.

** Includes Section 8 Mainstream Program funded with Section 811.

*** Only in Ohio.

Funding Approaches for Supportive Housing

For supportive housing to be a real option for people with disabilities in the future, the public systems that fund and provide housing and services resources must be willing to make significant changes in their programs and policies, and in their approaches to working together. It is tempting to say that only a substantial amount of new funding can create the incentives to encourage the housing and services systems to work together on supportive housing initiatives. While that may be true, it ignores the reality of current federal and state fiscal policies.

It is important to point out that even if new funding is made available, it will not guarantee that the necessary systems change will occur. For supportive housing to become the model of choice rather than a “reward” at the end of the residential continuum, it may be more important to re-direct existing resources with new policies than it would be to seek new funding during fiscally conservative times.

Housing Resources

Supportive housing can be expanded both through production and tenant-based rental assistance approaches. For supportive housing production to be affordable to people at SSI levels, debt free, or very low interest capital financing (e.g., one percent) plus some type of ongoing operating or project-based subsidy, must be provided. Operating subsidies are not designed to

fund any debt service. Project-based rent subsidies are designed to support the operating costs of the unit (which may range from \$300 to \$450 per unit per month), plus a limited amount of debt service up to the HUD-approved rent limit.

Tenant-based subsidies such as Section 8 vouchers make up the difference between what the tenant receiving SSI benefits can afford (i.e., \$150 per month) and the cost of private market rental housing. Given the demand for supportive housing, and the goals of choice and community integration within the ADA, both project-based and tenant-based approaches will be needed. Unfortunately, both types of subsidies are difficult to obtain from government housing funders who prefer to target higher income households and are reluctant to assume the high annualized cost of ongoing rent or operating subsidies.

Currently, there are an array of programs that can provide capital resources for housing development, but some are used primarily for “gap” financing rather than the core financing for projects. The accompanying chart illustrates the core housing programs that are used for both production and rental assistance strategies.

For supportive housing to be affordable to people at Supplemental Security Income levels, debt free or very low interest capital financing, plus some type of ongoing subsidy, must be provided.

Funding for Key Community Services by Funding Source

Program/Funding Source	Care Coordination	In Home Health	Personal Care	Skill Training	Day Services	Vocational Services	Community Support
Medicaid Home and Community-Based Services Waiver (primarily mental retardation/developmental disabilities)	✓	✓	✓	✓	✓		✓
Medicaid Rehabilitation Option (primarily severe mentally ill)	✓	✓		✓	✓	✓ (Not job-specific)	✓
Medicaid Personal Care Option (primarily elders and people with physical disabilities)			✓				
Medicaid Home Health (mandatory Medicaid service)		✓					
Targeted Case Management (all Medicaid enrollees with disabilities)	✓						
PACE (elders)	✓	✓	✓		✓		
Assisted living waivers (elders and people with HIV/AIDS)	✓	✓	✓		✓		
Vocational Rehabilitation (VR) Assertive Community Treatment independent living centers (primarily people with physical disabilities)			✓	✓		✓	✓
VR – employment services (technically for all disabilities – not always accessible to people with mental retardation/developmental disabilities or severe mental illness in local jurisdictions)				✓		✓	
VR - Adaptive equipment and renovations				✓		✓	
Older Americans Act (elders only)	✓	✓	✓		✓		✓
HUD 202 and McKinney Supportive Housing Programs (elders or people with disabilities who are homeless or at risk of homelessness)	✓						
State and Local General Fund Dollars (all disabilities, but usually categorical)	✓	✓	✓	✓	✓	✓	✓

Housing Resource Issues

The chart on the preceding page makes it clear that access to capital funds is not the core problem. However, access to sufficient capital (e.g., not having to tap into four or five different programs to complete the capital financing) is a problem.

Government housing agencies prefer to provide development capital as loans rather than as grants so that "program income" from the loan repayment can be recycled for new projects. Unfortunately, this approach does not work to finance supportive housing projects, because debt service on the loans simply adds to the monthly subsidy cost.

Recognizing this issue, the federal government modified the Section 202 Supportive Housing for the Elderly program and the Section 811 Supportive Housing for Persons with Disabilities program in 1991 to eliminate debt service on the capital and lower the monthly subsidy cost. Because the Section 202 and 811 programs "bundle" the development capital and operating subsidy funding, they are ideally structured for supportive housing development.

Unfortunately, new funding for these programs (particularly the Section 811 program which is funded at one-third the level of Section 202) has been extremely limited since 1995, when Congress cut these programs by 50 percent. Currently, only 1,600 new units are produced each year. A joint effort from both HUD and HHS would be needed to raise appropriation levels substantially.

With the exception of the 202 and 811 programs (and to a certain extent the McKinney Supportive Housing Program), the capital for supportive housing is not

"bundled" with the operating subsidy or rent subsidy funding. These subsidies are in the hands of PHAs (e.g., Section 8 vouchers) or are provided directly by HUD through the McKinney-Vento Homeless Assistance programs, not as a "package" with the capital funding. Only one state (Massachusetts) has designed programs (the Chapter 667 and Chapter 689 programs) that "bundle" both development capital and operating subsidies for housing for elderly and disabled households.

Some advocates have suggested that the McKinney-Vento Homeless programs be targeted for supportive housing development under *Olmstead*. This suggestion is somewhat ill-conceived for two reasons: these programs may not fund new housing units after 2002 because of the need to fund renewals of existing projects;⁶ and the *Olmstead* decision makes it clear that states should not use emergency shelters or other homeless venues as a means of complying with ADA mandates.

Housing Resource Opportunities

On the capital side, HUD's Home Investment Partnership (HOME) program should be a core resource for the financing of supportive housing. Anecdotal evidence suggests that most state and local governments do not currently allocate HOME funds for this purpose. However, states and local governments administering the HOME program can change their policies to establish a priority for supportive housing development, provide more funding per unit, provide HOME funding as a grant or an extremely low interest loan, or use HOME to fund transitional rent subsidies for people with disabilities. Policy changes of this magnitude may require leadership from HUD and from state governors. Their

⁶ Supportive housing advocates are concerned that appropriations for this program are not increasing sufficiently to fund the continuation of all McKinney-Vento projects currently funded as well as provide funding for new units of supportive housing.

roles also may be important to ensure that state and local Consolidated Plans mandated and reviewed by HUD (which controls the use of HOME, Community Development Block Grant, and Housing for People with AIDS funds) include an assessment of the need for supportive housing as a result of the *Olmstead* decision.

At the state level, policies and models for the use of HOME funds for supportive housing could “dove-tail” with the state’s use of

Accessing new funds for supportive housing must be combined with redirecting existing resources with new policies.

federal Low-Income Housing Tax Credits, as well as any other state capital financing resources. The Corporation for Supportive Housing has used such structured production strategies to

expand supportive housing in a number of states. Financing models must be simplified; application procedures should be designed as “one-stop” and integrated programmatically with rental assistance approaches to ensure affordability. Adopting tenant selection preferences linked to state Medicaid policies could facilitate links to supports.

Rental subsidy funds can be obtained for tenant-based supportive housing initiatives through the Section 8 program. During the past five years, more than 40,000 new Section 8 vouchers have been “set-aside” by Congress for people with disabilities. More are being sought for the FY 2002 HUD budget. In 2000, approximately 1,000 Section 8 vouchers were awarded to PHAs that agreed to use them for people receiving Medicaid Home and Community-Based Services. The 400 Section 8 vouchers HUD has set aside for the Access 2000 program also are available.

These initiatives are all a step in the right direction for HUD but there are issues in the housing delivery system that need to be

addressed. Since Section 8 set-asides for people with disabilities were first provided by Congress in 1997, PHAs have shown little interest and capacity to develop partnerships or strategies with the disability community. Concerned about this outcome, the Consortium for Citizens with Disabilities Housing Task Force in Washington, D.C. worked successfully with Congress and HUD on a policy to permit some Section 8 Mainstream vouchers to be administered by non-profits rather than by PHAs. This initiative holds some promise to create a new delivery system for Section 8 vouchers targeted to people with disabilities.

Under new HUD policies, all of the Section 8 vouchers referenced above can be used as project-based rental assistance. New project-based rules offer tremendous potential for an expansion of supportive housing development, including their use with a structured production program created at the state level, or as targeted resources in federal Low-Income Housing Tax Credit projects. However, it is extremely important for people with significant disabilities that the principles of choice and integration, through a scattered-site approach, underpin the use of project-based rental assistance models.

Finally, the chart also illustrates that an array of resources are available to provide accessibility modifications for people who need housing with special features or housing that is barrier-free. The issue here is providing better information and a more streamlined approach to access the program(s) that are the most available and/or appropriate. Programs have been created which maintain a “registry” of barrier-free subsidized housing and require owners to list all vacancies. This type of clearing-house provides a “one-stop” approach for accessible and barrier-free units and mini-

mizes the likelihood that they will be rented by people who do not need the special features of the unit.

The Role for Medicaid and Other State Programs

The Medicaid program is by far the largest source of federal funding, both for primary health and acute care services and for long-term care and community support associated with independent community living. Medicaid also is an important source of funding for the service coordination functions that are so critical to both project-based and scattered-site supportive housing models.

Medicaid includes a number of flexible provisions that can be used to finance services for people with disabilities living in supportive housing. These include Home and Community-Based Service Waivers, the rehabilitation option, the personal care option, targeted case management, and a variety of waiver approaches, including those that facilitate assisted living and the Program of All-Inclusive Care for the Elderly (PACE) demonstration.

In addition to the care coordination, health care, and social services that can be funded with Medicaid, there are other important resources that can be accessed and coordinated for people living in supportive housing. These include:

- The Ticket to Work and Work Incentive Acts, which provide new employment-related resources for people with disabilities wishing to work, and protections for Medicaid health care coverage when people with disabilities start earning marketplace wages.

- The Mental Health and Substance Abuse Block Grants and the Social Services Block Grant.⁷
- The Vocational Rehabilitation Act, which provides funding for a variety of employment related services, also funds more than 200 independent living centers for people with physical disabilities throughout the United States.
- The Older Americans Act, an important source of funding for community-based service outreach, care coordination, in-home supports, nutrition, and socialization services for people over 60 years of age.
- Service coordination funding available under HUD Section 202 elderly housing and HUD's McKinney Supportive Housing Program.

In addition to the federal funding sources described above, there is a substantial amount of state and local public funding for services for people with disabilities. In fact, despite Medicaid and other federal funding available for health and social services for people with disabilities, state and local funding usually exceeds or is equal to federal funding for these services.

Some proportion of state and local funding is dedicated to providing a federal match, primarily for Medicaid, but also for vocational rehabilitation services and for certain federal demonstration projects. The majority of state and local funding, however, is appropriated into specific categories related to both discrete disability groups and distinct service types. That is, there are specific appropriations for each disability

Medicaid is the single largest funding source for the supportive services provided to people with disabilities living in the community.

⁷ Both the federal government and most states treat this latter block grant as general revenue sharing. However, some states (e.g., Ohio and Iowa) maintain funding set-asides that provide maintenance of effort funding related to the old Title XX and then Social Services Block Grant programs.

group, and then within each disability group there are appropriations (or other requirements) for specific service types.

Service Resource Issues

Funding associated with institutional or other congregate care facilities is not likely to follow the person with a disability into an independent living setting. State regulations often prevent place-based services from being delivered in a person's own unit as opposed to a program facility. In addition, funding may be specifically appropriated to an institution or other facility, and thus only can be re-allocated by legislative action. A fully "bundled" program model with a *per diem* type reimbursement rate may be very difficult to "un-bundle" into a variety of individualized community services. Finally, it may be more difficult to document "medical necessity" for community support services in an independent living setting, whereas medical necessity is assumed in program facilities.

In general, state and local dollars have the potential to be flexible, non-categorical, and non-disability specific. However, state and local political traditions and the effects of population-specific advocacy efforts typically have resulted in an extreme degree of categorization. In addition to being categorical and disability-specific, most states continue to fund traditional place-based service models, and few state or local jurisdictions have specifically linked flexible service financing approaches with supportive housing initiatives. Finally, state and local jurisdictions are currently facing increased pressures to match federal Medicaid funds, which in turn places greater limitations on their ability to tailor local funding to either creative service system development or individualized service needs.

The combination of traditional Medicaid and state-funded facility-based service models (Intermediate Care Facility, Intermediate Care Facility for Mental Retardation, group homes, sheltered workshops, long-term day services, or day rehabilitation programs) plus SSI state supplements for residential facilities (group homes, board, and care facilities) has had the effect of capitalizing entire industries of health and social service providers. Each state has hundreds of small and large facilities, some of which are state owned and operated, which were capitalized by and remain subsidized by some combination of Medicaid, state and local general fund dollars, and SSI supplements. Many people have a stake in protecting these facilities, including the owners and operators, the employees, and in some cases the communities that receive economic benefits from the presence of such facilities. This presents one of the major challenges to states and local jurisdictions that desire to implement best practices by converting place-based service programs to mobile person-centered services.

The difficulty of funding unbundled and non-traditional services with Medicaid has been to a certain extent exacerbated by the implementation of managed care initiatives in recent years. Managed care initiatives in the public sector, including Medicaid, have produced several notable benefits, including improved access to care, greater flexibility of service planning, improved quality and outcomes for consumers, and re-investment in new non-traditional community services. However, in some jurisdictions the managed care organization or related intermediary, practiced in acute care utilization

Supportive housing should be person-centered and unbundled. The dollars should follow the person, and services should be coordinated across multiple service agencies.

management, has had difficulty adjusting to flexible, long-term community-based service models. This has resulted in cost and care shifting to other public sector programs instead of the desired integration and coordination of funding streams and service delivery focused on individuals with disabilities who, without community services, are at risk of institutionalization.

Currently, there are renewed efforts to contain Medicaid costs at the state level. In concert with these efforts, there has been advocacy for additional devolution of Medicaid responsibility to the states. These efforts may become a countervailing force to Medicaid program enhancements designed to expand community opportunities and alternatives for people with disabilities.

Finally, there is considerable confusion, conflict, and redundancy among the various federal and state requirements or initiatives related to care coordination. Most state categorical programs, plus certain Medicaid programs, fund some form of case management or care coordination. It is not uncommon for a person with disabilities to have several care coordinators participate in treatment planning, service monitoring, and other non-direct service activities associated with their care. Frequently, none of these care coordinators directly relate to the independent housing setting, and none have the authority to coordinate or access services from outside their own jurisdictions.

Service Resource Opportunities

Despite the above concerns, there are numerous opportunities for states to comply with the Americans with Disabilities Act and the *Olmstead* decision within existing service financing resources. In fact, there is a confluence of opportunities and motivations that could result in the next big sys-

tem change for people with disabilities in the United States. The *Olmstead* decision has provided a wake up call for state policy makers and system managers, but in reality it amplifies rather than changes the course of service system financing and delivery changes already underway. In fact, many states already have been implementing best practice approaches that foster and support independent community living. And, many states have been including consumers and their families in the planning and quality management of these best practice service models. In addition to stimulating state *Olmstead* planning activities, CMS has responded to state desires for flexibility and new service models and financing approaches, and that in turn has generated considerable experience at the state level in managing and delivering services outside of institutional walls.

CMS also has recently begun implementation of the Real Choice Systems Change Grant, a \$50 million nationwide initiative to foster creative state strategies for in-home and community-based services. Real Choice Systems Change Grants will provide states with the motivation and the resources to address many of the care coordination and service system delivery and financing changes outlined in this report. One of the primary opportunities will be to resolve both the redundancy and the lack of authority of care coordination functions, and thereby also address the barriers and inefficiencies created by categorical and disability-specific service funding and delivery approaches. These grants also may stimulate states to expand and improve state Home and Community-Based Service Waiver, the Medicaid Rehab Option, and related Medicaid services, and/or to pursue waivers or administrative plan amendments for specific supportive housing initiatives.

Recently, all states were given the opportunity to receive \$50,000 in Real Choice System Grant funding to support initial planning activities.

Most of the financing strategies for evidence-based approaches do not require complicated Medicaid waivers or additional state appropriations. They do require leadership, significant effort, and political will on the part of service system managers to redirect or redeploy existing service resources into new service delivery and financing models. Numerous evidence-based best practice models have met consumer and family needs and choices, as well as contain the life cycle and system-wide costs of service delivery for people needing and choosing long-term care in the community. Such best practice approaches also foster greater use of natural community resources and supports as opposed to relying on the public sector for all services.

Establishing non-disability-specific care coordination capacity – which becomes the single point of responsibility and accountability for people with disabilities living in supportive housing – is one example of this opportunity. State funds could be used to fund care coordinator positions in project-based supportive housing settings, and care coordination functions in multi-service community agencies could be dedicated to scattered-site supportive housing models.

These care coordinators can serve people without regard to financial eligibility or specific disability. The state can then figure out how much of the care coordination costs to bill to Medicaid and to various categorical sources of state funding. States also have opportunities to pool categorical state funding to create non-disability specific community support teams, supportive employment approaches, peer supports, and related community services that could be deployed on an as needed basis to serve people with various disabilities in supportive housing. Such pooling of resources also could increase their utility as a match for federal Medicaid, vocational rehabilitation, and homeless services and housing funds.

Another opportunity is to employ new financing and reimbursement approaches that provide direct incentives to attain independent community living outcomes for people with disabilities in the most cost-effective manner. These could include sub-capitation or shared risk arrangements, case rates, risk adjusted payments, and incentive payments for positive performance.

Financing evidence-based approaches requires leadership, significant effort, and political will on the part of service system managers to redirect or redeploy existing service resources into new service delivery and financing models.

Conclusion: A Vision for Change

Supportive housing strategies to help states meet their ADA obligations must begin with an interagency approach among state health, human services, and housing agencies. Each agency must be willing to modify existing programs and policies to accommodate the housing financing and supportive services coordination and delivery issues discussed in this

Innovation in supportive housing practices benefiting people with disabilities will depend on intangibles, including a culture of innovation and change, and the leadership it takes to sustain the process of system change.

report. Leadership from the state housing agency is critical, because its approach must be modeled by localities that receive HUD funding and by public housing authority officials who know relatively little about the *Olmstead* decision.

Future supportive housing strategies should rely on a mix of project-based as well as tenant-based models. With the

exception of assisted-living projects, project-based models should be low density and provide integrated housing through a mixed income/ mixed population approach. The CSH Connecticut program developed nine successful projects using this model.

Project-based models also should include a significant percentage (at least 10 percent) of barrier-free units, which could be leased through a central registry model.⁸

Project financing should be virtually debt free and provided through a “one-stop” or “uniform” application approach that is linked to operating subsidy dollars or

Section 8 project-based or tenant-based assistance. New assisted-living models of supportive housing could target “near” elderly people with disabilities age 50 and above who require services that are similar to those needed by frail elderly residents.

Tenant-based models can be designed to take advantage of new Section 8 set-asides for people with disabilities as well as policies that link vouchers to Medicaid programs. Transitional or “bridge” rent subsidies could be funded from SSI supplements or other state resources to provide immediate access to housing. Either HUD funds (e.g., HOME or Community Development Block Grants) or Medicaid funds could be used to make accessibility modifications.

Non-categorical care coordinators should be funded for both models, with on-site care coordination provided in project-based housing. For tenant-based housing, mobile care coordinators could be based in community agencies with a mission to serve all disability groups, including independent living centers, home care agencies, etc. Care coordinators should have access to a range of high quality, culturally competent, and clinically appropriate services and supports that are needed and desired by people with disabilities. Housing search and housing counseling services must be coordinated with housing providers and directly linked to care coordination.

⁸ Massachusetts has funded a central registry for accessible and barrier-free subsidized housing units. Owners of units (including public housing authorities) are required to list their properties as well as report all vacancies as soon as they occur.

As noted earlier in this report, service coordination and many of the community services and supports should be available 24 hours per day, seven days per week. Community-based services also should reflect evidence-based best practices (e.g., Assertive Community Treatment), or preferred practice approaches when firm evidence of the efficacy of certain models is not yet available.

Finally, innovation in supportive housing practices benefiting people with disabilities will depend on intangibles, including a culture of innovation and change, and the leadership it takes to sustain the process of system change. These dynamics can be fostered and enhanced by providing more support and technical assistance to states as they work to implement the housing and services mandates of the ADA.

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